



Catherine Fife

MPP Waterloo

Hon. Lisa MacLeod, MPP
Minister of Children, Community and Social Services
Hepburn Block
6th Floor, 80 Grosvenor St.
Toronto, ON M7A 1E9

May 7, 2019

Dear Minister MacLeod,

I am writing to you today to share a summary of recommendations written by parents in my riding who have children with Autism Spectrum Disorder (ASD). On April 15, 2019, Mark Dineen, Dr. Janet McLaughlin, Kuljit (Neetu) Mehan, Jennifer Beckett, and Sarah Jones sat around my kitchen table to talk about their ongoing struggle to secure adequate services for their children.

Attached is a report that summarizes what I have heard from parents in Waterloo about how a more comprehensive system would better serve the needs of children with ASD.

These parents have put a lot of time, research, thought and energy into these recommendations. I applaud their continuing advocacy and I hope that their recommendations are thoughtfully considered by the government.

Regards,

A handwritten signature in black ink, appearing to read "C. Fife".

Catherine Fife,
MPP Waterloo

C: Hon. Christine Elliott, MPP, Minister of Health and Long-Term Care,
Hon. Lisa M. Thompson, MPP, Minister of Education
Monique Taylor, MPP Hamilton Mountain, NDP Critic Children & Youth
Services

Autism Roundtable Summary Report – Waterloo

April 25, 2019

Home of MPP Catherine Fife

In Attendance: Mark Dineen, Dr. Janet McLaughlin,
Kuljit (Neetu) Mehan, Jennifer Beckett, and Sarah Jones

Summary of Key Recommendations

1. Provide a needs-based therapy program for autism and other disabilities without arbitrary caps or age cut-offs.
2. Therapies supported by scientific evidence, including ABA, physical therapy, psychology, occupational therapy and speech and language pathology, should be covered for anyone, regardless of age or diagnosis, under either OHIP or a similar model (fee for service, direct reimbursement from government to provider at a standard rate of service, rather than flowing money through families to providers). There should be no age or arbitrary hour caps on these services; they should be determined only based on clinical need.
3. Technological devices and respite should stay under their current programs (SSAH and assistive devices programs) and the waitlists for these programs should be eliminated.
4. There should be better school supports, including EAs trained in ABA and supervised by BCBAAs or psychologists, with additional supports from SLP, PTs, and OTs, so that everyone school age can receive meaningful education--this will also greatly decrease therapeutic budgets outside of school.
5. ABA providers (BCBAAs) should be regulated to protect vulnerable clients and ensure high ethical standards of care.
6. There should be an immediate expansion of capacity of ABA and other autism/disability services through further training programs. Otherwise, demand for services will greatly exceed supply of service-providers.
7. As needed, there should be targeted services for rural/remote/under-served communities (similar to programs to recruit doctors to rural areas or community health centres) to ensure that all families throughout Ontario have access to meaningful services.

Needs-Based Funding

Outstanding Issues

All parents present strongly expressed that their children have very different needs, are always evolving and require very different levels of support. Some parents have children who require full-time attendance in a private program that has low caregiver to child ratios, which is the ideal environment for their child to thrive and learn. Others have children who are able to be in mainstream classrooms at public schools, but still require some ongoing therapy both inside and outside of school. The parents also identified the precarious nature of Special Services at Home (SSAH) funding and its frozen waitlist as outstanding issues.

Desired Outcomes

Parents around the table, including autism policy researcher Dr. Janet McLaughlin, expressed support for a model that more closely resembles the way the public accesses health services through OHIP. In an

OHIP model, funding would not face arbitrary restrictions, but would instead be determined based on clinical need. In order to access the services they require to thrive and be healthy, children would be given referrals as they would for any other health condition, by a trained professional. For example, if a child had speech delays, their primary care provider could give them a referral to a speech and language pathologist that would be covered under OHIP (or an OAP program operating under an OHIP-like model), and said child would receive therapy as required for as long as it is needed for their health. A situation like this could be replicated for all of the medical services that children with ASD – and all people with disabilities – require.

The parents were interested in seeing Minister of Health and Long-Term Care Christine Elliott participate in discussions of the Ontario Autism Program, as they believe care for their children is a serious health concern and should be integrated into our current health care system. Rather than parents being given envelopes of limited funding and having to navigate the system, manage budgets and pay for services on their own, under a more integrated and regulated system, professionals at autism agencies or primary care providers should be able to provide referrals, with services obtained with an Ontario Health Card. An integrated system such as this would also have no age caps on services and no limit of funding based on arbitrary numbers. Instead, services would be provided based on the level of care someone requires as determined by a regulated health professional.

