Briefing Note for Minister Tracy MacCharles, Minister of Community and Social Services

Subject

Rethinking the Ontario Autism Program - Direct Funding as a Way Forward

Issue

Ensuring the delivery of a fiscally efficient, flexible, evidence-based and transparent intervention service to all children with autism spectrum disorder (ASD) for whom Intensive Behaviour Intervention (IBI)/Applied Behaviour Analysis (ABA) has been prescribed by an independent clinical psychologist and/or developmental pediatrician - in a timely manner and at the intensity and duration prescribed, regardless of their age.

Background

On March 29, 2016, the Ministry of Children and Youth Services (MCYS) launched its new Ontario Autism Program (OAP) the aim of which was to create a "more flexible" system in order to "provide a responsive continuum of supports."

This new OAP aims to harness the resources of two programs already in existence:

1. The Autism Intervention Program (AIP), which has as a goal to provide high quality, evidence-based intensive behavioural intervention (IBI) and related services, such as Child and Family Supports and Transition Services[1]; and
2. The Applied Behaviour Analysis Services and Supports program (ABA Services), which aims to "target the development of specific skills in the areas of communication, social/interpersonal, daily living and behaviour management/emotional regulation".[2]

Autism Intervention Program (IBI Services)

Until May 1, 2016, children in Ontario of all ages diagnosed with autism at or near the severe end of the autism spectrum were eligible to receive between 20-40 hours/week of Intensive Behavioural Intervention (IBI), more commonly referred to as "comprehensive

[1] Autism Intervention Program Guidelines, Ministry of Children and Youth Services, rev February 12, 2007

[2] ABA Services and Supports Guidelines, Ministry of Children and Youth Services, 2011

Applied Behaviour Analysis (ABA)[3], under the AIP. While the AIP's early years were characterized by its limitation to a cohort of 2- to 5-year olds (so-called "Early IBI"), Ontario later acknowledged that it was ethically and clinically appropriate to extend IBI to all children with these diagnoses, regardless of age, and to premise intervention strategies on individualized goals, as opposed to relying on a set of benchmarks.[4] Based on current practice, the average Ontario cost of IBI per child per year under the AIP is $56,000 and the range varies from $50,800 to $67,000.[5]

ABA Services Program

The Applied Behaviour Analysis Services (or ABA Services) program is a much less intensive service delivery model and is open to all children with a diagnosis of autism spectrum disorder regardless of severity. A block of this kind of programming is typically (although, not exclusively) conducted in group-based sessions during which parents are trained to work with their children on a previously established and defined subset of skills. ABA Services are generally at an intensity of 1- to 2-hours per week for 8-12 weeks and an average cost of $3,800 per child per block.[6] The program has not yet been externally assessed for its clinical or its programming benefits.

Ontario Autism Program

The new OAP aims to overcome the waitlist challenges plaguing autism intervention services in Ontario and to provide the youngest children waiting for intervention access to it in a timely manner. It is achieving the latter by removing access to intensive service for older children under the logic that these children have a lower likelihood of benefiting from IBI, when "benefit" is defined as "closing the developmental gap". Thus, a key part of the launch of the new OAP over the past month has been the announcement to parents of children over the age of 5 currently on the AIP wait list and those in service turning 5 this year that their children were no longer eligible for this service, despite their child's diagnosis and the clinical documentation they may have prescribing this intervention.

Families are being offered a one-time lump sum of $8,000 to purchase community-based services immediately and advised that they can place their names on the ABA Services list and await for the roll-out of the new, "moderate"[7] intensity service that the new OAP aims to build upon the ABA Services infrastructure, entitled the ABA Program This new program will also provide blocks of ABA programming for, initially, a maximum of 20 weeks and, later, a maximum of 32 weeks - ostensibly, based upon individual need, as long as this need is deemed to be within these predefined parameters. And, when a child's block is completed, he or she may return to to the waitlist and await another

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3 Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers, Behavior Analyst Certification Board, 2015, p. 14

4 Pre-Implementation Analysis of the Proposed Benchmarks for Intensive Behavioural Intervention (IBI) Services, March 21, 2010

5 Auditor General Report, Autism Services and Supports for Children, 2013, p. 77

6 Ibid.

7 What "moderate" means is unclear at this time. The range of levels of intensity has not been shared with families nor has any clarification been forthcoming during the family engagement webinar series.

rotation. The aim of the OAP is to ensure wait times do not extend to more than 6 months.

Intensive services, under the OAP, are only available to children between the ages of 2 and 4, regardless of the recommendations of diagnosing clinical psychologists or developmental pediatricians. These changes, it was argued, would eliminate the multi-year wait list times for IBI and would ensure that children receive intervention at a younger age thereby having a better chance at "closing the developmental gap".

