

## Chapter 3

### Section 3.01

Ministry of Children and Youth Services

# Autism Services and Supports for Children

## Background

Autism spectrum disorder (commonly known as autism) covers a range of neurological developmental disorders characterized by difficulties with social interaction and communication, repetitive behaviours and/or a range of cognitive deficits. The presence of symptoms and the degree of impairment vary from individual to individual; some people with autism have severe intellectual disabilities while others are high-functioning. This disorder is lifelong and has a significant impact on families and caregivers. Nonetheless, experts believe that treatment and support, especially through early intervention services, can help improve the functional abilities of affected individuals.

The prevalence of autism has been increasing. Whether this is due to a rise in the incidence of autism or a rise in the number of people being diagnosed is unclear. At the time of our audit, no statistics were available on the prevalence of autism in Canada or Ontario as a whole. But a March 2012 report by the National Epidemiologic Database for the Study of Autism in Canada indicated that the prevalence rate in southeastern Ontario was 1 in 77 in 2010, up from 1 in 190 in 2003. A similar upward trend has been reported in the United States. The Centers for Disease Con-

trol and Prevention (CDC) reported that autism affected 1 in 88 children in 2008, up from 1 in 150 in 2000. More recently, the CDC reported results from a 2011/12 public survey that show that autism affects 1 in 50 children aged 6 to 17. In fact, statistics released by the CDC and the U.S. Data Resource Center for Child and Adolescent Health indicate that autism is being diagnosed in children more often than juvenile diabetes, cancer and AIDS combined. Using the latest available prevalence rates provided by the CDC for 2008 and by the National Epidemiologic Database for the Study of Autism in Canada for 2010, we estimated that approximately 30,000 to 35,000 children with autism were living in Ontario at the time of our audit.

Children with autism may access a variety of services and supports, such as speech therapy, occupational therapy and mental health services. These programs are funded by various ministries, including the Ministry of Children and Youth Services, the Ministry of Education, and the Ministry of Health and Long-Term Care, and are accessible to all children who qualify. Our audit focused primarily on services and supports funded by the Ministry of Children and Youth Services (Ministry) exclusively to children with autism.

The Ontario Health Insurance Plan does not cover autism services and supports. However, although not legislated to do so, the Ministry has

since the year 2000 funded various services and supports for eligible children with autism up to age 18 and their families. Two significant components of what is funded are the Autism Intervention Program (AIP), which provides intensive behaviour intervention (IBI) services, and applied behaviour analysis (ABA)-based services. For a comprehensive list of autism-specific services and supports funded by the Ministry at the time of our audit, see Figure 1.

Ministry-funded autism services and supports are delivered to children in Ontario through approximately 90 community- or hospital-based agencies. These agencies are usually not-for-profit organizations. Some agencies also provide other services such as mental and family health services, and hence may receive funding from other government ministries and programs. The Ministry's nine regional offices are responsible for overseeing program delivery by agencies, and the Ministry's corporate office is responsible for policy development and program design.

In the 2012/13 fiscal year, transfer payments for autism services and supports comprised almost all program expenditures, and totalled approximately \$182 million.

Our Office reviewed the AIP in 2004 at the request of the Standing Committee on Public Accounts (Committee). Our review and the subsequent hearings of the Committee examined a number of questions and concerns, including cost effectiveness, service hours, and program performance.

## Audit Objective and Scope

The objective of our audit was to assess whether the Ministry has adequate procedures in place to manage a system of cost-effective autism services that are accessible to children up to age 18 with autism and their families, and to monitor that transfer payments are controlled and commensurate with

the amount and value of services provided. Senior ministry management reviewed and agreed to our audit objective and associated audit criteria.

Our audit work was conducted primarily at the Ministry's corporate office, at three of its nine regional offices, and at selected service providers in those regions. We reviewed and analyzed relevant files, program and financial data, and administrative policies and procedures. We also interviewed appropriate ministry and agency staff. To gain insight on how other jurisdictions administer autism services, we reviewed studies and reports from elsewhere in Canada, the United States, and select Commonwealth countries. We also met with representatives from Autism Speaks Canada and Autism Ontario, and an autism expert in the province to get their perspectives on autism services in Ontario. In addition, when designing our audit procedures, we considered comments from parents submitted to us directly or published. To determine how schools are trying to meet the needs of students with autism, we interviewed superintendents and relevant staff responsible for special education in four school boards in the three regions we visited. We also engaged two independent advisers from other jurisdictions who have expert knowledge on autism to assist us.

## Summary

Autism is becoming more prevalent in Ontario and in other parts of the world. In response to the increased demand for autism services and supports for children, the Ministry of Children and Youth Services (Ministry) has quadrupled autism funding over the last decade by increasing funding to its existing primary service—intensive behaviour intervention (IBI)—and introducing several new programs such as applied behavioural analysis (ABA)-based services and respite services. In this way, the Ministry has been able to provide service to more children with autism and their families.

**Figure 1: Autism Services and Supports Funded by the Ministry of Children and Youth Services**

Prepared by the Office of the Auditor General of Ontario

| Autism Services and Supports                              | Purpose/Description  | Start Date   | # Served in 2012/13                                       | 2012/13 Transfer Payments (\$ million) | % of Total Transfer Payments for Autism Services and Supports |
|---|--|--|---|--|---|
| Autism Intervention Program (AIP)                         | Provides assessment, child and family supports, intensive behaviour intervention (IBI), and transition supports for children diagnosed with an autism spectrum disorder (ASD) toward the severe end of the spectrum.   | 2000   | 2,000 children  | 115.4                                  | 64  |
| Applied behaviour analysis (ABA)-based services           | Provides time-limited skill-building services to children with ASD to improve communication, social/interpersonal, daily living and behavioural/emotional skills, with relevant parent support.  | 2011   | 6,200 children  | 25.0                                   | 14  |
| School Support Program (SSP)                              | ASD consultants (153 in 2012/13) assist educators (e.g., school board staff, education assistants and teachers) in publicly funded school boards to better understand how children with ASD learn and how the principles of ABA can help improve their learning.<br>ASD consultants also provide child-specific consultation and support to the Connections for Students model (a joint initiative involving the Ministry of Education and the Ministry of Children and Youth Services). In Connections, multi-disciplinary transition teams support children who are transitioning from IBI services to publicly funded schools. The transition team supports the child starting six months before leaving AIP until six months after leaving AIP and entering or continuing in school. | 2004 for SSP<br>2007 for Connections (fully implemented in March 2010) | 77,300* educators<br>1,250 children served in Connections | 25.0                                   | 14  |
| Respite services  | Provides temporary relief for families caring for a child with ASD while providing meaningful opportunities for the children to sustain their skill development and participate in community activities. Services include in-home respite, out-of-home respite and seasonal camps.   | 2007/08  | 8,100* children   | 7.8                                    | 4   |
| Intervention services covered outside the regular program | Provides funding to families for IBI services on a negotiated basis outside the regular system.  | 2004   | 47 children   | 2.6                                    | 1   |
| Potential program   | Provides one-to-one supports, including parent networking opportunities, training, and access to ASD experts and resources. Administered by Autism Ontario.  | 2006/07  | 6,800 parents/caregivers                                  | 2.5                                    | 1   |
| Transition services                                       | Targeted for children with ASD transitioning into adolescence and secondary school. The service priorities are crisis intervention, behavioural supports and/or skill-based training.  | 2006/07  | 1,000 children  | 1.5                                    | 1   |
| Other   | Includes reimbursement of tuition costs for AIP employees who pursue relevant education programs, funding for parent networking opportunities and resources through Autism Ontario, ABA registry, and local support in the South West region through the Windsor Regional Children's Centre.   | Various  | Various   | 2.1                                    | 1   |
| <b>Total</b>  |  |  |   | <b>181.9</b>                           | <b>100</b>  |

\* These may not be unique individuals.

Nevertheless, there are more children with autism waiting for government-funded services than there are children receiving them.

IBI is the province's primary method of therapy, but it is not being offered to the children for whom it is likely to make the most difference. Although scientific research shows that children with milder forms of autism have better outcomes with IBI, the program is currently available only to those children assessed as having more severe autism. Research also indicates that children who start IBI before age 4 do better than those who start after age 4. However, due to long wait lists for IBI services, children are not typically starting IBI until almost age 7 in Ontario. According to experts, early diagnosis and treatment of autism might reduce the need for more supports and services later on in life. The Ministry needs to re-evaluate its program design in order to maximize outcomes for all children served.

Although the Ministry formed an expert panel in December 2012 that will provide advice on some of the more contentious issues involving IBI (such as benchmarks for continuation of or discharge from this type of therapy), and recently introduced an independent review mechanism for when families disagree with service providers' decisions on IBI eligibility or discharge, more work may be needed.

Some of our other more significant observations include the following:

- We estimated that children with autism are diagnosed in Ontario at a median age of a little over 3 years. This is later than the recommended 18-to-24-month screening period endorsed by the Canadian Paediatric Society for children with risk factors. As well, the median wait time for children with autism in the three regions we visited to access IBI services was almost four years. Over the last five years, the number of IBI spots has remained relatively constant at 1,400, while the number of children waiting for IBI services increased by 23%. This means that an increasing number of children are not able to access early intervention.
- ABA-based services, which constitute the only type of provincially funded therapy in Ontario available to children with mild to moderate forms of autism, might not be sufficient for those who have a host of behavioural problems or goals to achieve, because the program allows a child to work on only one goal at a time; it then requires that the family reapply if it wants the child to receive further ABA-based services, with the child returning to the bottom of the wait list after each ABA-based intervention.
- It is up to each lead service agency to decide how to allocate ministry funding between two IBI service delivery options: direct service, where the child receives service directly from a service provider at no cost; or direct funding, where the family obtains funding from a lead service agency to purchase private services on its own. Wait times for IBI services can differ significantly between the two options and among regions depending on how lead service agencies have allocated their funding and available capacity. In one region in 2012, the average wait for IBI services under the direct funding option was five months longer than the average wait under the direct service option. In another region, the situation was reversed.
- In general, children receiving IBI under the direct service option received fewer hours of therapy than they were approved for. For example, at two lead service agencies we visited, children who were discharged from IBI in 2012 had received a median of only 20 hours of therapy per week, even though they had been approved for at least 27 hours of service per week. The agencies told us that this was because they would “ramp up” to the full level of approved hours at the start of the service period and “ramp down” hours closer to the end of the service period, a practice not clearly explained in the program guidelines. We also noted that any missed or cancelled appointments by the child or the therapist could not

be made up at a later time. At the time of our visits, two of the three agencies were not tracking actual hours of IBI services received by children under the direct-funding option.

