



Ontario Autism Program

WHAT WE HEARD

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The Ford government delivered devastating changes to the Ontario Autism Program that hurt children and families across the province. In addition to these cruel cuts, the Conservatives let down Ontarians by closing the door to meaningful in-person consultations, ensuring these critical decisions would be made in back rooms by Conservative insiders. This opaque and callous approach has left families, children living with autism, health professionals and experts in the dark for months.

Since the Ford government's announced changes, Ontario's New Democrats have continued meeting with families, educators, clinicians, experts and people living with autism to discuss the impact of these changes on their lives. New Democrat MPPs have spoken with thousands of families by hosting twenty-four town halls and roundtables in ridings across the province, attending rallies organized by parents and autism advocates, and meeting with constituents in their community offices.

We want to share what we have heard from the many Ontarians who have shared their stories with us. Parents, people living with autism, advocates and allies already sent a clear message: The Ford government has made things worse for the Ontario Autism Program, turning a broken Liberal program into a disastrous Conservative one.

Julia & Sean SUDBURY

The budget of a government reflects their priorities. The new Ontario Autism Program tells us how little you prioritize our children. Don't hand us a fraction of the required cost and abandon us. We'd rather wait for needs-based therapy that will help our children reach their full potential.

We cry a lot. Will our kids ever get invited to sleepovers? Will they have friends? Will they be able to find jobs and be productive members of society? We mostly cry because we can't afford what our child needs and you aren't providing it.



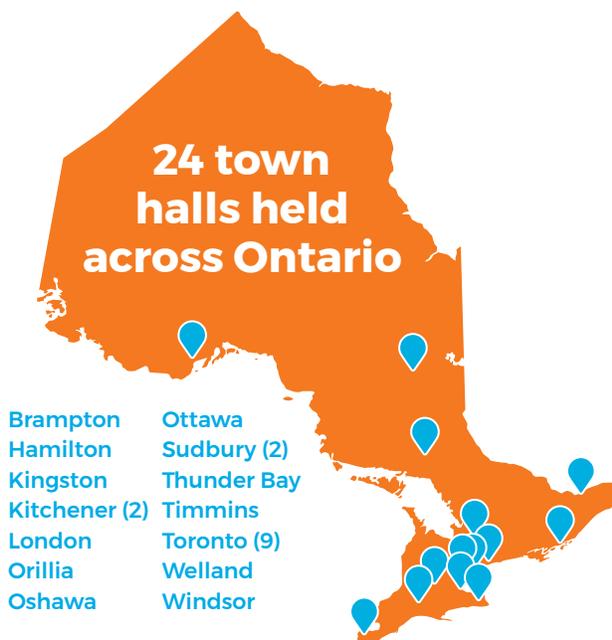
*Cover image: Sudbury father Sean Staddon and his son Chaz (two)

How we engaged families

SINCE FEBRUARY 2019, New Democrat MPPs have hosted 24 in-person town halls and roundtables in their communities, engaging over 1,200 families, advocates, and allies. Even before the Ford government's disastrous changes to the Ontario Autism Program, the existing Liberal program had not been meeting the needs of families and children living with autism. Because of this, New Democrats have long made it a major priority to regularly connect with Ontarians on this important issue.

We held town halls all over the province. Everyone who attended a town hall in their area had an opportunity to share their thoughts on the changes to the Ontario Autism Program. Many families and people living with autism shared their personal stories, the challenges they already faced in accessing services, and how the Ford government's new changes would make life harder and more expensive.

Thousands of Ontarians also made their voices heard at Queen's Park, at rallies across the province, through phone calls, and in smaller meetings with their local New Democrat MPP.



Heather

WINDSOR MOM

We need a plan that will meet every child and student's individual needs or they will all suffer. This is not a situation that Ontarians should be facing. The government's proposed changes to the Ontario Autism Program are devastating to children with autism in Ontario. Children with autism need access to the appropriate individually-based ABA and IBI therapies, regardless of age. A birth date does not depict the developmental age of each individual child.

Benita B.