Observations

Spending on autism services has more than quadrupled from the province's initial $44 million investment to $192 million in 2013-14.[8] Meanwhile, wait lists have remained a constant area of concern for both the program and its stakeholders. While, the province boasts strong intervention capacity, it also suffers from a reliance on wait lists, challenges in delivering appropriate clinical service, and high operating costs.

Intervention Capacity

When the AIP was launched, a key argument for the adoption of the current regional service delivery model was a lack of sufficient capacity within the community. Since then, Ontario has invested in developing qualified therapist capacity and now has an excellent and growing supply available to meet demand. A 2011 MCYS report on the status of autism and behaviour training certification within the province confirmed that "573 students have already graduated from this program and enrolment in 2009-10 grew to more than 399 students. This will continue to increase the pool of qualified therapists'.[9] Today, accounts among families, practitioners and in the media speak less frequently of a lack of resources and more often of unleveraged, qualified private resources.

Ontario also boasts an excellent supply of both clinical psychologists and Board Certified Behavior Analysts (BCBAs) and a growing field of developmental pediatricians as well. From the perspective of front-line delivery of ABA programming,BCBAs are experts in behaviour analysis, the science underpinning all ABA approaches, and an essential component of a rigorous ABA clinical supervision team. In 1999, when the AIP was launched, Ontario had no BCBA capacity to leverage for this function. Today, Ontario has the highest number of BCBAs in the country at 433. British Columbia currently has 96 registered BCBAs and Alberta only 20.[10]

Waitlists

Waitlists seem to be a systemic trait under the current regional service provider model. At the end of 2015, 13,966 children were on the ABA Services wait list while a further

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[8] See Annex 1 or MCYS Results-based Plan Briefing Book, 2014-15, Ministry of Youth and Children's Services, for details on this rise in costs

[9] MCYS Results-based Plan Briefing Book, 2010-11, Ministry of Youth and Children's Services

[10] See the Behavior Analyst Certification Board registry, for details on BACB certificants, including their location.

2,192 children awaited IBI.[11] Indeed, a critical weakness of the current approach to autism intervention service delivery in Ontario is that wait lists themselves are viewed as a necessary evil. Even the recently announced OAP ABA Program[12] not only *anticipates* wait lists but, as mentioned earlier, has actually established *targets* for them.

From an ABA programming standpoint, little about this approach makes sense, as the vast majority of the children that were just removed from the AIP IBI wait list were on it because their diagnoses are either severe or near the severe end. In other words, the recommended course of treatment is *intensive* intervention over a *sustained* period of time - not moderate intervention in blocks of time. And, such an approach increases the risk of fiscal waste, as the likelihood of children *losing* learned skills in-between blocks of treatment will most certainly increase meaning that some may have to revisit earlier goals more than once at taxpayers' expense.

In short, *many* children are simply being asked to switch wait lists today, as part of the program reform strategy, and all children are being asked to wait in-between iterations of ABA programming - whether or not the maximum duration or intensity under the new rules is in line with the child's clinical needs. This is not an individualized approach nor does it reflect the flexibility that the new OAP aims to deliver.

Clinical Services

Ontario prides itself on delivering autism intervention services in an evidence-based manner, which is both a laudable and prudent approach to public policymaking. For ABA interventions, the *science is Applied Behaviour Analysis* - a very specific discipline with its own code of conduct and clinical guidelines. The Ontario Association for Behaviour Analysts (ONTABA) has noted that "many of the reviews and meta-analyses cited in the January 2014 report titled Autism Spectrum Disorder in Ontario 2013[13] conflate studies of ABA interventions with studies of other intervention models that are sometimes described as "behavioural" or "based on ABA" but do not have the well-established defining characteristics of ABA or comparable supporting evidence".[14]

This is important since, while there is much overlap between studies for a clinical psychology research audience and ones for those engaged in ABA research and practice, a targeted review of studies focusing on *skill development* and *independence* (as opposed to a potentially discriminatory emphasis on changes to IQ or age) confirm both the value and validity of ABA interventions - even comprehensive ABA - for children over the age of 5. This divergence from the perspective on outcomes stems from, among other factors, the fact that the ABA literature does not assess "success" against a goal of "closing the developmental gap". The aim, in ABA, is to ensure that each child develops as many skills and as much autonomy as possible so as to be able to navigate adulthood more independently. ABA is not a cure nor is it a tool to make children with autism "normal".

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11 Over 16,000 children on Ontario wait lists for autism services, National Post, November 3, 2015

12 This program, it has been explained to families, will replace AIP, for children over 5 and will provide intervention up to "moderate" intensity for a limited duration through a Direct Service model, i.e. through services organized via one of the regional service providers.