- Of the children discharged from IBI services in 2012/13 on a province-wide basis, those under the direct funding option received on average almost one year more of services than those under the direct service option (35 months versus 25 months). In fact, almost 25% of children under the direct funding option received more than four years of services compared to only 5% of children under the direct service option. The Ministry has not collected data that would indicate whether children's outcomes were better under one option compared to the other.
- Since 2006, the Ministry has reimbursed up to 60 individuals for a total of \$21 million for the ongoing cost of IBI therapy outside of the regular service system. Per child, this represents more than double the amount that a child in the regular service system typically receives. Furthermore, some individuals were reimbursed for more than the maximum of 40 hours a week of service, as well as for expenses not directly related to their therapy. Expenses included holding fees to retain a spot with a therapist and the cost of trips and admission to local attractions. Children in the regular service system are not entitled to these.
- Both the Ministry of Children and Youth Services and the Ministry of Education have taken some actions to address the 34 recommendations contained in the 2007 document entitled "Making a Difference for Students with Autism Spectrum Disorders in Ontario Schools." However, more work is necessary to ensure that ABA methods are being effectively used to educate children with autism. Almost half of all schools boards reported in 2012 that they were not always incorporating ABA techniques into programs for students with autism. Only 38% of school boards reported

that all their teachers who taught children with autism had participated in ABA training sessions. Furthermore, in light of the fact that many school boards have acquired their own expertise on teaching children with autism with funding from the Ministry of Education, the Ministry of Children and Youth Services needs to determine whether the \$25 million it spends on Autism Spectrum Disorder consultants for training and consulting with teachers under the School Support Program is providing sufficient value.

- The Ministry was not collecting information that would be useful to help it monitor compliance with program guidelines or the quality of services provided.
- The Ministry has not collected information or set targets that can be used to assess program effectiveness and outcomes, even though it identified relevant performance measures to do so almost 15 years ago.

## OVERALL MINISTRY RESPONSE

The Ministry of Children and Youth Services appreciates the work of the Auditor General and welcomes input on how it can further improve autism services in Ontario.

Since Ontario implemented its first autism program, the Ministry has increased funding for autism services and supports, from an initial investment of \$14 million in 2000/01 to \$182 million in 2012/13. New areas of research, approaches to diagnosis, prevalence rates and treatments for autism spectrum disorders (ASD) are continually emerging and shifting the autism service-delivery landscape. As well, children and youth with ASD are not a uniform group; their needs vary depending on the severity of their ASD, their cognitive functioning and their adaptive behaviours. The government is committed to providing responsive services and supports that are based on research evidence for this growing and diverse group of young people.

The Ministry continues to increase funding for direct treatment for children and youth with ASD, expand the range of services available, as well as increase support for families and training for service providers. These autism-specific services and supports are just some of the services that children with autism and their families can access. Some children with ASD may also access other services for children and youth with special needs, such as rehabilitation services, mental health services and respite programs.

In addition, the Ministry has taken the following steps:

- In December 2012, it established the ASD Clinical Expert Committee, an expert panel to provide the Ministry with clinical guidance on up-to-date, evidence-based research on autism that will help inform the design and administration of autism programs in Ontario.
- In August 2013, it began a review of autism services with a view to improving early identification, access to early diagnosis and intervention, efficiency of service delivery, and families' experiences with the AIP and ABA-based services.
- It has been collaborating with partner ministries to streamline access to services—specifically, supporting children transitioning from IBI to school since 2008/09; and supporting youth transitioning from school to adult developmental services, further education, employment and/or community living starting in 2013/14.

The Ministry is also planning to re-allocate \$5 million to the AIP in the 2013/14 fiscal year to increase IBI spaces and consequently decrease wait lists. Most of the funds will be re-allocated from the School Support Program.

## Detailed Audit Observations

### AUTISM STRATEGY

Canada does not have a national strategy on autism. In March 2007, a Senate committee recommended that the federal government establish a comprehensive national autism strategy in collaboration with the provinces and territories. However, no such strategy was developed because both consensus and evidence on autism-related issues was lacking. Instead, the federal government has chosen to address knowledge gaps by, among other things, funding research and associated initiatives.

Ontario does not have a provincial autism strategy. However, in May 2013, the provincial legislature passed a motion to create a select committee to work on a comprehensive developmental services strategy for Ontarians. This strategy is to address the needs of children and adults with a developmental disability, including autism, and to co-ordinate the delivery of developmental programs and services across many provincial ministries. In particular, the committee is expected to consider the following types of needs: educational, work related, social and recreational, and housing, as well as supports for parents such as respite care. The committee was established in October 2013 and is expected to present a final report in May 2014.

Other provinces, including Saskatchewan, Manitoba and Nova Scotia, have released autism action plans within the past five years. Most of these plans highlight the need for better access to professionals for more timely diagnosis, so that children with autism may receive interventions at a younger age. In addition, since 2008, many U.S. states have implemented autism plans that include partnerships between professionals and children's families, access to financing for services, early and continuous screening for autism, community services organized for easy use, and transition services for youth entering the adult system.

## DIAGNOSIS

Numerous studies indicate that early intensive intervention can significantly enhance outcomes for children with autism. As a result, early diagnosis is key. Currently, there are no biological tests that can detect autism. Autism is usually diagnosed by behavioural evidence such as observing the child and/or obtaining a history on the child's development from parents, caregivers or speech-language pathologists. In Ontario, only those children who have been formally diagnosed with autism may apply for provincially funded autism services and supports. A family physician, psychologist or developmental paediatrician must provide the formal diagnosis. Since no data is collected by the Ministry of Children and Youth Services, the Ministry of Health and Long-Term Care or the Canadian Paediatric Society on the wait time to get such a diagnosis, we inquired at each of the three IBI service providers we visited. Based on their experience with children and families who are referred to their intervention services, they said the process to get a diagnosis could take three to 12 months, depending on where in the province someone lives.

The Canadian Paediatric Society endorses screening children for autism spectrum disorders between the ages of 18 and 24 months if a parent expresses developmental concerns or a child has risk factors, such as an older sibling with autism or problems with social or communication skills. The U.S. Centers for Disease Control and Prevention recommends that children be screened for autism at 18 months and again at 24 months.

The Ministry does not have data on the age at which children are first diagnosed, even though one of the objectives of the IBI program when it was announced in 1999 was to identify children with autism by age 3 in order to maximize their opportunities for early learning. However, service providers maintain data on the age of referral to their services. Based on the assumption that a child will be referred for IBI therapy soon after diagnosis, the age at time of diagnosis should approximate the age

at time of referral to autism services. We calculated the median age at time of referral for all children on the wait list for IBI services at the end of February 2013 in the three regions we visited and found it to be 38 months.

## ACCESS TO INTERVENTION SERVICES

The Ontario government funds two types of autism intervention services or therapies—intensive behaviour intervention (IBI) and applied behaviour analysis (ABA)-based services. According to the Ministry, IBI focuses on improving the rate of a child's learning and his or her progression across a broad range of skill areas, while ABA-based services focus on mastering specific skills, often one at a time, and learning to apply them in everyday settings. These services are available to children up to their 18th birthday. Some children qualify for both types of interventions. Figure 2 describes the differences between IBI and ABA-based services as offered in Ontario.

Intervention services are delivered by community agencies. The Ministry has selected nine lead service agencies to deliver IBI services and 13 lead service agencies to deliver ABA-based services. Lead service agencies may subcontract with other service providers to help deliver services in their region/area. Lead service agencies are responsible for all aspects of service delivery, including clinical decisions regarding eligibility, service intensity and duration, and time of discharge; wait list management; and transition support. The Ministry has developed program guidelines for both IBI and ABA-based services. The Ministry's nine regional offices are responsible for monitoring service agencies to ensure they conform to these guidelines.

Families whose children are accepted in the IBI program have a choice between two service delivery options.

- *Direct service option:* The Ministry provides funding directly to the lead service agencies, which hire therapists for children with autism, and provide ancillary services such as parent

training and resource material. There is no cost to the recipient.

- *Direct funding option:* The lead service agency determines the number of approved

hours of service to which a child is entitled and funds parents \$39 per hour to purchase private IBI services. The lead agency must approve the private IBI provider selected by

**Figure 2: Comparison of Intensive Behaviour Intervention (IBI) and Applied Behaviour Analysis (ABA)-based Services**

Prepared by the Office of the Auditor General of Ontario

|   | IBI Services – Start Date 2000   | ABA-based Services – Start Date 2011  |
|---|--|---|
| Service description                                       | IBI is an intensive application of ABA to teach new skills. It involves a step-by-step process that teaches language, social interaction, play, fine motor skills and self-help skills. Each skill is broken down into its simplest components and then taught through constant repetition and reinforcement. The goal is to create pathways in the child's brain to support normal functioning. | ABA uses methods based on scientific principles of learning and behaviour to promote positive behaviours and reduce problematic ones. ABA-based services provide time-limited skill-building services to children with autism. These services are intended to improve communication, social/interpersonal, daily living and behavioural/emotional skills. Parents learn the strategies taught to their children and can incorporate these techniques into daily activities. |
| Treatment delivery mode                                   | Primarily one to one.  | Primarily group-based.  |
| Setting   | Primarily service-provider location or home. Children usually receive services when other children are in school; some children may attend school part-time.   | Primarily service-provider location or community (e.g., grocery store, public transit). Children receive services after school or on weekends.  |
| Intensity and duration                                    | 20–40 hours per week, delivered for 2–3 years.   | 2–4 hours per week, delivered for 2–6 months.   |
| What happens at the end of service block                  | Child is discharged. Reapplication is not permitted.   | Child is discharged, but may reapply to further develop skills or to address new needs.   |
| Who provides this service                                 | The Ministry contracts with 16 service providers (9 lead service agencies and 7 additional agencies in the 2 regions with the largest demand for service). Some service providers subcontract with other providers to deliver IBI.   | The Ministry contracts with 13 lead service agencies who partner with over 40 subcontractors to deliver ABA-based services and supports.  |
| Who is eligible   | Children at the severe end of the autism spectrum, as determined by the lead service agencies.   | All children with an autism diagnosis.  |
| Number of children discharged from service in 2012/13     | 675  | 6,500   |
| Number of children receiving services in 2012/13          | 2,000  | 6,200   |
| Number of children waiting for services on March 31, 2013 | 1,700  | 8,000   |
| Age of children in service                                | Median age is 7; 90% are aged 10 and under (as of October 2012).   | Median age is 8; 90% are aged 14 and under (as of June 2012).   |
| Average provincial cost per child                         | \$56,000 per year  | \$2,800 per block of service  |



the parent. If the private service provider charges more than \$39 per hour, the parent pays the difference.

