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Nov 14-15

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Dear Members,

Six days after I wrote the last entry for the President’s Desk, the Ontario government announced changes to the Ontario Autism Program (OAP). As you know, this announcement was incredibly destabilizing for our field in Ontario and for many children, youth, adults, and families across the province. We have entered a time of uncertainty and it is no surprise that emotions are running high. I completely understand the feelings of disbelief, disappointment, fear, and anger amongst those in our community.

The history of our field in Ontario has been closely tied to serving children, youth, and adults with Autism and this history was built on the commitment of improving the lives through evidence-based interventions. During my years with ONTABA, I have had the honour of meeting many professionals who have dedicated their careers to improving the lives of children and youth with Autism by providing evidence-based intervention, a value which may be lost in the new found direction of the OAP. I empathize with the professionals who have lost their jobs and with those who are facing imminent loss of employment. These professionals made a commitment to their career because they believed in the science.

In this storm, I’m sure you have noticed the galvanized efforts of behavior analysts, caregivers, self-advocates and professionals from a variety of disciplines who have united to advocate for the future of the OAP, and for those who may benefit from behavior analytic services.

ONTABA is committed to its goals outlined in our strategic plan and we will continue to work towards completing these goals. We will continue to work to build a collaborative relationship with the government in order to promote behavior analysis and inform policy based on science so that those who may benefit can access evidence-based, needs-based services.

As a field, we have found ourselves in the public eye more than ever and it is not a surprise that this has resulted in both support and criticism of our science and our field. As behavior analysts, we need to remember to use the knowledge and skills afforded to us by our science. We need to remember that our behavior affects those of others; if we are adversarial, we cannot expect others to receive us in an open, trusting, and collaborative manner. We need to take responsibility, remain professional and find a way forward to construct workable and collaborative relationships with all stakeholders.

With this in mind, ONTABA will continue to seek guidance from our behavior analytic community and from the community at large. As we work to influence positive change and shape misinformed opinions of the science of behavior, let’s look to the literature and fellow behavior analysts to help guide our actions. For example, Morris 1985, (an oldie but a goodie) reminds us that we should not forget the importance of assessing the environment and contingencies surrounding other’s philosophies (i.e., information available to them) and their behavior. If indicated, we need to reduce barriers, set long and short-term goals, and seek support from other professions when
As a starting point, ONTABA encourages members and those who support behaviour analysis to:

Meet with, or continue to meet with, your local MPP to discuss the OAP and the importance of behaviour analytic services being available for those who wish to access them. Connect with a parent or person who is affected by the policies developed by the government and attend a meeting together. Use the May 6th members email as a resource for major themes to highlight during consultations.

Show the community that behaviour analysts are caring people who have chosen a profession dedicated to helping others. Let’s show the community all the positive things behaviour analysis can do to benefit society. Send your inspiring examples to website@ontaba.org so we can disseminate to the community at large (or post them yourself on our Facebook page or tag @ONTABA1 on Twitter). We respectfully request that you ensure you have permission to share these examples publicly.

Remember that behaviour analysts are part of a larger community. We must be willing to listen to others perspectives and engage in behaviours that foster collaboration. To paraphrase a close colleague of mine, collaboration often requires us to engage in difficult discussions, to be willing to sit across the table from each other even when it’s uncomfortable in order to find a solution that works. Consider reading Multidisciplinary Teaming: Enhancing Collaboration through Increased Understanding (2019) by LeFrance and colleagues for further considerations on collaboration.

Whether our interactions are with other members, other professional disciplines, the government or the community at large, I encourage you to continue to look to our vision of fostering a culture of excellence, integrity, and expertise for the advancement and promotion of the science of behaviour analysis as guiding principles.

Sincerely,

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Jennifer Cunningham
President, ONTABA

References

Got Something for an Upcoming Issue?
The ONTABA Analyst is produced quarterly. The remaining issues for 2019 will be released in July, and October. Interested? Send it to us! newsletter@ontaba.org
SPOTLIGHT ON:

OAP

An interview with Adrienne Perry, PhD, C. Psych, BCBA-D.
Professor in the Department of Psychology,
Faculty of Health, at York University

By Raluca Nuta
Treasurer, ONTABA

In your experience, what was the typical process for families of children with ASD to access treatment, before ABA was government-funded in Ontario?

Basically, there was no process, because there was no program. There was some behavioural expertise in some of the big Regional Centres, and a few places like Surrey Place and TRE-ADD, but most families just muddled through the best they could. Some may have been able to find a day care where people knew what they were doing. Most kids were in school in various segregated classrooms of variable quality. Some parents just stayed home with the kids and did their best. It was quite hard for families. A few parents who had read about ABA, and had the means, brought experts in from the States to train staff and do in-home programs.

What were the initial steps taken by yourself and other professionals to get the first OAP off the ground?