LONDON GRANDMA

Brendan is my 19-year-old grandson and he is high-functioning autistic. Everyone seems to want to put people like Brendan on disability, but they don't need to be on disability.

The biggest gap in our system for Brendan is that no one is helping connect him with employers who are willing to hire him. There needs to be training for employment help centres to be able to better support adults with autism, and education for employers to understand that this is a way they can contribute to their communities. Otherwise, people get lost in a grey zone.

What we heard

AFTER YEARS OF being forced to fight the previous Liberal government, families feel even more betrayed and frustrated by the Ford government's changes to the Ontario Autism Program. Many families feel that they have been waiting years to access services, only to have those services cut. Families are fearful that their children will not receive the support they need to thrive.

Below are the top six themes we heard over many months of consulting with families, experts, advocates, clinicians and people living with autism.

Services should be provided based on need

THE OVERWHELMING MAJORITY of families believe that services for children with autism should be provided based on the individual child's needs, as determined by a clinical expert.

We heard repeatedly that the Ford government's decision to apply a standard rate for age-based funding was harmful and does not serve the best interests of the children. Instead, families would

Monica

HAMILTON MOM

My son is not independent, not toilet trained, has no social skills, problems with loud sounds, will still throw the odd tantrum, does not sleep through the night at times. With the cuts to the OAP funding to only \$5,000 a year, what strides my son is achieving will decline. I don't want my son to regress.

It is not his fault he has a neurological disorder. He has a right to be able to reach his full potential.

prefer access to as many or as few services as their clinical professional deems necessary for their child.

Parents and people living with autism reminded us that autism does not end at age 18, and services for adults with autism should still be offered. This could include therapy, housing support, employment training, mental health services and other services.

David P. TORONTO DAD

I am the father of a now almost eight-year-old daughter Kaley, who is non-verbal on the autism spectrum. She can't speak for herself on her situation, so I will.

Kaley was diagnosed just before her third birthday. Once we got the diagnosis we spent 25 months on the wait list for direct funding. In that time we spent upwards of \$30,000 of our savings and income out-of-pocket to pay for therapies to help our daughter. Alas, we couldn't afford the hours per week that were recommended and her advancements plateaued quickly, though she was a happier child overall.

Changes to the program mean that I will not be able to continue my daughter in this program. I make a modest income in Ontario, but I do not have \$66,000/year I can put aside for her. I may have to change careers or look at reducing my income so that we can qualify for full funding. We have even discussed leaving the province, moving somewhere new to try and find better options for Kaley. The new plan which will now take into account my income won't be able to even fund more than 2 hours a week for her. At that rate, no therapy will take, and she may even regress.

The financial burden is overwhelming

THE FORD GOVERNMENT changed the Childhood Budget starting April 1, 2019, placing a cap on the amount of support that families can receive. This cap is dependent on the age of the child and their family income, with steep claw-backs for middle-income families. Neither the needs of the child nor where they are on the autism spectrum is a factor in funding.

Families whose children are under six years old are eligible to receive up to \$20,000 per year. Families whose children are over six years old are left with a smaller portion of the Childhood Budget and are only eligible to receive a maximum of \$5,000 a year. Some families pay as much as \$90,000 a year for the services their kids need, meaning they are only eligible to receive funding for a small fraction of their costs.

One of the most common things we heard from families across the province was that the Ford government's changes put them in a painful financial position — they simply couldn't afford to cover the cost of therapy for their child once coverage from the program ran out.

While some families said that any support was helpful, most parents told us that they would rather wait to receive full funding so that their child could receive the adequate level of therapy needed.

We also heard from many parents who were afraid that their child would regress if they were unable to afford the amount of therapy their clinician determined was necessary.

Provide a range of evidence-based services

FAMILIES TOLD US that they would like access to therapies that are backed by medical evidence. Overwhelming, the preferred choices

Faith

TORONTO MOM

My son needs clinically-assessed services, and currently he needs ABA therapy, occupational therapy and some speech-language pathology to help with language comprehension and some other skills. The funding age cap does not allow him to have his needs met. The clinical assessment is important so we can support him where he really needs it. I am not a therapist, clinician, or psychologist. I'm a mom and I'm trying to do the best I can for my son.