The IBI lead service agencies administer both service delivery options and determine the number of spots available for each option in their region. At the time of our audit, about 60% of IBI recipients had chosen the direct service option. Although families under the direct funding option may be required to pay out-of-pocket expenses, we were told that those who choose this option do so because they may not wish to switch from the private provider they started with while waiting for government-funded services or because it gives them more control over scheduling sessions.

### Eligibility for Intervention Services

Although a child might be diagnosed with autism, ministry guidelines restrict IBI services to children up to the age of 18 whose autism is more severe. By comparison, children with autism in most other provinces are eligible for IBI services regardless of severity, but only until they start school.

Eligibility assessments are conducted by clinical staff and approved by the clinical director at each lead service agency. Clinical staff usually include therapists with either a community college diploma, university undergraduate degree or graduate degree in psychology or a related field. Clinical directors are required to have a doctoral degree in psychology and to be registered or eligible for registration with the College of Psychologists of Ontario. Ministry guidelines require that eligibility be assessed within four to six weeks after an IBI referral is received.

Our analysis of ministry data for the period 2009 to 2012 showed that IBI service providers declined almost 1,900, or 34%, of assessed IBI applicants. In the service providers' opinion, 74% of the declined applicants did not have severe autism, 24% were not expected to benefit from IBI, and the remaining 2% did not have autism, contrary to the physician's diagnosis. In December 2012, the

Ministry introduced an independent review mechanism where parents can appeal when their child is assessed to be ineligible for service.

One-quarter of children who apply for IBI are declined services because their autism is not considered severe enough. Research suggests that these children would do better with IBI. For example, a 2005 study found that treatment outcomes for IBI were best predicted by pretreatment language skills, social responsiveness and the ability to mimic others. Similarly, a 2010 study concluded that better IBI treatment outcomes are linked to, among other things, children who initially had higher adaptive behaviour abilities. Further, the results from a 2006 study commissioned by the Ministry appear to lend support to this research. Although the study was of children with severe autism only, it did find that children in this group who were initially higher functioning made the most progress. In particular, 57% of the children in the higher-functioning group achieved average functioning or had substantial improvement, compared to only 7% of the lower-functioning children. This highlights that IBI is potentially more effective when a child is already higher functioning to begin with.

Based on our discussion with service providers and a review of their data, we noted the following:

- The Ministry does not collect data on the length of time between referral and eligibility assessment, so we obtained and analyzed data from two of the three regional service providers we visited. For children who began receiving IBI services in 2012, 75% of them were assessed within six weeks in one region, whereas in the other region only 28% were assessed within six weeks. We could not use data from the third region we visited because, contrary to ministry guidelines, children were placed on the wait list before a diagnosis of autism was confirmed, and as a result eligibility assessments were delayed until a firm diagnosis was obtained. The data from this service provider did not indicate which children had a confirmed versus provisional diagnosis.

- The Ministry does not mandate (a) a common assessment tool or combination of assessment tools or (b) the intake criteria that clinicians should use to determine IBI eligibility. The agencies we visited use anywhere from four to seven tools to assess eligibility, of which two tools are common to all three agencies. Clinicians use their professional judgment when determining whether a child is eligible for IBI. Research indicates that the choice of assessment tools is not straightforward, given the wide range of ability that children with autism have.
- One expert we spoke to told us that on occasion the condition of a child who was assessed as ineligible for IBI may worsen over time and become more severe. Based on our discussion with clinical directors, children are not usually re-evaluated if they didn't meet the IBI eligibility criteria on the first try, unless the child's development changes. However, neither the Ministry nor the lead service agencies had any criteria or guidelines to indicate how significant a child's change in development would have to be in order to warrant a re-evaluation.

### Wait Information

After being formally diagnosed, children with autism generally have to wait to access Ministry-funded autism services. For example, although half the children with autism in the three regions we visited are diagnosed by just over 3 years of age, more than 75% of children don't actually start IBI until after they turn 6. Similarly, about two-thirds of children who start ABA-based therapy are 6 and older. Children assessed as eligible are placed on the wait list based on the date they are initially referred to the program. During the time a child is on the wait list, Ministry-funded agencies offer some support to families (such as parent education and consultation). Children with autism might also be waiting for government-funded speech and occupational therapy. This has led to a situation

where families with financial means can acquire private services for their children while they wait for government-funded services, but other families are unable to.

### Waiting for IBI Services

In the five-year period ending December 2012, the IBI wait list has grown from 1,063 to 1,748. The regions of Central East (covering York and Durham regions, Barrie, and Peterborough), Hamilton–Niagara, and Toronto account for 80% of the increase in the wait list.

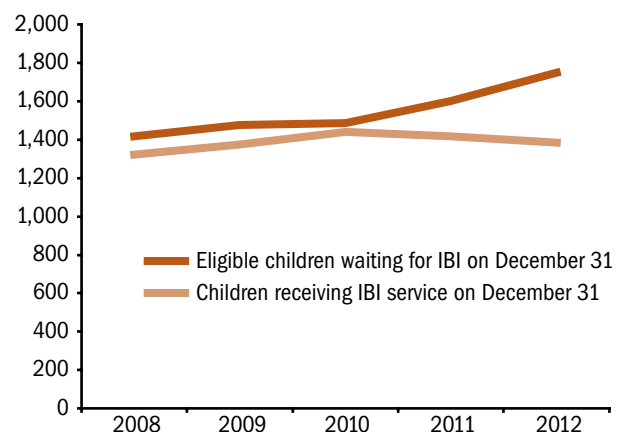
As seen in Figure 3, from 2008 to 2012, more children were waiting for IBI services than were receiving services. The number of IBI spots remained relatively constant at 1,400 during this time, while the number of children waiting for IBI services increased by 23%.

The Ministry does not track how long children wait for IBI services, but it did advise us that it will start collecting data in 2013/14 to calculate average wait times. We obtained and analyzed wait-time data—that is, the length of time from referral to starting IBI—from the three regions we visited and noted that the median wait time for IBI services in 2012, for all three regions combined, was 3.9 years.

It is up to lead service agencies to decide how to allocate ministry funding between the direct

**Figure 3: Number of Children Waiting for, and Receiving, Intensive Behaviour Intervention Service, 2008–2012**

Source of data: Ministry of Children and Youth Services



service option and the direct funding option, and wait times for IBI services can differ between the two depending on how lead service agencies have allocated their funding. In one region in 2012, the average wait for IBI services under the direct funding option was five months longer than the average wait under the direct service option. In another region, the situation was reversed. The agencies involved said it is a challenge to find the appropriate mix of spots for each service delivery option because of the pressure to alter their clinical capacity to meet ever-changing demand.

The last time the Ministry significantly increased funding for IBI services in order to reduce the wait list was in 2007/08, when funding was increased by almost 30%, or \$21.5 million. This resulted in a 25% increase in the number of children receiving services as of March 2008 compared to the same time the year before. However, there was no reduction in the wait list; in fact, the wait list increased by 17% because the increase in service demand continued to surpass the increase in capacity.

Since our last review in 2004, the Ministry has made efforts to increase and retain the number of therapists providing IBI services. Between 2004/05 and 2009/10, the Ministry provided \$3.2 million to the Ontario College Graduate Program in Autism and Behaviour Science to train almost 1,000 new IBI therapists; between 2007/08 and 2009/10, the Ministry provided \$1.3 million to train over 400 IBI therapists to deliver services under the direct funding option model; and between 2005/06 and 2012/13, the Ministry paid \$3 million in tuition reimbursements to 350 employees delivering services under the direct service option model who were upgrading their credentials. Despite these efforts to enhance system capacity, service providers in the three regions we visited told us that, while they have no problem recruiting IBI therapists, they do have trouble recruiting and retaining qualified senior therapy staff to supervise them, and therefore have on occasion filled these more-senior clinical positions with less-qualified people.

We were informed anecdotally that some children with persistent parents were able to access services more quickly than others who had been placed on the wait list before them. To assess the risk that some children may have received preferential treatment in accessing services, we analyzed wait lists in the three regions visited and compared the order of children's start dates for IBI services with the order of their referral dates. However, because the documentation maintained by the agencies in this area was not clear, we could not determine definitively whether any preferential treatment had been given at the agencies we visited. In addition, there may be some legitimate reasons for out-of-sequence starts. For instance, there are cases where children are better suited to the type of delivery mode that becomes available (group session versus one-on-one), or where children are transferred from another area of the province and the original referral date is honoured.

### Waiting for ABA-based Services

ABA-based services were fully implemented in Ontario in February 2012. Based on province-wide data collected by the Ministry, the wait list for such services almost tripled within one year—from 2,800 as of March 2012 to 8,000 as of March 2013—as more people became aware of the services. Children who started services in the 2012/13 fiscal year waited an average of 2.4 months to begin ABA-based therapy. But the average wait time varied across regions from three weeks (Eastern region) to over six months (Hamilton–Niagara region).

## PROVISION OF INTERVENTION SERVICES

### Intensity and Duration of Service

Numerous studies have examined the relative effectiveness of IBI intervention at varying degrees of intensity. In general, the more intense the therapy, the greater the gains in functionality.

According to IBI program guidelines, children may be eligible to receive up to 40 hours of IBI

services per week, with the expectation that the number of hours will generally fall within the range of 20 to 40 hours per week (in other words, about four to eight hours per day, five days a week). The approved hours are determined by clinicians at the lead service agencies. Each quarter, the Ministry collects data on the average number of approved hours for children receiving services, as well as the highest and lowest number of approved hours from each IBI lead service agency. Based on our review of ministry data for children receiving IBI services in 2012, we noted the following:

- Children were approved for an average of 23 hours of therapy per week.
- The average approved amount of therapy across regions ranged from 21 to 27 hours per week, regardless of the service delivery option. In general, that difference translates to an extra day of therapy each week.
- Only one region approved the maximum of 40 hours per week, and that was under the direct funding option. Under the direct service option, none of the regions approved more than 35 hours of service a week.

The Ministry does not collect data on the actual IBI hours provided. In addition, at the time of our audit only one of the three service providers we visited tracked actual hours of therapy for children receiving services from private providers (direct funding option), even though they approve the invoices. Based on our review of actual IBI service hours under the direct service option, as recorded by two regional agencies, children who were discharged in 2012 received a median of 20 hours of therapy per week over their entire course of treatment, even though they had been approved for 27 and 30 hours, respectively, at the two agencies. The agencies told us that this was because they would “ramp up” to the full level of approved hours at the start of the service period and “ramp down” hours closer to the end of the service period. In the middle period of service, additional hours were not provided to compensate for the ramp-up and ramp-down. One expert we consulted told us

that ramping up was common practice to ease the child into therapy, and ramping down was less common but could be appropriate for allowing a child to start transitioning to school. The practice of ramping hours up or down is not clearly explained in the program guidelines, other than to state that the clinical director or supervising psychologist can modify a child’s hours upon reviewing his or her progress at regular intervals.