By the late 1990s, I and others (parents & professionals) were advocating for ABA-based early intervention to be publicly funded, based on the powerful research demonstrations (e.g., Lovaas, etc.) that had been coming out since the mid-1980s. Many professionals in the community were ignorant of (or frankly skeptical about) early intensive ABA treatment and how dramatically effective it was for some children. I was working at the MCSS directly operated TRE-ADD Program (Treatment, Research, and Education for Autism and Developmental Disorders) at that time, where we provided behavioural treatment in classrooms and group homes, as well as respite care, family support, and research. We started a behavioural Parent Training Program (Perry & Condillac, 2010) and then an IBI Kinderclass program in partnership with the Toronto Catholic District School Board (this later became Surrey Place’s KinderCampus).

Around that time, I was seconded to the Ministry to be the clinical lead in the design of the new “Autism Initiative” which was part of a suite of early childhood programs (e.g., preschool speech & language, healthy babies, infant screening, etc.) in a branch of government called the Integrated Services for Children Division (with combined resources from Health, Community & Social Services, and Education ministries). It was actually a really exciting time! The government wanted an early intervention program for autism that was based on research, and designed the way it should be. It was an opportunity of a lifetime, as civil service jobs go.

We looked at what other places were doing and, of course, all the research literature. We developed some guidelines for best practices (for detailed background, see Perry (2002). We chose the term Intensive Behavioural Intervention (IBI), partly because the term ABA had a negative, punishment-oriented connotation to some people in the field, and we wanted to emphasize that the program would be intensive, behavioural, and an intervention rather than an “analysis”. There were very few people with relevant qualifications so one of the first tasks was to develop a staff training program, which was headed up by Dr. Joel Hundert.

The program was originally designed for young kids, with more severe symptoms only. Diagnostic eligibility was (then DSM-IV) Autistic...
Disorder or “the severe end of the autism spectrum”, and about 70% of those kids would also meet criteria for an Intellectual Disability. This is, of course, a much narrower group than what is now considered ASD (IBI is not necessarily needed or appropriate for all on the spectrum). Similarly, it was originally supposed to be a Pre-school program only, where kids would receive high quality and intensity IBI for maybe 2 or 3 years before going to school. That was the model from the research studies where most children were 2 to 4 years at intake).

The idea was to significantly alter kids’ developmental trajectories such that they would need much less (maybe no) special supports in school. After a few years, parents realized that their kids, now older, would be going into a school system that was not very well prepared for their kids with autism, and didn’t dovetail well with the IBI approach. Basically, parents saw the benefit of ABA and wanted their children to continue with it. Some lawsuits were launched to argue against the age limit and, although the lawsuits were lost on appeal, the government did not go back to having an age limit for the program.

Since kids were no longer leaving the program when they turned 6, waitlists started to grow dramatically, with new young children being added to the waitlist but not being able to receive service because the program was full. Thus, the very children the program was designed for were not able to access it!

The program was expanded multiple times and various attempts were made to find ways to promote greater flow through so that young kids could receive service but these were fraught with clinical and political challenges. The less intensive ABA Services program was also developed so that there was a greater range of services for the very large and diverse group of children and adolescents now considered eligible for the program.

Since the implementation of the first OAP, what has its impact been on children with ASD and their families?

I think it’s fair to say generally that the impact of the program has been enormous overall for thousands of kids and families, and also in terms of the remarkable capacity building that has resulted in trained behaviour analysts and therapists. When I was BCBA certified there were only 10 of us in Ontario. Now there are hundreds and hundreds and this is directly attributable to the autism program.

Now a more data-based answer. There are several publications about the Ontario IBI program. A few highlights would be: About one-quarter of 332 kids made very significant gains; about half made more modest gains; and the remaining quarter did not show benefit on standardized measures (Freeman & Perry, 2010; Perry et al., 2008). A wait-list controlled study showed IBI kids did significantly better than the comparison group (Flanagan, Perry, & Freeman, 2012). We’ve also looked at predictors of outcome, which included child’s age at intake, as well as level of cognitive ability, adaptive ability, and autism severity (Perry et al., 2011; Perry, Blacklock, & Dunn Geier, 2013). A study of kids who started IBI over the age of 6 showed they made minimal progress on standardized measures (Blacklock, Perry, & Dunn Geier, 2014).

In various other studies, we have looked at measuring quality of IBI treatment and the role of parent involvement as well. Most recently, we published a long-term follow-up study (Perry, Koudys, Prichard, & Ho, 2019) of youth (16 years old on average; 10 years since the end of IBI) showing that outcomes such as IQ and adaptive skills were generally stable since the end of IBI. Also, these adolescents showed typical rates of emotional difficulties (as rated by parents, teachers, and youth themselves) such as anxiety (Koudys, Perry, Ho, & Charles, submitted) and certainly no one had PTSD!
In your opinion, what would the OAP look like in a perfect world?