13 Autism Spectrum Disorder in Ontario 2013, Autism Spectrum Disorder Clinical Expert Committee Report

14 ONTABA Response to MCYS Ontario Autism Program, April 27, 2016

It is an intervention to ensure that children diagnosed with autism may, to the best of their abilities, engage in their lives as independently and as fully as possible in future years. Clinical services that do not recognize this miss the point of both less intensive ABA and IBI.

A number of program and system biases are evident within current clinical practice. As mentioned above, programming focuses on changes to age and/or IQ as indicators of success, which raises both legal and clinical concerns. Also, program measures encourage perverse bureaucratic behaviours in a system environment in which there is limited oversight by public servants or political staff. Finally, service delivery processes relating to evaluations, assessments and discharge of service have long been critiqued by stakeholders for being duplicative and opaque regarding how so-called "individualized" program goals and other criteria are established.

Defining Success in ABA/IBI Programming

As implied above, how one defines success is as important as how one assesses outcomes. Traditionally, while the AIP has defined clinical success in terms of changes in IQ and adaptive scores, it has conceptualized program success in terms of the volume of children accessing IBI annually. Both definitions, when considered more closely, severely limit the validity of the conclusions reached. A child's ability to meet ABA programming goals may depend on many variables unrelated to age or IQ. It is curious that the research conducted on AIP cases, therefore, which associates outcomes with these two variables, does not test quite as rigorously the potential independent impact of the delivery method on outcomes observed, i.e. level of intensity, the appropriateness of the goals, duration of programming in relation to other studies with a wider range of timelines, etc. In practice, for example, most children who receive or have received service under the AIP did so at an intensity of 20-25 hours/week, i.e. the low end of what is clinically advised for comprehensive ABA[15] and, in some regions, the number of hours was (is) standard across all or most qualifying children. Similarly, the clinical research supports prescribing *more* than the minimum number of hours per week to children who have compounding challenges to acquiring new skills[16] but this has not been a consistent practice under the AIP, raising questions in court cases and elsewhere of whether the data upon which the analysis of program outcomes is based is valid. What *is* clear is that conclusions reached through an examination of AIP cases should be considered in light of the fact that AIP research has focused intensely on traits within children as the explanatory variable of outcomes but little serious examination has been conducted on the traits of the system of service delivery.

And, as mentioned earlier, the science of ABA does not consider changes in IQ scores to be the key indicator of ABA program success. Instead, success (or "mastery") is determined by goals established within each child's individual program. Ontario's singular focus on "closing the developmental gap" ignores the vast potential of the majority of this cohort, who may never do so but who may, with appropriate intervention,

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15 Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers, Behavior Analyst Certification Board, 2015, p. 14

16 c.f. Smith et al, Effects of Low-Intensity Behavioral Treatment for Children with Autism and Mental Retardation, Journal of Autism and Developmental Disorders, 2006, 36 (2), p.211

achieve levels of independence in adulthood that are both fiscally beneficial and clinically desired. "Intensive comprehensive ABA programs have research support for children up to 8 years of age. [And, the] research supports a minimum of 30-40 hours per week (6-7 hours daily, 5-6 days/week) of intensive ABA treatment initially, an amount appropriate for this age level."[17]

Defining Program Performance Success

AIP program "success" is measured against the number of children who access it and not how well they fare in it[18]. Program measures that base success on the number of children accessing IBI annually when the system being accessed has limited capacity both punishes practitioners aiming to provide service until such time as clinically recommended and rewards those who move children through the system quickly, whether clinically advised by the child's supervising team or not. While this was, most certainly, not the desired aim of establishing such a program goal, it is one that, behaviourally, should have been anticipated. It is incumbent upon the Ministry to develop an approach to the public provision of autism intervention support that is both premised upon what science does exist while, also, acknowledging blind spots and gaps - and that rewards the "right" kinds of oversight and coordination behaviours in those delegated the task of managing public resources.

Clinical Pitfalls of Bureaucratization

Templatization of Programming

Individualization is a challenge for large bureaucracies. Bureaucracies lend themselves towards templating and the development of "efficient" processes that may or may not have significant impacts on the service being delivered. In the case of ABA service delivery, where the individualization of goals and goal tracking is critical, the bureaucratization of review processes and the templating of program goals is highly problematic. What may seem like a logical developmental path for one child with autism may be a disastrous one for another. Similarly, what may seem like a positive learning environment for one child can be highly aversive to another. This is why clinical supervision teams for ABA programming are so important, as they are able to scan for each child's "tells" and act to redirect programming, when road blocks or opportunities emerge for skill acquisition, or anticipate next steps so that therapy teams are always teaching to the horizon. The regional service provision model has not proven to be particularly *flexible* or *transparent* in how or if it has effectively achieved the core aim of *individualized* ABA for the children it serves.