Children might also be receiving fewer hours of service than they have been approved for because of cancelled therapy sessions. The program guidelines state that service hours lost, because either the child or the therapist was unable to attend the appointment, cannot be made up at a later time. In our 2004 autism review for the Standing Committee on Public Accounts (Committee), the service providers we reviewed were providing significantly fewer hours of service on average than the suggested minimum of 20 hours. In November 2006, the Ministry informed the Committee that all service providers were required to track lost service hours and that the Ministry would meet with lead service agencies to develop a more standardized approach to define lost service hours across the province. The Ministry further indicated that agencies had been asked to track lost service hours, but the Ministry did not receive that data. We followed up with the lead service agencies we visited, and found that one agency was not aware of this requirement and had not been tracking lost service hours. The other two agencies were tracking lost hours only for those served under the direct service option. In this case, lost service hours due to unavailable staff accounted for 10% of approved hours at the one agency and 5% of approved hours at the other. In any case, the Ministry was not monitoring lost service hours or the reasons for them.

We also noted that, for the 675 children discharged during the 2012/13 fiscal year, on a province-wide basis, those under the direct funding option received Ministry-funded IBI services for longer periods than those under the direct service option, as shown in Figure 4. Significantly more

**Figure 4: Percentage of Children Receiving Different Durations of IBI Services Under Each Service Delivery Option**

Source of data: Ministry of Children and Youth Services

|            | Direct Service Option (%) | Direct Funding Option (%) |
|------------|---------------------------|---------------------------|
| ≤1 year    | 22                        | 19                        |
| >1-2 years | 33                        | 19                        |
| >2-3 years | 31                        | 23                        |
| >3-4 years | 9                         | 16                        |
| >4 years   | 5                         | 23                        |

Note: Percentages are based on files for children discharged from IBI in the 2012/13 fiscal year.

children under the direct funding option received services for longer than four years as compared to children under the direct service option. On average, children under the direct funding option received IBI services for 35 months, whereas children under the direct service option received IBI services for 25 months—a difference of almost one year. The Ministry had not followed up on these differences.

In addition, the average length of time in IBI varied across the province for both service delivery options, as shown in Figure 5. For example, the average length of service obtained under the direct service option was 15 months in the Eastern region compared to 34 months in the Central East region. The average length of service under the direct funding option ranged from 11 months in the Northern region to 49 months in the South West region.

We also noted circumstances where children did not receive IBI therapy once they got to the top of the wait list. Two of the lead service agencies we visited told us that they reassess children for suitability once they get close to the top of the wait list because their functionality sometimes changes during the wait period. Both agencies said that if a child is determined to be unsuitable for IBI upon reassessment, they encourage parents to seek other services, such as ABA-based services. In 2012, approximately 20% of the children in one region and 30% in another region who had got to the top of the wait lists were deemed unsuitable for IBI

therapy and referred to other services. The agencies told us anecdotally that the children had more often been found unsuitable because they met or exceeded the skills-set that IBI is meant to teach. However, neither agency systematically tracked the reasons children were found to be unsuitable at time of reassessment or analyzed whether the children had participated in private therapy or other types of interventions that could explain their change in functionality.

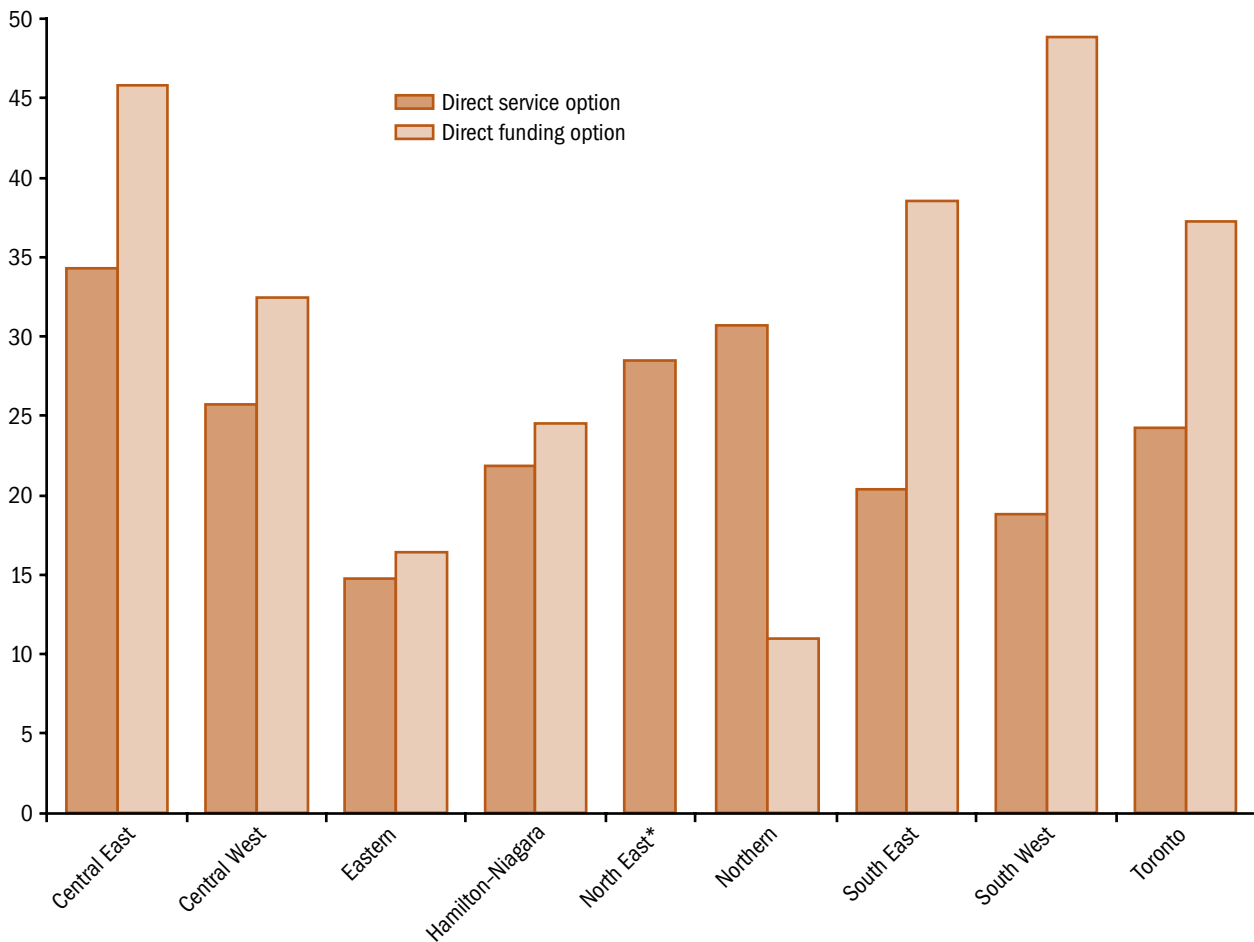
ABA guidelines indicate that services typically will be provided for two to six months and for two to four hours per week. Although the Ministry collects data on the length of time children who have been discharged from ABA-based services spent receiving them, it does not collect data on the number of hours of services they received per week to compare against recommended guidelines. We obtained data from service providers in the three regions we visited on children who were discharged from ABA-based services from inception in 2011 to December 2012, and found the data to be unreliable for analyzing both the duration and intensity of services provided.

### Discharge Decision

According to the Ministry, agency staff and stakeholder groups, one of the main complaints from families in the three regions we visited was disagreement with the discharge decision. The Ministry informed us that the decision to discharge a child from IBI therapy is a clinical one made by the lead service agency in each region, regardless of whether the child receives services provided by a lead service agency or private services paid by the Ministry. Between 2006 and 2012, more than 3,500 children in Ontario were discharged from IBI services as follows: 70% no longer needed IBI, 8% declined services, 3% moved out of region, and 19% for other reasons. To understand what “no longer needed IBI” means, we sampled a number of files in the regions we visited and found that discharge reasons could include: benefits from IBI

**Figure 5: Average IBI Duration in Months for Children Discharged During 2012/13, by Region and Service Delivery Option**

Source of data: Ministry of Children and Youth Services



\*This region does not have any direct funding option clients due to a lack of private providers in the region.

have been maximized, IBI has not been effective in changing developmental level, IBI has been effective and child will benefit more from learning in a natural environment, and child has not made any significant progress since last assessment.

Over the years, attempts have been made to establish consistent provincial discharge or “continuation” criteria. The first set of clinical continuation criteria was developed in 2006 by clinical directors in service agencies but was not finalized. Instead, in November 2007, the Ministry assembled an expert panel to determine “clinical practice guidelines.” Subsequently, the Ministry struck another panel to arrive at benchmarks for the newly developed guidelines. These benchmarks

were presented to the Ministry in September 2008. In March 2010, the Ministry hired a consultant to conduct a pre-implementation review of the benchmarks, but the consultant found that there was not enough information in the clinical files to be able to conclude on the benchmarks. Although it has spent \$330,000 to date, the Ministry has not concluded on discharge criteria. Other jurisdictions do not need discharge criteria given that their services usually end when children reach a specified age.

In October 2012, the clinical directors of the IBI programs agreed on and approved a common set of discharge criteria, which are more comprehensive than previous benchmarks. The three lead service agencies we visited indicated that they would be

implementing these revised criteria in their regions. But at the time of our audit, each was following different discharge criteria, which included a combination of the updated clinical continuation criteria from 2006 and the 2008 clinical practice benchmarks. However, we also noted that the region that uses benchmarks indicated it would refer to them on a case-by-case basis, and clinicians would apply professional judgment in making discharge decisions.

In December 2012, the Ministry formed yet another expert panel to, among other things, provide advice on whether benchmarks are appropriate for IBI discharge/continuation decisions. At the time of our audit, the committee was expected to report back to the Ministry in October 2013.

Also in December 2012, as mentioned previously, the Ministry introduced an independent review mechanism, empanelled by a roster of independent reviewers managed by an external agency, to be used when families disagree with the service providers' decision on eligibility or discharge. We were informed that reviewers will use their clinical judgment to rule on whether the decision made by the original IBI service provider was consistent with the information noted in the child's file.

At the time of our audit, the Ministry told us that there has been and continues to be disagreement among the expert community on whether there should be a consistent set of discharge criteria. However, without consistent criteria, there is no assurance that clinicians assessing the same child would reach the same decision on whether the child should continue or be discharged from IBI. Furthermore, there is a conflict, whether real or perceived, when the lead service agency is responsible for determining when services should end, while at the same time being responsible for managing wait lists and meeting targets for the number of people served.