Kerry

OTTAWA MOM

As children who are currently in service have their funding slashed on April 1 this year, they are going to be forced into the school system. This is a problem that will affect not only the ASD population but other special needs populations and the neurotypical (NT) population as well.

My son Jack, even when supported in an integrated classroom, is a distraction to everyone in the room. I know this, teaching staff knows this, and soon his classmates will know this as well. Educational Assistant (EA) support in classrooms is already incredibly hard to come by. What is to happen as children with severe diagnoses are forced into classrooms without appropriate support?

This is a question that should be weighing heavily on the minds of everyone with school-aged children. Are school boards even aware of the storm of special needs children that are headed their way in 40-some days?

were Applied Behaviour Analysis (ABA) and Intensive Behaviour Intervention (IBI), provided they are administered by adequately trained and certified professionals.

But parents want services to expand beyond ABA and IBI. We heard that the Ontario Autism Program should consider including services like speech-language pathology, physiotherapy, occupational therapy, and mental health services.

Parents also sought respite support, with many families deeply concerned by possible Ford government cuts to the Special Services At Home and Enhanced Respite programs.

More support in schools

MANY PARENTS COMMUNICATED their desire for increased support in schools. They would like to see more classrooms for children with autism, and more educational assistants with training to support their children. Some would also like to see spaces in schools for ABA therapy.

Experts and parents with children in the school system noted that Individualized Learning Plans are not often followed closely enough because schools lack resources, or because teachers and education assistants lack training.

The majority of parents told us that they fear their child will be forced to prematurely enter or increase their time in regular classrooms because of the revised Childhood Budget. They are worried that they may not be able to afford respite care or adequate therapy hours for individualized one-on-one treatment.

These parents raised concerns that the Ford government's cuts to schools across the province will only make the situation worse, as schools will have fewer resources for both children with autism and neurotypical children.

Parents are fearful that schools will be forced to use school exclusions more frequently.

Build service capacity

ONTARIO ALREADY HAS a shortage of trained



Alina

NORTHWESTERN ONTARIO MOM

I am a wife and a mother to three incredible children. One of our daughters was diagnosed at around 2 years of age as severely autistic (non-verbal). My daughter's name is Fiona and now she's 3 and half years old. The new OAP made no attempt to ensure adequate infrastructure was in place, or enough therapists were available, particularly in Northwestern Ontario.

Beyond affecting her life and development, this wait is affecting my future. I did my part. I followed due diligence. I observed and recognized her maladaptive behaviours very early on. I pushed for diagnosis through a ridiculously long gauntlet of health professionals, therapists, psychometrists, and wait lists.

This is financially stunting myself, my family, and adding great stress to our lives. We don't live an extravagant lifestyle — we live in rural Northwestern Ontario. Moving to a larger city centre for care is currently not an option for our family.

Fiona's care, like that of many others like her, is 24 hours a day, 7 days a week, 365 days a year. There is never a time than an ASD parent/caregiver is not "on". It is exhausting. Not just a tired feeling, but a 'deep down to the core' exhaustion of the spirit. This is breaking me. But I love her.

ABA therapists. Under the Ford government's changes to the Childhood Budget less money will be provided per child, leaving even fewer resources for therapists. As a result, at least 175 therapists have reported that they were laid off.

Families across the province were deeply troubled by this development. They fear that the private therapy centres that do manage to remain open will have longer waitlists and even higher fees.

Parents and people living with autism in northern, rural and remote areas were most concerned about the lack of resources available to

them. These concerns were echoed and expanded on by those who have been forced to deal with the long-standing shortage of Francophone and First Nations service providers. They shared many suggestions for re-location and education incentives to increase the number of ABA providers they could readily access.

Help navigating the system

BY PROVIDING ONLY direct funding (Childhood Budget), the Ford government is leaving families on their own to find private providers and decide the type and level of service that falls within their budgets. Families will be forced to take on the role of employer and manager. Not all families have the expertise or time to do this.