Duplication of Effort

Duplication of costly processes is also an area of concern in the current model of service provision. Duplication of effort or process absorbs scarce fiscal resources. In the case of IBI and ABA services, it increases wait times for things like diagnostic assessment for those who really need it. Duplication also creates confusion as to the purpose of the reviews being undertaken. And, it places onerous assessment demands on children who are already in crisis. To demonstrate, in the AIP, the majority of the population of

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[17] Report of the Task Force of the California Association for Behavior Analysis, California Assoication for Behavior Analysis, 2011, p. 12

[18] MCYS Results-based Plan Briefing Book, 2014-15, Ministry of Youth and Children's Services, p.32

children on the waitlist provide diagnostic materials to the AIP from qualified clinical psychologists or developmental pediatricians. Despite the fact that many of these families pay out of pocket at costs averaging $2,000-$4,000[19] for these diagnoses (or wait on long wait lists for publicly funded ones), the AIP process is to engage in the same kind of eligibility assessment with these families as it does with those who have a less fulsome diagnosis.

Costs

The current system grapples with costs that significantly exceed similar services available in the private sector. In 2008, MCYS' Costing Analysis of Autism Intervention Program concluded that the range of costs per hour of DSO IBI therapy received was $47 to $87 per hour, averaging $55 per hour. The same study put the range of costs per hour of DFO IBI therapy between $27 and $44 per hour with the average cost per child being the amount established by MCYS for Direct Funding at that time, i.e. $37 per hour[20]. In 2008, the cost of program administration as a share of the total cost averaged 10%.[21] In 2013, an audit of autism service delivery showed that administration costs had grown and 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".[22]

Regional Service Provision versus Direct Funding

A strategy that does not leverage every taxpayer dollar for the purposes of front-line intervention misses its mark. Despite Ontario's current annual autism budget of $190 million, only 2,245 children received IBI last year, while 2,192 remained on the IBI waitlist. At the same time, 16,000 children were waiting for a block of ABA Services.[23] If one uses the average cost of annual IBI service delivery, i.e. $56,000/child and multiplies it by the number of children served last year the cost of the status quo service delivery is significantly lower than the annual budget of $190,000,000 at $125,720,000, i.e. ($56,000 x 2, 245). While the remaining $64,280,000 can most likely be validated in terms of where and how the funds were spent, it remains the case that these same fiscal resources could have delivered IBI to 1,147 of the children on the above-mentioned waitlist ($64,280,000/56,000). Based upon known values, one can extrapolate that, if each child receives 25 hours/week of services at an hourly rate of $40/hour over a period of 50 weeks (2 weeks off per year), the yearly cost for IBI per child would be $50,000. With the current budget envelope, 3,800 children could be provided with service immediately at the low end of intensive intervention ($190,000,000/$50 000) as opposed to the 2,245 children served last year under the current model. In other words, the current costing of $84,632/child (based on the total budget divided by the number of children served) is 169% of the cost of the same service using a Direct Funding approach.

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19 Andrea Gordon, The Odyssey to Get Your Child Diagnosed and Treated, The Toronto Star, December 14, 2015

20 See Annex 2 or view this data online in infographic form at Why Direct Funding, 2016

21 MCYS Costing Analysis, 2008, p.ii

22 Auditor General Report, Autism Services and Supports for Children, p. 77, 2013

23 Over 16,000 on Ontario wait lists for autism services, National Post, November 3, 2015

Long-Run Savings of IBI/ABA

A 2006 cost-benefit analysis of implementing IBI for all children under the-then iteration of Ontario's IBI program estimated that doing so would have saved then-taxpayers over $43 million in 2003 dollars.[24] This analysis did not consider savings of moving away from the more costly regional service provider model. Like the researchers who undertook the 2006 study, today's stakeholders are also concerned that the current goal of publicly-funded autism intervention does not sufficiently take into account the fiscal benefits of the long-run independence of children currently at high risk of requiring life-long public care. Given the crucial importance of independence in adulthood to the children involved and the long-run fiscal benefits reaped by "paying now"[25] instead of later, it is both reasonable and prudent to invest autism service resources on efficient, flexible front-line service delivery that reaches all who need it in the way that they need it.