## RECOMMENDATION 1

To help ensure that children with autism and their families have earlier access to autism sup-

ports and services, the Ministry of Children and Youth Services (Ministry) should:

- work with the Ministry of Health and Long-Term Care and the medical community to facilitate the identification and diagnosis of autism in children before age 3, in accordance with the original objective of the Ministry's intensive behaviour intervention (IBI) program; and
- monitor wait times as well as wait-list data across the province for both IBI services and applied-behaviour-analysis-based services.

To help improve program transparency and ensure equity of service in the best interests of the child, the Ministry should:

- ensure that clear eligibility, continuation and discharge criteria for IBI services are developed and are applied consistently, so that children with similar needs can access a similar level of services;
- ensure that service providers clearly specify, for every child, the reason that the child is discharged from the IBI program and report this information to the Ministry for analysis; and
- review the reasons for significant regional differences in the use of the direct service option and the direct funding option, and ensure that decisions on the capacity to provide each service are being made objectively.

## MINISTRY RESPONSE

As part of a review of autism services initiated in August 2013, the Ministry is reviewing barriers to early identification, diagnosis, assessment and treatment with a view to identifying opportunities for improvement. After focused discussions with families, research experts, health and medical professionals, and inter-ministerial partners in education and health, the Ministry will develop a plan to improve early identification and access to diagnosis and assessment.

In 2013/14, the Ministry began collecting and monitoring data that allows it to track average wait times for children who began receiving services in the reporting period under the Autism Intervention Program (AIP) by either service delivery option, and under ABA-based services. The Ministry will consider collecting and monitoring wait-time data for children on the wait list.

The AIP guidelines clearly state that clinical directors, who oversee the provision of IBI services, are responsible for eligibility and discharge decisions. Clinical directors are regulated health professionals and are responsible for taking into account the individual goals of each child, using their clinical judgment and the most up-to-date research to make decisions.

In 2012, the Ministry established the Independent Review Mechanism to allow for arm's-length reviews of eligibility and discharge decisions. Independent reviewers, who are regulated health professionals, conduct reviews to determine whether the original AIP clinical decisions are consistent with the information in children's anonymized case file materials based on the AIP guidelines, up-to-date IBI research and their clinical judgment. As of mid-September 2013, independent reviews had been completed on 93 cases. In almost 90% of cases, reviewers were in agreement with the original decisions made by clinical directors in the AIP.

As the Auditor General has described, the Ministry has sponsored several attempts to develop consistent decision-making criteria for the AIP. However, specific decision-making criteria have not been implemented due to the results of an impact analysis on children receiving IBI and the emergence of continually evolving research. The Ministry established the Clinical Expert Committee to, among other things, provide clinical guidance on evidence-based research, including advice on clinical practice guidelines and benchmarks. The Committee

will submit its report to the Minister in late fall 2013, at which time the Ministry will review the recommendations and consider next steps.

The Ministry currently collects some information related to discharge from the AIP, and will consider collecting additional information related to discharge.

The Ministry is aware that there are different levels of demand for the direct service option and the direct funding option in various parts of the province. Beginning in 2013/14, the Ministry started to collect distinct wait-time data for each service delivery option to help determine appropriate adjustments to program design. The wait-time data that the Ministry has now started to collect will allow the Ministry to measure agencies' success at matching their capacity to the demand for each service delivery option in their regions.

### Appropriateness of Intervention Methods

Since IBI is available only to children whose autism is found to be toward the severe end of the spectrum, children with milder forms of autism qualify only for ABA-based services. However, service providers in the regions we visited told us that the ABA-based services might not be sufficient for those who have a host of behavioural problems or goals to achieve. The reason for this is that the ABA program allows a child to work on only one goal at a time and then requires that the family reapply if it wants the child to receive another ABA-based service. The child returns to the wait list in the meantime. Experts to whom we spoke indicated that these separate blocks of therapy do not work for correcting all types of behaviours, because gains made might be lost in between blocks. According to one expert, this approach will not work for some behaviour targets that are interrelated and that should therefore be worked on at the same time. Children with multiple behavioural problems likely



require more intense support than is offered under the current ABA model.

Other methods of intervention that have been proposed to the Ministry include the following.

- In 2008, the Ministry commissioned an expert clinical panel to look into non-IBI interventions. The review concluded that there is sufficient evidence to recommend at least two focused interventions (Picture Exchange Communication System, which is an aid for people with autism and other special needs, and an intervention that focuses on facilitating attention skills) as part of a comprehensive program based on the developmental needs of the child. We asked the Ministry whether these methods had been adopted and were told that clinicians can use their judgment in deciding whether to complement ABA and IBI therapies with these two interventions.
- In June 2010, a working group made up of service providers from across the province recommended to the Ministry a model for an ABA-based continuum of services that included three levels of intervention depending on the child's needs. The model essentially includes the current ABA program, the IBI program and a "specialized ABA-based service" that would offer six to 12 months of individualized services for three to 12 hours per month to match the child's needs. However, the Ministry has not adopted this recommendation.

In December 2012, the Ministry formed a panel of experts to, among other things, identify effective interventions and treatments besides IBI and ABA-based services.

At the time of our audit, the Ministry was relying on parent training to provide parents with strategies to support their child's development and manage his or her behaviours at home as they await services, or to complement the strategies used by therapists. Parent workshops and parent training sessions are available under both IBI and ABA services; almost 40% of ABA service hours are provided to parents/caregivers. To further support parents/caregivers,

the Ministry is developing a resource kit that would provide families of children diagnosed with autism with information about all stages of their child's progress and development. The goal of the resource kit is to increase understanding of autism and the range of programs and supports available.

## RECOMMENDATION 2

To help ensure that children with autism have access to evidence-based interventions appropriate to their needs, the Ministry should consider the costs and benefits of offering additional types of therapies and interventions not currently provided, and existing interventions at various degrees of intensity.

## MINISTRY RESPONSE

The Ministry agrees that children should have access to evidence-based interventions appropriate to their needs.

As noted, the Ministry established the Clinical Expert Committee to confirm that Ministry-funded autism programs continue to be consistent with the latest research findings. The Committee is examining evidence-based research on autism interventions and will provide the Ministry with advice to inform policy design and program development.

## Intervention Services Funded Outside the Regular Program

Over the last seven years, the Ministry has reimbursed up to 60 individuals a total of \$21 million for the cost of IBI therapy and other expenses, outside of the regular service system.

Over 40 of these individuals were still actively claiming IBI therapy and other costs as of March 31, 2013. These individuals, ranging from 14 to 25 years old, have not followed the regular IBI progress review process. As a result, the Ministry does not know whether their needs have changed

or are significantly different from the needs of those funded through the regular program. These individuals have been receiving services for at least twice as long as children in the regular program. In addition, at the time of our audit over half were 18 years or older and hence would no longer qualify for any services offered by the Ministry. On several occasions, the Ministry had considered options for transitioning this group to mainstream programs (including adult services offered by the Ministry of Community and Social Services), but these plans were never implemented.

Some individuals' claims were processed by the Ministry and others by the lead service agencies in the regions where they reside. We noted that individuals whose claims were processed by the Ministry submitted (and were reimbursed for) higher-value claims than those whose claims were processed by the lead service agencies.

We reviewed all claims submitted for reimbursement by a sample of individuals in the 2011/12 and 2012/13 fiscal years to determine if claimants were reimbursed for the same type and level of services and at the same rates as those funded under the direct funding option. At the one service agency we visited, they were; but at the Ministry, they were not. Specifically, we noted that almost half of the individuals we sampled who had their claims processed by the Ministry were consistently reimbursed, over many months, for therapy beyond the maximum allowed 40 hours per week. In addition, the Ministry reimbursed expenses to which children under the regular government-funded program are not entitled, such as two months' worth of "holding fees," totalling about \$6,500, to hold the individual's time slot with his or her therapist over the summer months; the purchase of a laptop computer; admission to local attractions; and travel costs incurred to fly in therapists for consultation.

### RECOMMENDATION 3

To ensure that children with autism and their families receive an equitable level of service and

support and to address existing inequities, the Ministry of Children and Youth Services should apply the same program guidelines to all those who meet the eligibility criteria.

### MINISTRY RESPONSE

The Ministry agrees that children with autism and their families should be treated fairly and equitably. The Ministry will consider options for meeting this objective for families who receive funding outside the regular program.

## AUTISM SERVICES AND SUPPORTS IN SCHOOLS

Children spend up to six hours a day in school, and this will start at younger ages as Ontario fully implements full-day kindergarten by September 2014. According to the Ministry of Education, in 2011/12 about 16,000 students in publicly funded schools had been formally identified with an autism spectrum disorder (ASD) by an Identification, Placement and Review Committee. There may be many others who have not been formally identified. As previously noted, most of these students will not have begun any therapy by the time they enter school.

Under the *Education Act*, schools are to provide appropriate supports to children with special needs, including autism, while also attending to the needs of the other children in the classrooms. Special education staff in school boards we interviewed told us that most children with autism are placed in regular classrooms; some are placed in special education classrooms along with students with other types of exceptionalities; and a very small number with significant behavioural problems are placed in segregated school settings with additional resources.

In September 2006, the Minister of Children and Youth Services and the Minister of Education assembled a group of experts to provide advice on improving school supports for children with autism. The group members were asked to identify

successful education practices in Ontario and other jurisdictions; provide advice based on their background and expertise; and produce a report with recommendations to be presented to both ministers. The group's February 2007 report, "Making a Difference for Students with Autism Spectrum Disorders in Ontario Schools," contained 34 recommendations for province-wide implementation. The two ministries involved were responsible for implementing those recommendations that applied to them. The ministries provided us with actions they have taken on each recommendation. Some action has been taken on all recommendations. Notable actions are highlighted in Figure 6.

### Autism Training for Educators

The Ministry of Children and Youth Services introduced the School Support Program (SSP) in 2004 to enhance supports available to publicly funded school boards for students with autism. The program is delivered by the same nine lead service agencies that deliver IBI services. It employs about 150 autism spectrum disorder consultants (ASD

consultants) to provide training and consultation services to educators (school administrators, teachers and education assistants) to help them understand how the principles of ABA can be applied to improve the way that students with autism learn. The Ministry's program guidelines do not specify credentials for ASD consultants, other than to state that they require superior skills (knowledge of autism, ABA principles and behavioural teaching strategies) generally obtained through education and experience in a relevant field. In April 2012, agencies that deliver the SSP also launched a website to provide school boards with an online resource guide on effective educational practices for students with autism. Online resource tools are beneficial from the perspective that teachers and education assistants can access them when needed.