Well, there is no such thing as perfect program... No one program can’t be all things to all people. In my opinion, we need to think in terms of three age groups: pre-school, school-aged, and post-school.

The ideal would be to have a preschool program that provides 2 or 3 years of high quality, high intensity IBI for the kids who need that, such as kids with an autism diagnosis plus intellectual disability. But that’s not necessarily appropriate for all kids. The range of other options needs to be fleshed out and would include child care, speech & language, and so on. Then there are some kids who are school aged and who continue to need comprehensive ABA services. The question is not whether that is needed. The question is where it should happen, and who should pay for it. I believe it should happen in the school system. Then, we need to consider the post school system, which right now has even fewer resources and longer wait lists. This is another frontier we have to address in future as a field.

I also think we need a combination of public and private service delivery options. About 70% of parents in the OAP historically have opted for the public program. This has traditionally given more flexibility to families with different circumstances, e.g., immigrants, families with high stress, single parents, etc. Some families can and are able to be more involved in the management of their child's program, but other families struggle to balance all of those pieces. I worry about what will happen to these families in the current regime.

References


Committee Updates

ASD Committee

The ASD Committee has had a busy start to the year! Our committee members have dedicated many volunteer hours to completing items on our work plan and we would like to thank everyone for their hard work. Our activities from January to April 2019 include the following:

Carobeth Zorzos will be stepping down as co-chair, to focus on her clinical work. Nancy Marchese will be serving as co-chair with Carly Eby. The ASD Committee would like to sincerely thank Carobeth for her leadership. Luckily, Carobeth will remain as a Committee member.

We held a Town Hall on March 2nd. 200+ members attended, both in person and online. It was an informative and productive meeting that resulted in a list of action items that (in addition to our work plan) will keep up focused and motivated in the months ahead.

We wrote and distributed a Primer on ABA to share with parents, professionals, and community members.

We designed an infographic on What is ABA and What is it Not? We are currently working on additional infographics to increase understanding and awareness about ABA.

We attended a meeting with MCCSS staff to discuss revisions to the OAP, implications for children and youth with ASD, their families, and practitioners.

In the meeting we were able to communicate our commitment and desire to be involved in the consultations taking place in the coming months.

We continued information gathering for the development of a possible ABA demonstration projection in rural/remote areas in Ontario. This included a call with RAPON representatives from Northern Ontario.

We continued to work on the development of an ASD self-advocate and parent advisory committee.

We worked on "Practical Solutions for an Equitable, Effective, and Efficient Ontario Autism Program," which we expect to present to MCCSS and various stakeholders.

We met with Autism Speaks Canada to discuss potential ways to collaborate, such as linking ONTABA reports (e.g., OSETT-ASD, OSETT-CB, etc.) to their website, as well as contributing to their Connect page, and family resource site.

We continued to maintain contact with Autism Ontario to discuss possible collaboration opportunities.

We look forward to providing details on our 2019 Work Plan in the next newsletter.

Adult Services Committee

The Adult Services Committee is keenly interested in expanding its membership to include individuals working with adults across sectors to maximize our reach and ability to meet our goals. Forensics, Older Adult Populations, Health Care, Mental Health Care, Multidisciplinary Practice are just a few of the areas that would be helpful additions to our committee. We are looking forward to moving ahead with our ambitious workplan with your assistance!
Website Committee

The website committee will be preparing for some changes in the upcoming year. These changes are likely to include: switching to a new payment processing system, and modification of the current membership directory into a registry. Members are reminded that the call for papers for the 2019 ONTABA conference will be open on the website in May of 2019 and will close in early September of 2019. Conference registration will be open on the website in August of 2019 and will close in late October of 2019. The website committee is also looking forward to leveraging online platforms and social media to further promote ONTABA’s organizational objectives.

Professional Practice Committee

The Professional Practice Committee (PPC) would like to invite our membership to submit professional practice questions to professionalpractice@ontaba.org. We will endeavor to answer your questions or connect you to evidence-based practice resources. We look forward to hearing from you!

Professional Development Committee

The Professional Development Committee is excited to announce that CEUs will now be processed automatically using the CEU Helper app. This will make signing up, tracking and collecting your ONTABA CEUs so much easier for this year’s events.

Public and Community Relations Committee

The public and community relations committee is pleased to announce that ONTABA will be participating in Toronto’s Autism Speaks Walk on Sunday June 2nd. You can sign up as a member of our team (TeamOntaba2019) through the Autism Speaks website or by contacting the committee (publicrelations@ontaba.org). If you do not want to participate in our team come drop on by our booth! We hope to see you at Nathan Phillips Square.