Conclusions

Ontario's long-term investment in intervention training and infrastructure should be a symbol of what government can do right. This focus on capacity means that, today and future generations are able to benefit from the skills of well trained individuals and excellent community- and home-based programming. Ontario should be embracing the capacity it has helped create in the form of certified instructor therapists and BCBAs. In doing so, ABA programming will benefit from the wisdom of experts throughout the community who understand how to establish specific, measurable, achievable, relevant, and time-bound goals that can bring out the potential in each individual child.[26]

Ontario should also be embracing this long-term approach in its strategic vision for future autism intervention services, ensuring that the programmatic path is one that provides children with *available*, *accessible*, *flexible*, *individualized* and *timely* support. This strategic vision should put children with autism at its centre, recognizing that, for *a few*, developmental gaps may be closed, but, *for all*, autism is a lifelong diagnosis. ABA intervention, whether prolonged and intensive or of shorter duration and moderate, is the only evidence-based intervention at this time to support children with autism in developing language, social, life and other skills. Ontario's approach to reforming its intervention services should acknowledge its critical role in developing children's independence into adulthood and refocus its program goals accordingly.

And, the costs associated with delivering IBI via the regional service delivery model far exceed those of Direct Funding families for community-based service provision - even when administration and management costs are taken into account. While it is acknowledged that service "pockets" continue to exist within the province, an approach that triages under-serviced areas, while engaging a parallel strategy to increase capacities over time, and finds efficiencies in the remaining regions of the province would allow

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24 The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario, Motiwala et al, 2006, 1 (2), p. 136

25 Pay Now or Pay Later: Autism Families in Crisis, Standing Senate Committee on Social Affairs, Science and Technology, Final Report, March 2007

26 ONTABA Response to MCYS Ontario Autism Program, April 27, 2016

children to access critical interventions immediately. With budget allocations already in place, a revised, "new" Ontario Autism Program could address the needs of all children with autism in Ontario in a manner that is in keeping with the principles of ABA and of fiscal prudence.

In short, a Direct Funding Model that puts children and their families at its centre would be an effective and forward-thinking iteration of this new Ontario Autism Program. Ontario already delivers funding of this kind under the Passport Program through the Ministry of Community and Social Services (MCSS) and mechanisms are already in place for Direct Funding Options under the budgets of all of regional service providers. Changing the direction of the reform would not, therefore, require new programming but, rather, a reinvention of the existing one already under your purview.

Recommendations

It is recommended that you:

1. Redefine the goal of ABA/IBI intervention in Ontario to ensure that it reflects the aims of the ABA literature;

2. Adopt a Direct Funding Model as the centrepiece in the new Ontario Autism Program;

3. Begin transitioning resources currently committed to the regional service provision model towards Direct Funding immediately in those regions where capacity exists to do so.

4. In regions where capacity does not exist, implement a short-term policy of offsetting the purchase of Direct Services, if these are more costly, until such time as less costly capacity is in place; and,

5. Commit to a strategic vision and plan for autism service delivery that does not include short-term waitlisting as a means of triage but, rather, ensures that the service delivery is individualized, continuous, timely and flexible with regard to intensity, duration and location.

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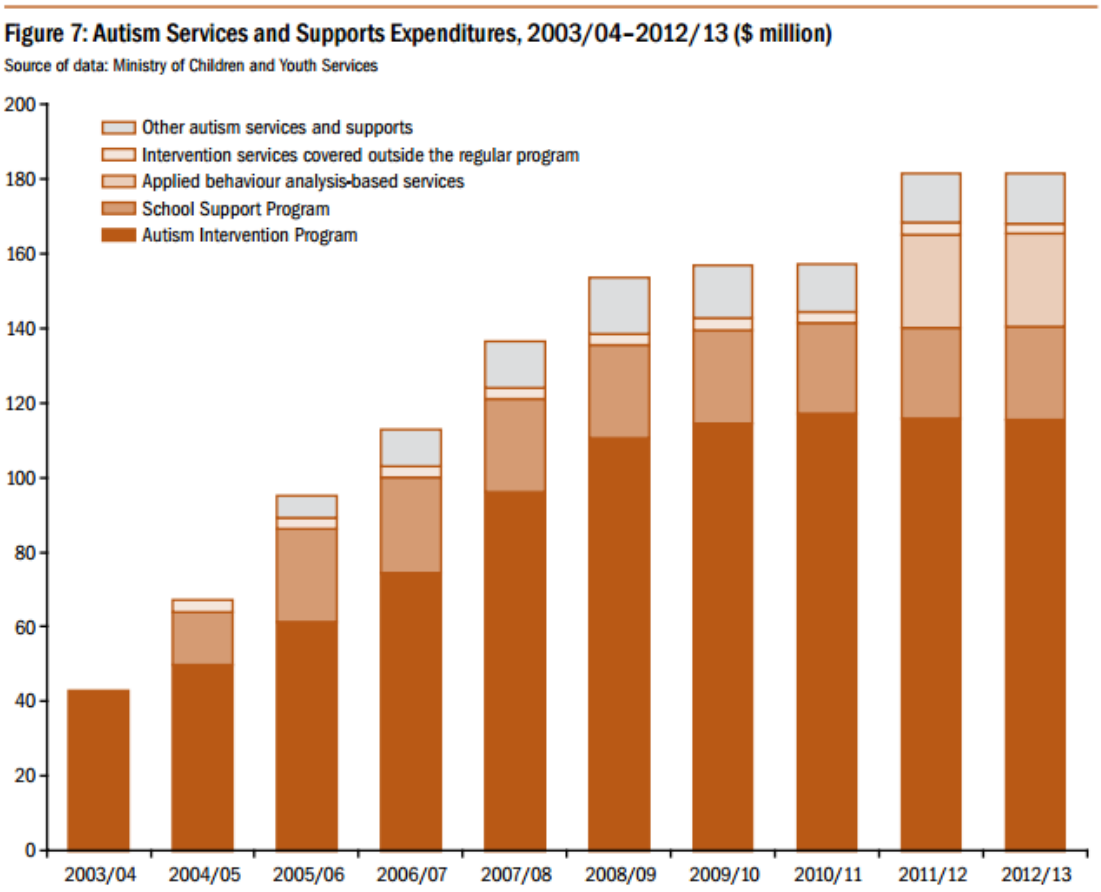
Dated: May 4, 2016