We noted the following concerns with the School Support Program:

- There were significant variances in the activities of ASD consultants across regions in the 2011/12 fiscal year. For example, the average number of service hours per consultant, for training, planning, consulting and

### Figure 6: Notable Actions Taken on 2007 Report Entitled "Making a Difference for Students with Autism Spectrum Disorders in Ontario Schools"

Prepared by the Office of the Auditor General of Ontario

#### Ministry of Education

Implemented requirement that appropriate ABA teaching strategies be incorporated for students with autism.

Provided \$37 million from 2006/07 to 2012/13 to school boards and the Geneva Centre for Autism for educator autism training.

Provided \$45 million from 2008/09 to 2012/13 to school boards to hire professionals with ABA expertise to provide training in ABA teaching strategies and to enhance collaboration between service providers and schools.

Hosted ABA Professional Learning Days in March 2012 and May 2013 to promote the sharing of evidence-based resources and effective practices.

#### Ministry of Children and Youth Services

Implemented Connections for Students model, which uses transition teams to help children with autism move from IBI services to schools.

Funded a variety of support programs to help families care for children with autism, such as respite programs, March Break Reimbursement Fund, and summer camps.

Together with the Ministry of Education and the Ministry of Health and Long-Term Care, developed a shared vision for integrated speech and language services for children from birth to Grade 12 to enable seamless access to such services in a more timely and equitable manner. The proposed model is being tested at select sites since 2011.

Together with the Ministry of Education and the Ministry of Community and Social Services, is implementing integrated transition planning for young people with developmental disabilities starting in the 2013/14 school year.

resource development combined, ranged from 137 hours to 1,009 hours, and the average number of educators and support staff served by each consultant ranged from 177 to 1,321. We noted that of the three agencies we visited, only one could account for all of its consultants' time. The other two indicated that their ASD consultants worked part-time on SSP initiatives and spent their remaining time providing ABA-based services. In other words, service providers were using SSP funding to deliver ABA-based services, for which they had already been separately funded. The Ministry had not analyzed the information to identify the causes of such variances among regions, nor was it aware of the inappropriate use of SSP funding.

- The Ministry does not require service providers to survey all publicly funded school boards to determine how useful they found the services of the ASD consultants and whether the consultants met the needs of the school boards. Representatives from three of the four school boards we interviewed told us that they don't use Ministry-provided ASD consultants very much, because they have their own ABA expertise in-house, and as a result the consultant added little or no value.
- One school board told us that it preferred to pay for a commercial web-based autism resource tool for teaching strategies, rather than use the SSP's online resource tool at no charge. An expert we spoke to also highly valued the commercial tool. Prior to the development of the online resource tool, the Ministry had not instructed agencies to review whether existing commercial online resources could meet educators' needs.

The Ministry of Education has also introduced a number of initiatives in recent years to help educators teach students with autism. The most significant was the 2007 implementation of a policy to incorporate ABA methods into programs for students with autism and provide planning for the

transition between various activities and settings. To support this policy, the Ministry of Education provided school boards with new funding (\$11.3 million in 2012/13) to hire board-level professionals with ABA expertise to provide support, including coaching teachers on ABA techniques, and to enhance collaboration between service providers and schools. In addition, since 2006, the Ministry has provided \$37 million to school boards and the Geneva Centre for Autism to provide autism training to educators. The Geneva Centre for Autism is an organization in Ontario that provides clinical intervention services and training programs.

We noted the following about the initiatives implemented by the Ministry of Education:

- In 2008, Autism Ontario surveyed parents of children with autism and found that 45% reported that ABA methods were never incorporated into programs for their children, and an additional 34% said ABA methods were incorporated only some of the time. The Ministry of Education has surveyed school boards annually on this same issue and has noted a slight improvement in this area. Specifically, in 2012, 56% of school boards reported that programs for students with autism always incorporated relevant ABA methods, compared to 51% in 2009.
- The Ministry of Education has recommended to school boards that staff with ABA expertise have the following competencies: postgraduate studies or equivalent field experience in autism and behavioural science; experience working with children and youth who have special education needs (particularly those with autism); and training in ABA principles from a recognized institution. However, the Ministry of Education did not ensure that school boards hired such staff with the recommended competencies.
- Neither the Ministry nor the Ontario College of Teachers (College), the body responsible for accrediting Ontario's teacher education programs, can provide specific data on the

amount and content of special education training currently provided by faculties of education under existing teacher education programs. Starting in September 2015, when all teacher education programs in Ontario are expanded to two years, they will include an enhanced focus on special education. The College, with input from the Ministry and others, will also be developing a guide for faculties of education with examples and details of expected course content. This is an opportunity for the Ministry to help ensure that future educators obtain the necessary knowledge to help school boards comply with the Ministry's 2007 policy on incorporating ABA methods into programs for students with autism.

- According to the Ontario College of Teachers, teachers who complete a qualification course about teaching students with communication needs and autism are exposed to ABA methods. But as of May 2013, only 500 of Ontario's 234,000 teachers had completed this course. At the time of our audit, the Ministry of Education told us that over 16,000 educators have been trained by school boards or the Geneva Centre for Autism to use ABA teaching strategies in the classroom. Overall, however, according to the Ministry of Education's 2012 survey, 62% of school boards reported that not all their teachers who work with children with autism have had formal training in ABA strategies. At the four school boards we visited, this lack of formal training was somewhat mitigated by the fact that they had their own ASD resource teams with whom teachers could consult.

### Transitioning from Community-based Intervention to Schools

To help children leaving the IBI program to start school or return to school full-time, the Ministry of Children and Youth Services along with the Ministry of Education introduced the Connections for

Students (Connections) initiative in 2008/09. By March 2010, the initiative had been implemented province-wide.

The Connections initiative is centred on a multi-disciplinary, student-specific, school-based transition team that includes parents, school board staff, a principal or designate, and an ASD consultant from the Ministry-funded agency that delivers the School Support Program. This team is established approximately six months before the child leaves the IBI program and is intended to provide support until at least six months after the child starts or returns to school.

In 2011/12, about 1,200 children received transition support services in the Connections initiative, which we calculated represents over 90% of those children who were discharged from IBI within the applicable period (from October 1, 2010 to September 30, 2012). The service agencies we visited estimated that their ASD consultants spend 25% to 55% of their time on Connections matters.

We reviewed a sample of files for children discharged from IBI between April 2011 and February 2013, and determined that, for the most part, children's strengths, needs and issues related to the transition process were discussed in monthly transition meetings in the presence of an ASD consultant, the child's parent and teacher. However, in 20% of cases, there was no evidence that ASD consultants transferred instructional strategies involving ABA to school staff.

## RECOMMENDATION 4

To better ensure that children with autism receive cost-effective supports while in school, the Ministry of Children and Youth Services, in conjunction with the Ministry of Education, should:

- review the need for the use of autism spectrum disorder (ASD) consultants at many school boards that already employ people to provide similar services, and ensure that all ASD consultants are effectively utilized;

- define minimum training requirements to assist existing and future educators to use applied behaviour analysis (ABA) principles in the classrooms, and monitor uptake of these education programs; and
- assess the usefulness of various online and other resource tools available to assist teachers with effective educational practices for students with autism, and facilitate cost-effective access to the best tools available.

### MINISTRY OF CHILDREN AND YOUTH SERVICES RESPONSE

The School Support Program (SSP) was designed so that its ASD consultants work closely with school boards to customize their services based on local needs and, as a result, delivery of the program may vary across the province. When the program was first introduced in 2004, there were few autism-specific or ABA supports available in schools. Since then, school boards have developed increased expertise and capacity to support students with ASD. In the context of this increased school board capacity, as well as the cumulative positive impact of the SSP in building capacity among educators, the Ministry has taken some initial steps to review the SSP and is planning to move \$3.6 million in 2013/14 and \$4.5 million in 2014/15 from the SSP to the AIP to relieve some of the wait-list pressures for IBI services.

The Ministry will direct service providers to prioritize SSP services that are child-specific (for instance, the Connections for Students initiative) over other types of SSP services provided to school boards (for instance, board-wide training or resource development). The Ministry will continue to work with the Ministry of Education to assess how to use the program's remaining resources to best meet the needs of children with ASD.

### MINISTRY OF EDUCATION RESPONSE

The Ministry of Education recognizes the importance of training educators who work or may work with students with ASD to use ABA principles in the classroom. The Ministry recently established a provincial ABA Expertise Working Group to define training requirements to assist educators in incorporating and using ABA principles in the classroom. It also plans to conduct regional consultations in spring 2014. The Ministry plans to communicate these training requirements at the third annual ABA Professional Learning Day in April 2014.

The monitoring of the uptake of ABA training is conducted at the school board level. However, the Ministry will annually monitor how training requirements are implemented by school boards starting in 2015.

The Ministry will communicate training requirements to assist educators in incorporating and using ABA principles in the classroom to the Ontario College of Teachers and faculties of education as an example of an effective special education instructional strategy.

The Ministry recognizes that in recent years a wealth of research and resource materials has become available on how best to support students with ASD. The ABA Expertise Working Group is expected to identify resources that have proven to be effective in improving the outcomes for students with ASD by spring 2014. Such resources will be disseminated via an online forum for professionals with ABA expertise that the Ministry plans to launch in spring 2014. The Ministry will continue to facilitate educators' access to the best tools on how to support students with ASD.

### Transition Services for Older Children

Changes, such as moving from elementary to secondary school, entering adolescence or completing

secondary school, can be challenging for children with autism and the people responsible for their care.

Since 2006, the Ministry has provided annual funding totalling \$1.5 million to approximately 40 agencies to help children with autism transition into adolescence and high school. These agencies provide services such as developing interpersonal and coping skills; coaching youth with employment, volunteer or recreational activities; crisis intervention; behavioural supports; and family counselling and support groups to give parents the skills to help their children transition. This funding is also used for purposes other than transition planning, such as enhancing respite services and training parents or caregivers on the disorder. In the 2012/13 fiscal year, the program served approximately 1,000 youths and their families.

Based on our discussions with service providers that deliver transition programs in the three regions we visited, access to these programs varied from referrals through schools to youth hand-picked by the agency. Wait time for such services could range from 4 months to 3 years.

To help children transitioning within the school system (for example, moving from one grade to the next or changing schools), boards we visited have autism resource teams, ABA experts, and special education resource teachers to support teachers who have students with autism. These supports include providing advice to teachers in developing behaviour safety plans and individual education plans, responding to crisis situations, and providing linkages to post-secondary schools and work experience.

When it comes to transitioning youth to the adult system, representatives from school boards and stakeholders told us there is a shortage of adult services, so some parents stop working to stay home with their adult child. In addition, school boards did not generally collect data on what becomes of youth with autism after they leave school. By 2014, all Ontario students will have a unique identifier that will follow them to post-secondary education. The government will

have the means to at least track students with autism who go on to college or university.