In addition, because it is a vital resource for all parents of children with disabilities, SSAH funding should continue without any waitlist. Programs and providers (such as specialized camps, respite workers, etc.) are already operating and providing services, so this program does not require the creation of resources, but merely for increased funding to flow to all who qualify for respite supports.

Assessments

Outstanding Issues

Without a thorough and interdisciplinary assessment, there is an inability to provide effective, appropriate services for children. ASD is a varied diagnosis and services need to be tailored to each child in a variety of areas including behaviour, speech and language pathology, physical, psychological and occupational therapy.

Desired Outcomes

Systems already exist that could provide assessments, they just need to be utilized and regulated. Parents prefer that these necessary assessments are done by regulated professionals, and do not think that they should be restricted to one person assessing a whole child. Speech assessments should be done by speech pathologists, behaviour by psychologists or board certified behaviour analysts, etc. This is not dissimilar to how someone who has had a stroke is assessed – a team of health professionals conducts individual assessments and then referrals for services are determined based on what each professional deems necessary.

Regulation of ABA Providers

Outstanding Issues

There is currently no regulatory college in Ontario that oversees providers of ABA therapy. While many services ASD children receive are provided through regulated health professionals (RHPs) (e.g. speech and language pathologists) – ABA therapists are not regulated. This also means there is no formal

process for complaints or issues with service delivery, and that anyone can call themselves an ABA therapist, opening up vulnerable clients to abuse.

Parents referred us to the OMHLTC's information about RHPs, which explains that: "Health regulatory colleges are responsible for ensuring that regulated health professionals provide health services in a safe, professional and ethical manner. This includes, among other things, setting standards of practice for the profession and investigating complaints about members of the profession and, where appropriate, disciplining them."

(http://www.health.gov.on.ca/en/pro/programs/hhrsd/about/regulated_professions.aspx). The parents asked that the HPRAC report on regulating ABA services providers be released (<https://hprac.org/en/applied-behaviour-analysis.asp>).

Desired Outcomes

The parents all recommend that the province create a regulatory college for ABA therapists, similar to the Applied Behavior Analyst Certification Board (<https://www.bacb.com/>). In this model, all behaviour technicians working with children would be supervised by regulated Board Certified Applied Behaviour Analysts (BCABA).

Education System

Outstanding Issues

The school system is not currently equipped to adequately care for and properly teach many ASD children. There is no structure in place to accommodate the differing needs of children with autism, which can lead to exclusion from schooling for children, and in some cases, poor educational outcomes for all children in a school when a child is not treated and taught in the way necessary for them to learn and thrive. All children in Ontario should be able to access a public education where they are able to learn and grow, and without proper supports that outcome is not possible for many children with ASD.

Desired Outcomes

Schools need professionals such as BCBAs, SLPs and OTs integrated into the design of curriculum and learning plans as well in supervisory roles at schools to aid teachers, behaviour technicians, and education assistants in their teaching of children with autism. This would ensure that the education system is not just set up for dealing with the behaviour of children with ASD, but that its goal is to teach and for the children to learn, in a way that is meaningful to them. This would look different in different situations; for example, a child may need a specialized classroom so they can learn and are not disruptive to other students, or they may need an education plan that has them in a mainstream classroom with adequate supports. Their needs should be regularly assessed in consultation with parents/caregivers, as they may change over time. EAs working with children with autism should receive specialized training, including behaviour technician certification and regular supervision by BCBAs. Additionally, education budgets should be increased to allow for every child who requires EA support to receive it at the recommended level. Finally, therapy teams working outside of school should have more robust forms of communication and integration with teams within school, to ensure seamless, effective supports and transitions between the two contexts.

Open and Transparent Consultation Process

Outstanding Issues

Parents felt that the February 2019 announcements to changes to the program and subsequent updates and consultations have lacked transparency. There is a lack of clarity around a number of aspects of the process, including: who was waiting on the list (e.g. how many people on the waitlist had previously received services and what are they currently waiting for); who is doing consultations; who is conducting surveys; how are conflicts of interests being vetted; how are parents being selected to participate in feedback process; how are members of other political parties involved; and the determination process for members of the expert advisory committee.

Desired Outcomes

The current situation is a crisis for families and as such, consultations need to be done immediately with an eye on swiftness and transparency. School budgets are currently being created and plans are being made for the September 2019-2020 school year. Many autism therapists have already lost their jobs, including locally at centres such as KidsAbility. Schools, therapy centres and families need to plan their finances and schedules for the 2019-20 school year. Parents are requesting that open, transparent, and evidence-informed consultations and recommendations begin as soon as possible and are enacted with the speed that is required for their children to thrive immediately and into the future.