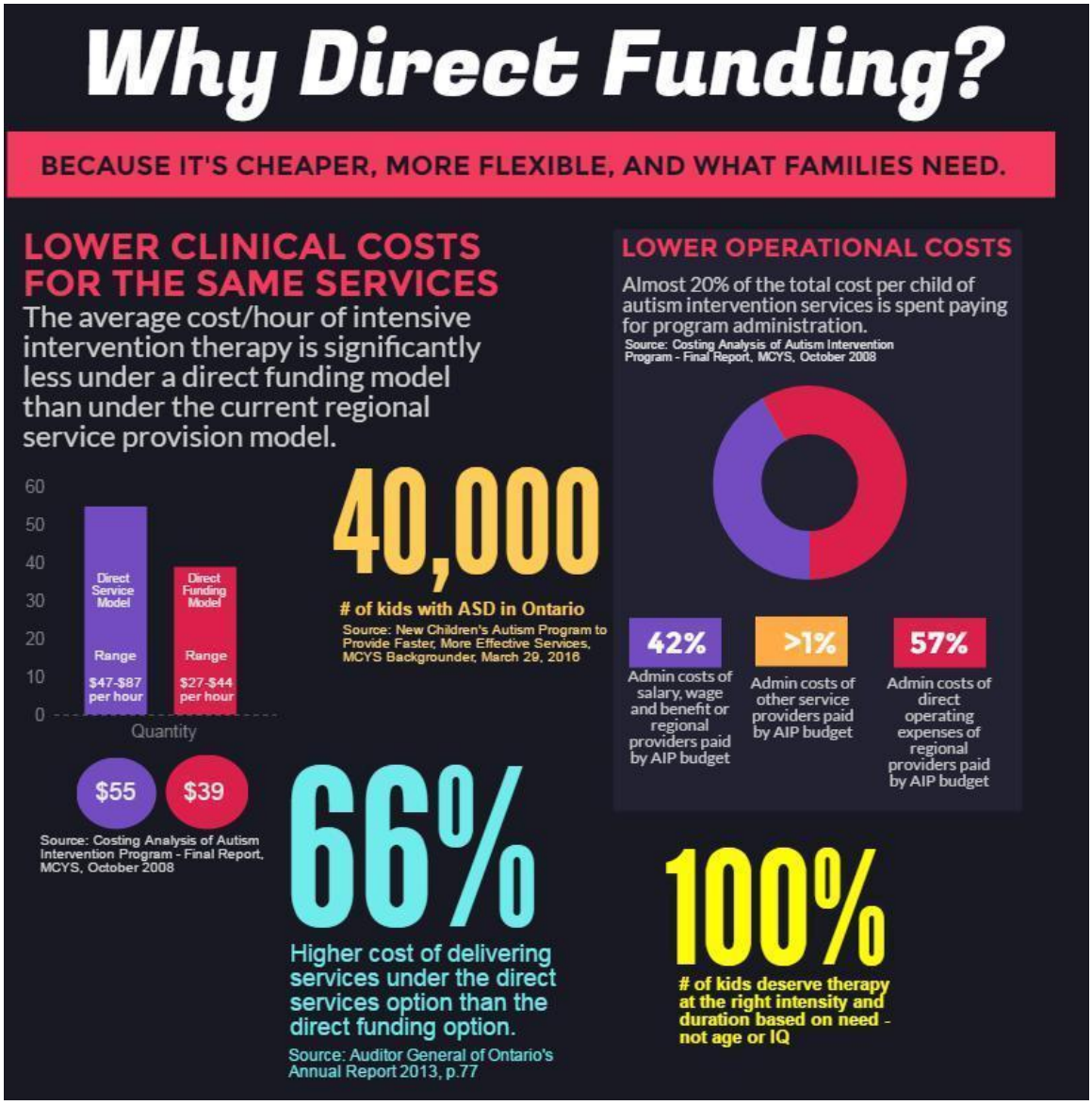
Annexes

Annex 1 - Autism Services and Supports Spending - 2003-2013



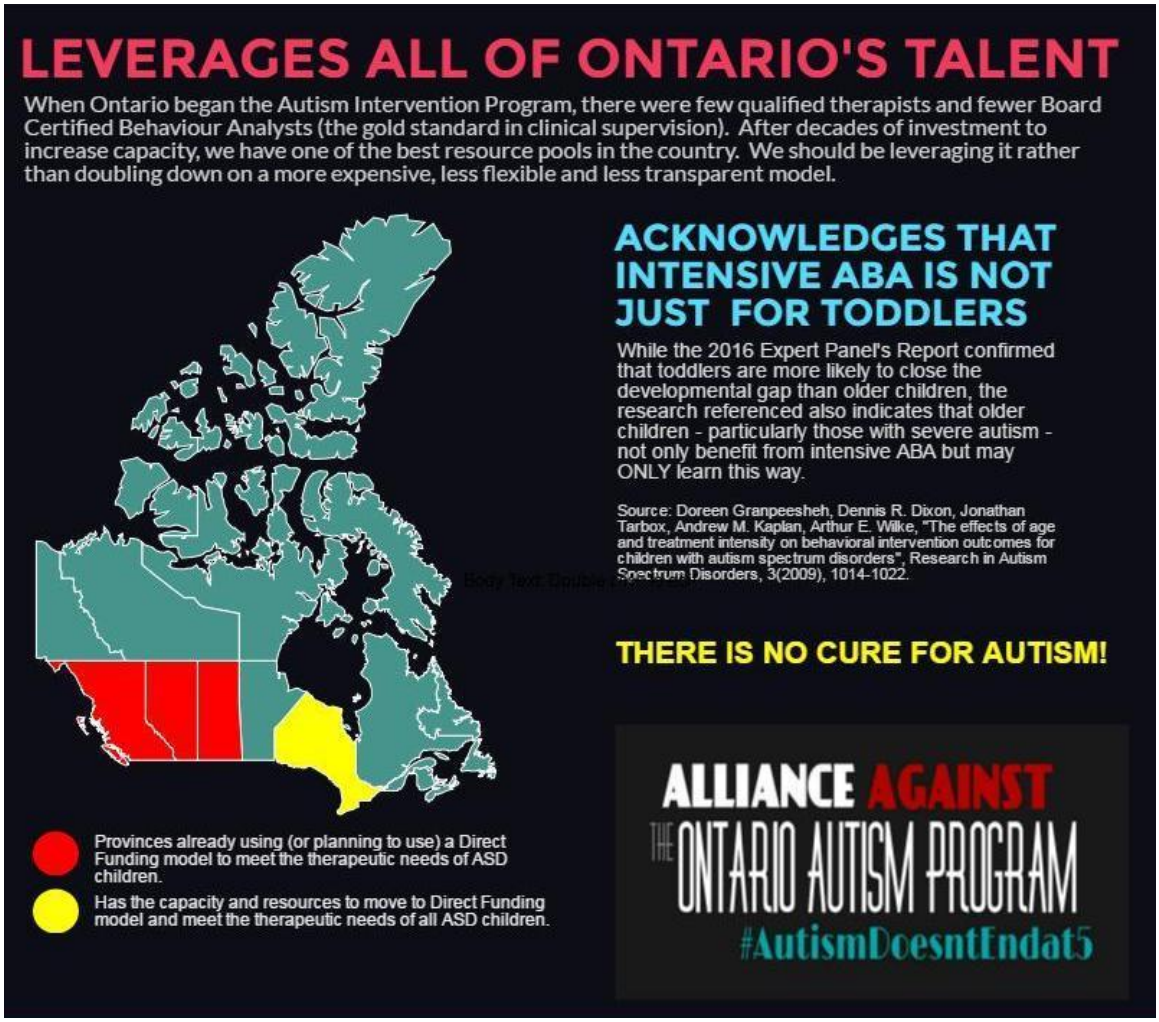
Source: Auditor General Report, Autism Services and Supports for Children, p. 76, 2013

Annex 2 - Why Direct Funding?