In 2011 the Ministry of Children and Youth Services and the Ministry of Community and Social Services introduced a transition planning framework for young people with developmental disabilities and indicated that planning is to begin early. In December 2012, the Ministry's regional offices implemented protocols to formalize transition planning responsibilities between organizations funded by either the Ministry of Children and Youth Services or the Ministry of Community and Social Services, and to help establish expectations for a more systematic, co-ordinated and transparent approach to transition planning for youth with developmental disabilities. In January 2013, the initiative was expanded to include the Ministry of Education with the intent to help support smooth transitions from secondary school to adult developmental services, further education, employment, participation in life activities and community living. The inclusion of the Ministry of Education in the transition planning process required revising the recently implemented protocols. The protocols took effect at the start of the 2013/14 school year, after our audit fieldwork had been completed. The agencies are expected to implement transition planning for youth as part of their existing program funding.

We noted the following concerns with the transition planning process:

- It is unclear whether community agencies that serve youth or adults with autism are required to participate in transition planning. The transition planning protocols are designed for youth and adults with developmental disabilities and are not specific to youth with autism. Neither the protocols nor the framework define developmental disabilities. The Ministry recognizes that the meaning of developmental disabilities currently differs under the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* and the *Child and Family Services Act*, and there is no definition under

the *Education Act*. In September 2013, an implementation guide developed by the ministries of Children and Youth Services, Education, and Community and Social Services was provided to school boards to advise them that students with exceptionalities besides developmental disabilities—for instance, autism—could be considered eligible for transition planning. However, it also stated that community agencies were “expected to continue to use their current practice regarding the definitions of developmental disabilities.”

- The Ministry is unable to tell us how many youth with autism will be addressed by this framework. Anticipating that there would be a large volume of youth and adults affected by this transition planning initiative, the Ministry has prioritized its implementation to first serve adults still residing in children’s residential services, then young people aged 14 to 17 who are in children’s residential services, and finally young people 14 and over who are not in children’s residential services. The Ministry does not have data on the number of youth with autism in each of the three priority groups. People we consulted suggest that most youth with autism are in the last priority group.
- We reviewed the outcomes listed in the framework and noted that they were mainly focused on aspects of the transition plan and did not define what would constitute a successful transition. Further, the Ministry had not otherwise established a process to assess whether individuals made a successful transition—for example, through satisfaction surveys.

As mentioned previously, the Legislature recently created a select committee to work on a comprehensive developmental services strategy for Ontario that will help co-ordinate the delivery of developmental programs and services across ministries, with a particular focus on needs related to education, work and housing.

## RECOMMENDATION 5

To help ensure that appropriate services and supports are available to persons with autism as they prepare to leave the children and youth system, the Ministry of Children and Youth Services, in conjunction with the Ministry of Community and Social Services and the Ministry of Education, should develop processes to assess whether individuals with autism made successful transitions, including surveys to gauge satisfaction for those who made the transitions and their families.

## MINISTRY RESPONSE

The Ministry of Children and Youth Services, the Ministry of Community and Social Services, and the Ministry of Education have worked collaboratively to establish processes that support integrated transition planning. Through integrated transition planning processes, young people with developmental disabilities, including autism, will have a single integrated transition plan that will inform educational planning, help the young person transition from secondary school and child-centred services to adulthood, and help prepare parents or guardians and other family members for these transitions.

As part of the implementation of integrated transition planning, the three ministries are developing a plan to evaluate the effectiveness of the integrated transition planning protocols.

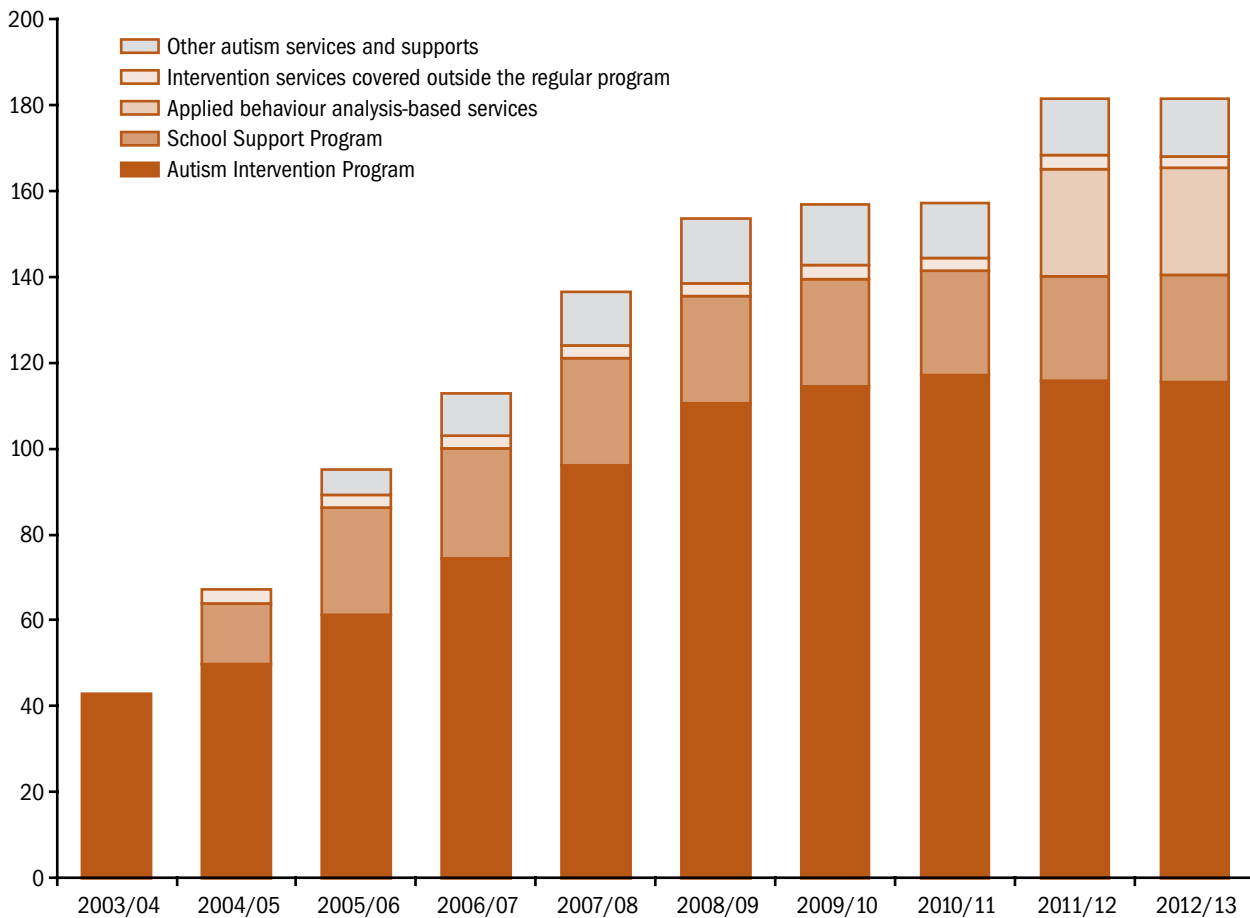
## AUTISM FUNDING

Between 2003/04 and 2012/13, the Ministry quadrupled annual autism funding from \$43 million to \$182 million, primarily through an almost three-fold increase in funding for IBI services and through the introduction of measures such as the School Support Program and applied behaviour analysis-based services, as illustrated in Figure 7.



**Figure 7: Autism Services and Supports Expenditures, 2003/04–2012/13 (\$ million)**

Source of data: Ministry of Children and Youth Services



As previously mentioned, there has been a wait list for autism therapies since program inception. Based on the prevalence rates of autism in South-eastern Ontario from 2003 to 2010 (the only prevalence rates available in the province), the change in total program funding surpassed the change in the prevalence rates for each year from 2004 to 2007, yet this still did not significantly reduce the wait list for IBI therapy. From 2008 to 2010, the change in prevalence rates surpassed the change in total funding by an average of 8% a year.

Over the five-year period ending in 2012/13, transfer payments to service providers for IBI services increased by 20%, while the number of IBI spots remained virtually unchanged at 1,400. During this time, the number of children who received IBI services increased by 14%, which could have been due to a number of factors, such as improved

operational efficiency at agencies, fewer hours of therapy being offered to children, and/or children being discharged from therapy sooner.

### Reasonableness of Funding Allocation

In order to assess whether resources were being distributed equitably across the province, the Ministry would need to compare funding distribution to the demand for services across the regions. However, it had not done so by the time of our audit. Demand for services is represented by children being served and those waiting for service. We compared eight of the regions on this basis (we omitted one region because it places children on the wait list before diagnosis, contrary to policy) and noted that in two regions, their share of total funding was not in proportion to the demand for services in those regions.

We analyzed unit costs for two of the most significant autism services and supports in the 2012/13 fiscal year, and noted a wide variation in cost per service provided across regions, as illustrated in Figure 8. Significant variances were noted in the prior year as well, but had not been followed up by the Ministry.

### Comparison Between Service Delivery Options

In November 2004, the Ministry told the public accounts committee that it would examine the cost variances for IBI services between the direct funding model and the direct service model. In 2008, the Ministry hired a consultant to conduct a costing analysis of the IBI program. Among the consultant's findings was that for the 2005/06 fiscal year, the average cost per hour under the direct service option was \$55 and ranged from \$47 to \$87 across the nine regions, whereas the average cost per hour under the direct funding option was \$37 and ranged from \$27 to \$44 across the nine regions. According to the consultant's report, the lead service agencies' reasons for higher unit costs per hour under the direct service option included the following:

- the direct service option gives clients access to a wider range of clinical services and covers all IBI-related costs (such as travel, materials, equipment, assessments, progress reviews, parent meetings), while parents themselves pay these costs under a direct funding option arrangement;
- providers under the direct service option have higher staff costs because their therapists are more likely to be unionized, their therapists

are likely to receive more clinical supervision, and therapists' costs are incurred for cancelled appointments; and

- providers under the direct funding option might be charging parents more than the capped rate, with parents paying the difference.

The Ministry informed us that it took no action on the consultant's findings because it felt there were too many variables across regions and the report was not conclusive enough to lead to any kind of costing benchmark. However, the Ministry did not attempt to do a more meaningful analysis of the reasons for the cost variances under the two service delivery options. In particular, the Ministry has not required agencies to track and submit supervision and direct therapy hours for either service delivery option.

Due to a lack of information on actual IBI therapy hours, we analyzed the average cost per child for one year of therapy under both service delivery options in the three regions visited and noted that it costs 66% more for the government to deliver services under the direct services option than it does under the direct funding option, even after we allocated overhead costs—costs for administration, wait-list management, and clinical supervision—between the two service delivery options. This analysis does not include any amounts that parents would pay out of pocket under the direct funding option.