This is especially difficult for families with multiple children on the spectrum. There are also a number of equity considerations, as recent immigrants and low-income people have the most difficult time accessing support.

Families told us that they did not have enough information from the government to plan out their child's therapy or their personal finances, and that this lack of certainty is a cause of considerable stress. These families shared that the current Ontario Autism Program lacks transparency, and that the Ministry of Children, Community and Social Services deliberately withholds important information.

Far too many families feel that they are in the dark about when they will receive autism funding, which is critical for planning their finances and their child's care.

Regulation for ABA providers

FAMILIES AND EXPERTS told us that Ontario needs better regulation of the ABA therapy industry, especially as the Ford government pursues their agenda of privatization for the autism therapy system. Parents told us they would like

Amy

TORONTO MOM

Language barriers and the lack of ABA therapists in the north are a reason why the direct service option needs to exist. The fact that it's being eliminated is a huge problem. As it stands, even for Canadian-born parents it is hard to navigate the system. For a new Canadian, or someone who is not strong in English, good luck.

Sadly, the kid will suffer. The majority of the parents at my service provider require interpreters for meetings. Families need direct service-type options to navigate the system. For some there is a stigma and reluctance to seek help. It is a lot of work for families to find a service provider with the new system, so people will be less likely to get their kids help. With an option to have the government help take care of some of those steps for you, you will see a lot more success.

Alison

HAMILTON MOM

The new funding model does not promote or include any sort of oversight system to help parents ensure they are getting evidence-based services. In short, these changes will effectively eliminate the opportunity for the majority of parents to choose evidence-based comprehensive behavioural treatment, and leave parents vulnerable to paying for services that are ineffective, or worse, may harm their child.

The evidence-base for intensive behavioural intervention and applied behaviour analysis is clear, in terms of facilitating positive outcomes for children with ASD. I am gravely concerned about this announcement.

to see oversight of what constitutes ABA therapy to ensure their children receiving the right services and that they are not taken advantage of.

Parents also shared their desire for better clinical oversight of behaviour plans, in order to ensure children in therapy receive an appropriate amount of therapy hours. This is of particular concern now that many providers are privately operated

Other important ideas

WHILE THE SUBJECT of our community engagement—and of this report—is autism services, we also heard that children and adults

with other disabilities should be able to access therapy as needed. There is no reason why the autism diagnosis should be better supported than other diagnoses, such as Down syndrome, fetal alcohol spectrum disorder, or any other disability.

Many families also wondered why autism services are not provided for under OHIP, and called for therapy to be covered.

A path forward

ONTARIO NEW DEMOCRATS have listened to the concerns of thousands of families and people living with autism across the province, in addition to the recommendations of experts and advocates. The recommendations in this report are based on what we have heard from consultations since the Ford government's changes to the Ontario Autism Program and are in-line with the concerns Ontarians have been sharing about the program for many years.

A revamped Ontario Autism Program must be created through good faith collaboration with parents, families, caregivers, experts, service providers, and people living with autism. The program must be based on a person's need, not their age, with needed supports following individuals as they age.

The new program must recognize that autism is a spectrum disorder with individuals on the spectrum requiring a wide diversity of supports. Supports should be tailored to each individual's distinct abilities and challenges, while being delivered through high-quality public services and by trained service providers.

Families in communities across the province have expressed their frustration with the Ford government, and in particular their distrust of the Minister presently overseeing the Ontario Autism Program. To ensure the revamped program delivers the results families and people living with autism expect and deserve, the government must immediately strike a non-partisan Select Committee at arms-length from the government.

The Select Committee would be tasked with reviewing recommendations coming from the Ford government's recently announced consultations as well as the recommendations put forward from months of NDP consultations, and report back to the Legislature. During this time it is critical that funds continue to flow to families while the Select Committee does its work. The Select Committee would then oversee the implementation of those recommendations as quickly as possible. Families and people living with autism should not have to wait any longer to receive the supports they deserve.