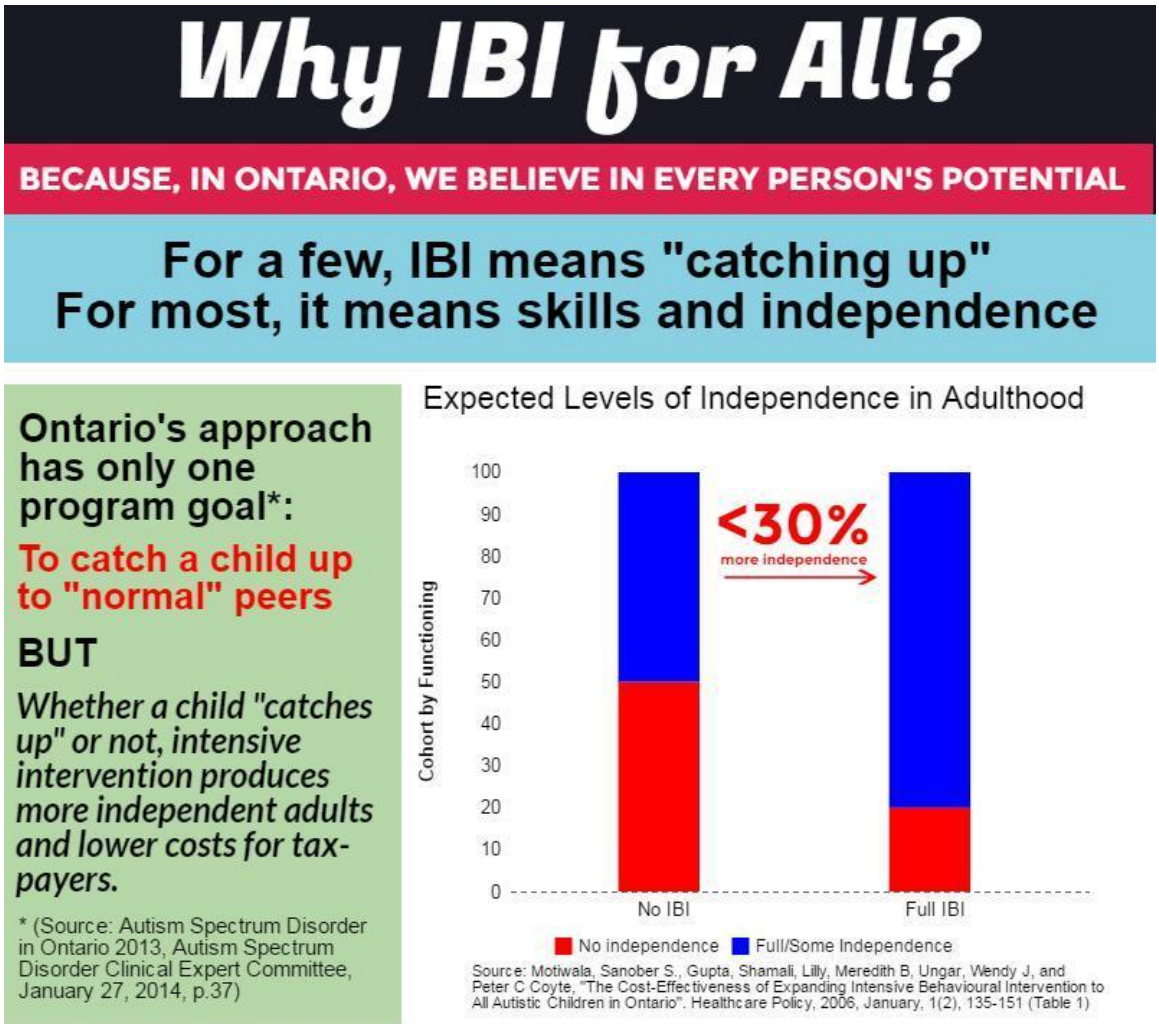
Source: [*Why Direct Funding Infographic, Alliance Against the Ontario Autism Program, 2016*]

Annex 3 - Ontario's ABA Talent



Source: [Why Direct Funding Infographic, Alliance Against the Ontario Autism Program, 2016]

Annex 4 - Why IBI For All?



Source: [*Why IBI For All Infographic, Alliance Against the Ontario Autism Program, 2016*]