The committee is also pleased to announce the return of the Evening of Behaviour Analysis. So block off the evening of Friday August 16th as we have some exciting speakers and activities. More details will be sent shortly, so look out for our Facebook posts!

Conference Committee

This year’s conference committee is hard at work planning the 2019 Annual ONTABA Conference. It is set to be held on at the Metro Toronto Convention Centre. A big thank you to everyone who took the time to complete the Conference Survey, we have taken the results to make informed decisions about this year’s conference.

We are pleased that Jonathan Tarbox and Thomas Szabo will be guest speakers at the conference, look out for updates for who else will be joining us this year! As well, the call for papers, ignite sessions and posters will be going out in the very near future, we look forward to seeing all the submissions. See you in November!
Welcome to the “What Would You Do?” column on ethical and professional dilemmas in ABA. Please submit your questions, issues, dilemmas or tricky situations to newsletter@ontaba.org. My responses are my own, and are not intended to represent the Behavior Analysis Certification Board (BACB®), ONTABA, or any other organization with whom I am affiliated. Responses should not be taken as specific legal or professional advice as it is not possible to have or provide enough information in a column of this nature.

Ontario has seen a major shift in policy for the Ontario Autism Program, funded by the Ministry of Children, Communities, and Social Services. ONTABA members have identified several corresponding ethical issues and I have attempted to answer a few of them here.

What is my responsibility if my client’s services are being discontinued prematurely due to this funding announcement?

My column in the Jan 2019 newsletter covered discontinuation of services exclusively. Behavior Analysts must discuss changes in funding at the earliest opportunity (BACB Code, 2.12 D), and the interruption/discontinuation of services is covered extensively in the BACB code (BACB Code, 2.15). However, I will add that in addition to the needs of the client, behavior analysts might want to consider making referrals to organizations that can provide for the needs of families given the additional stress on parents at this time. Behavior Analysts seek necessary consultations and referrals in the best interest of their clients (BACB Code, 2.03a). Families can seek mental health supports through their GP, employee assistance programs (if they have these), private health insurance (if available), local hospital or community mental health agencies, crisis support hotlines and text services.

What do I do if a child with more severe needs requires intensive behavioural intervention, but parents will only be able to afford 15 hours per week of services?

This may become a reality for many families under the new program guidelines, though continued advocacy by parents, professionals and organizations like ONTABA might help to mitigate the issue. However, in the interim, some families are looking for services that they can afford, even if less than optimal. There are a number of issues to consider. First, to operate with integrity, we must be operating from within our evidence base and recommending services that will be effective (BACB Code 1.01). As such, Behaviour Analysts must provide descriptions of services and potential outcomes that are consistent with the reduced intensity (BACB Code 2.12 C). Second, Behaviour Analysts can plan treatment to capitalize on child’s learning, and make the most of the funding available (BACB Code 2.09 A).

For example, if a young child still naps or is tired in the afternoon, consider dividing the 15 hours into 5 mornings. If an older child also has

Have a Question or a Topic for What Would You Do?
Send it to Us!
NEWSLETTER@ONTABA.ORG
We have a youth in our program with more complex needs (e.g. ASD and Intellectual Disability) and safety concerns are paramount and they were previously removed from school due to behavioural challenges. How would we support them with roughly 2 hours every other week?

Considering what can be done with the available supports, might be an appropriate solution while advocacy for more intensive supports continues (BACB Code 2.09 C) ABA interventions that focus on a single goal can be effective at lower intensity for some individuals, while others may still need more intensive supports. There may be services including evidence-based behavioural supports, public school programs, day treatment programs, or residential supports for children with ASD and IDD who have complex care needs in your region that are funded from outside of the OAP. Be realistic about what can be achieved with limited resources and advocate for the necessary levels of support.

I have always respected the requirement to not engage with my current clients on social media, but the current situation is leading many parents to post testimonials about ABA and even mention service providers by name. What should I do?

These are trying times and many families are sharing private information as part of their advocacy efforts. Behaviour Analysts cannot stop families from posting their own information. They should, however, refrain from using testimonials from their current clients in their advertising whether solicited or unsolicited (BACB Code, 8.06). Obtain consent from families to use their information in direct advocacy efforts with the government that are not aimed at recruiting clients to the organization (BACB Code, 8.05 B) even if the information has been posted by the family in the public domain. Behaviour Analysts using client information as part of advocacy, should distinguish their advocacy efforts from advertising. For example, combining information from multiple organizations when advocating might provide a stronger argument and not be mistaken for advertising from a particular organization. Behaviour Analysts should do their best to protect privacy, even if consent to share identifying information has been obtained (BACB Code, 8.05 C). Think of advocacy in the media as you would a public presentation or lecture. A good “Rule of thumb” is to provide only the information necessary to make the argument.

As this situation continues to unfold, please send your questions to newsletter@ontaba.org.

References