The direct funding option rate of \$39 per hour, set in 2006/07, is meant to capture all aspects of required services including direct therapy, supervision, travel and materials. The rate has not been reviewed since.

However, rates obtained by families often depended on their negotiating skills; we noted

**Figure 8: Unit Costs of Selected Autism Services, 2012/13**

Source of data: Ministry of Children and Youth Services

| Autism Service/Support | Basis of Comparison                                     | Provincial Average (\$) | Regional Variation (\$) |
|------------------------|---|-------------------------|-------------------------|
| IBI                    | Cost per child per year of service                      | 56,000                  | 50,800–67,000           |
| ABA                    | Cost per hour of service to children, youth and parents | 140                     | 70–340                  |

instances where the same private provider charged clients different amounts for the same service. For example, for the same one-month time period, one provider charged a client its established fees for all hours of service provided, which exceeded the client's allowance by \$480 for the month; the same service provider charged another client for fewer hours of services than what the client actually received, just so the client could be fully reimbursed by their direct funding option allowance, resulting in the latter client saving \$460.

### RECOMMENDATION 6

To ensure that all regions use autism funding cost-effectively to meet local demands, the Ministry of Children and Youth Services should:

- ensure that all lead service agencies place children on the wait list for IBI services only after determining their eligibility, and review whether its funding allocation is aligned with service demand;
- periodically compare and analyze agency costs for similar programs across the province, and investigate significant variances; and
- review the reasonableness of the hourly rate under the direct funding option, which was set in 2006.

### MINISTRY RESPONSE

The Ministry will direct all AIP agencies to review their practices for placing children on wait lists and ensure that their practices are consistent with the AIP guidelines. The Ministry will direct agencies whose practices are not in line with the guidelines to bring their practices into compliance by December 2013. The Ministry will also consider reviewing how funding allocations are aligned with service demand for the AIP.

The Ministry will consider comparing and analyzing agency costs for similar programs across the province.

The Ministry will review the hourly rate for the direct funding option in the AIP.

### OVERSIGHT OF SERVICE PROVIDERS

The Ministry collects service-level and financial data from its service providers on a quarterly basis for each service and/or support offered. Service data tracked includes, among other things, the number of children receiving IBI services, number of children discharged from IBI services, aggregate number of days that children who started IBI waited for service, number of hours of ABA-based services received by children, and number of consultation hours provided by ASD consultants under the School Support Program. Targets are set for each of these areas. Regional offices follow up with service providers when actual levels of service provided differ from targets by more than 10%.

Several years ago the Ministry also began collecting monthly data from service providers for IBI services, respite care and the Connections initiative. Some of the monthly data requested is similar to that submitted quarterly (for example, the number of children who ended IBI services in the period) and some is different (the number of children waiting for IBI services, and a breakdown of children in IBI by service delivery option). Unlike the quarterly information, no targets are set for these data elements.

We had the following concerns with the data collection and analysis:

- Some regional offices we visited did not verify data that is submitted by the service providers. As a result, some data forwarded to the Ministry was not accurate. For example, in one region, the lead IBI service agency reached its target for number of children served in IBI by, contrary to policy, including children still waiting for direct services but whose families were receiving consultation services from a senior therapist. In another example, an ABA partner agency submitted the wrong quarter's data on the number of children waiting for service and the number of days they waited for services. The data was understated by 330 children and 36,000 days in total.

- Some information reported to the Ministry was non-verifiable; for instance, for the School Support Program, service providers we visited tracked participation at training sessions via a head count rather than a sign-in list. In addition, because participants were not individually identified, the Ministry could not determine how many unique individuals were served and how many hours of training or consultation services each received.

We also noted that the Ministry did not collect information that would help it monitor compliance with program guidelines and evaluate program effectiveness. For example, the following information would be useful to monitor and evaluate the IBI program:

- wait time for each child on the wait list to determine the individual's length of wait for services;
- percentage of families on the wait list that received support services;
- number of IBI service hours actually delivered to each child per week to determine whether the agency actually provides between 20 and 40 hours of service each week;
- lost hours of service by cause; and
- change in a child's functionality from the time he or she starts intervention until the time of discharge.

## RECOMMENDATION 7

To better monitor whether service agencies are meeting key program guidelines and providing quality services, the Ministry of Children and Youth Services should review the type of data that agencies are required to submit, and ensure key information is received and analyzed, and periodically verified through site visits.

## MINISTRY RESPONSE

Every year, the Ministry reviews its data requirements to improve data collection. In 2013, the Ministry focused its review on the quality, reli-

ability, transparency and relevance of the data. As a result of this review, the Ministry adjusted the amount and type of data being collected. For example, the Ministry is now collecting and analyzing information relative to the number of service hours that children and youth receive and the length of time they wait to receive service. The Ministry is also tracking the number of children and youth who receive their eligibility assessment for the AIP within the four to six weeks prescribed by the AIP guidelines. The new data collected should help the Ministry's efforts toward continuous quality improvement.

The Ministry will consider collecting the additional information suggested by the Auditor General.

## EFFECTIVENESS OF AUTISM SERVICES AND SUPPORTS

Because the prevalence of autism is increasing and government's financial resources are limited, it is imperative that the Ministry evaluate the effectiveness of its autism services and supports periodically to ensure that children with autism receive the most appropriate and effective services that meet their needs.

### Performance Indicators

Similar to other provinces we researched, the Ministry does not publish any outcome measures to assess its autism services and supports. The Ministry has only one performance measure—the number of children receiving IBI at year-end. However, this is not useful in assessing the effectiveness of the Autism Intervention Program (AIP).

In the 1999 Cabinet submission for the AIP, the Ministry proposed a number of relevant long-term performance measures that would help track the success of the program. These included: identifying children with autism by age 3; significantly

improving functioning for two-thirds of children receiving three years of intensive therapy, and successfully integrating half of these children into regular classrooms; avoiding future health, social service and education costs; and ensuring that 80% of parents are satisfied with services. However, we found that the Ministry has not collected information to measure the achievement of any of these objectives. Furthermore, in November 2004, during a public accounts committee hearing following our 2004 special report on IBI services under the AIP, the Ministry stated that it would develop more outcome-based performance measures but it has yet to do so.

With regard to ABA-based services, the Ministry expects all service providers to collect information pertaining to child outcomes, parent/caregiver outcomes, parent/caregiver satisfaction with service delivery, and system outcomes. Similarly, with regard to the School Support Program, the Ministry expects service providers to provide annual reports outlining achievement of key outcomes. However, in both cases the Ministry does not specify any performance measures. For the ABA program, we noted the only outcome data that the Ministry has asked service providers to submit was on the number of children who met their goals upon completion of ABA-based services, which in 2012/13 was 88%. Although this would be a good performance indicator, no target was set and no other objective performance outcome data was collected, such as that which could be obtained from parent satisfaction surveys, for instance. In the case of the School Support Program, no service quality or outcome-based information was collected.

### Program Evaluations

In 1999, the Ministry indicated that it would evaluate the program to demonstrate that it is making a difference to families of children with autism. The Ministry further noted that it would modify the program based on evaluation data in order to increase the likelihood of meeting its long-term objectives.

In 2006, the Ministry commissioned an external consultant to evaluate the outcomes of children who received Ministry-funded IBI services. Specifically, the goal of the study was to determine whether children showed significant improvement and to identify factors that predict greater improvement. The consultant reviewed the case files of over 300 children who received IBI services at any time between 2000 and 2006, and among other things compared their assessments at time of entry and exit from the program. The study found that 75% of children showed measurable progress or improvement, and a subset (11%) of them achieved average functioning. Improvements were seen in the severity of their autism, their cognitive level, and their adaptive behaviour (that is, communication, daily living, socialization, and motor skills). Improvements were noted with all groups of children regardless of their initial level of functionality, but those who were initially higher functioning had the best outcomes or made the most progress. Children who started IBI before age 4 did better than those who started after age 4. Children who received two years or more of IBI did better than those who received a shorter duration of IBI. The consultant concluded that the initial level of a child's functionality was a better predictor of improvement, although it didn't account for all the variability, followed by the child's age at the start of therapy and then the duration of therapy. While the study had its limitations, the experts we consulted said these findings were valid and consistent with other research. Despite the results of this evaluation, no modifications were made to the program, such as letting children with milder forms of autism access IBI.

Although the IBI program has been implemented in Ontario since the year 2000, no study has followed the cohort of children who received or were denied IBI services in that time to help assess the program's long-term impact. In addition, no study has been done to determine whether children's outcomes differ by service delivery option. Without such studies, the Ministry has not been able to assess whether the program is effective as designed.

The lack of a long-term effectiveness study (that is, a study looking at the long-term outcomes of children with autism who acquired intervention services at a younger age) is not unique to Ontario. Having said that, we noted that a national study, funded by the Canadian Institutes of Health Research and others, is following groups of children with autism from diagnosis until age 11. The study was announced in 2004 and will continue until 2014, and includes children from one part of Ontario. The initial findings of this study speak to the importance of developing ASD intervention services that are delivered as early as possible and are diverse, flexible, and sensitive enough to meet the needs of children with ASD who have very different clinical profiles and follow different developmental pathways.

### RECOMMENDATION 8

To help ensure that services and supports for children with autism are meeting their needs, the Ministry of Children and Youth Services should:

- develop performance measures and targets for each of its autism services and supports to assess their effectiveness in improving children's outcomes;
- conduct periodic program evaluations, including parent satisfaction surveys, and consider conducting a long-term effectiveness study of children who received IBI services and children who were denied IBI services; and
- modify services and supports as required.

### MINISTRY RESPONSE

The Ministry agrees that it is important to assess the effectiveness of its services and supports for children and youth with autism and to adjust the programs if necessary so that they are as effective, cost-efficient and accessible as possible.

The Ministry strategically reviews the autism data that is collected to ensure it addresses five areas—effectiveness, efficiency, accessibility, equity, and client profile. The Ministry will continue to evaluate its data with a view to developing a broader autism services evaluation plan, including performance indicators and targets.

The Ministry has developed an ABA-based services evaluation plan with key performance indicators to assess program effectiveness, efficiency and accessibility, and families' experiences with ABA-based services and supports. This plan also includes the use of evidence-based tools to assess client outcomes and client satisfaction with ABA-based services. The evaluation began in fall 2013. Based on this work, the Ministry will consider options for measuring family experience in the AIP.

The Ministry will continue to closely monitor external research on the effectiveness of its programs, including research being conducted by the Canadian Institutes of Health Research on the effectiveness of the AIP.