

National Autism Policy Goals: A Summary

Our vision, by 2022:

- **A Communication Charter of Rights** for non-verbal and semi-verbal individuals, for fair access and accommodations in **all** aspects of Canadian life, including educational mandates for teachers, therapists, health care providers and first responders.
- **Community inclusion** for autistic toddlers and preschoolers. Ban segregated IBI and ABA centres. Include autistic preschoolers in everyday life and the world of play with their peers.
- **Inclusion in schools** for autistic children. Meaningfully engage universal design experts to share best practices and models. Incentivize their use across Canada, with the goal of phasing out segregated classrooms. Bans on seclusion and restraint.
- **Independent supported living (ISL)** for autistic and/or IDD adults, with priority government funding to existing ISL projects and new ideas. A government commitment *not* to fund new segregated housing projects.
- **Employment access** for autistic adults. Train employers on making their interview processes and workplaces accessible, based on models (e.g., Microsoft). Close all sheltered workshops. Focus on training or employing autistic people in all career fields and not just jobs that stereotypically employ autistic people (e.g., IT and banking).
- **Community education** about autistic communication/AAC and accessibility, developed with **autistic self-advocates as project leaders**. Launch programs for: First Responders; medical professionals; teachers; transit workers; and others.
- **Independent financial audit and service evaluation** of all autism-related services, charities, and programs that receive government funding. Root out the bad players and create better systems of sustainability and accountability.
- **An autistic “census”**, either creating a category in the existing census or through community consultations to determine our needs. Government gathers its own robust data (*not relying on provider “data”*) to make informed funding decisions.

National goals: Discussion and policy-specific proposals

Communication access/AAC

20-30% of autistic people are non-verbal or have unreliable speech. This means that like some other disabled people, we need access to augmentative and alternative communication platforms, called AAC. AAC is any means of communication--aside from verbal speech--that allows someone to use language. AAC can include: pictures; gestures; sign language; visual aids; and speech-output devices like phones or iPads.

The average time it takes for an autistic child to receive this essential communication access is 2.5 years. That is 2.5 years too long. Government funding programs must begin to adequately fund the services and technologies that allow non-verbal autistic children to communicate--and their caregivers to properly communicate with them. The Government should also de-fund ABA, which disempowers non-speaking children and denies them essential accessibility tools.

As one of our members, who was first denied AAC, notes: "When I found AAC it was like throwing a drowning person a lifeline. It has changed my life. I was able to get employment supports; they set me up with an employment support worker who helped me find and apply to jobs...I went from minimum wage, followed by unemployment, to a full time job where I am constantly getting praise for the quality of my work.

"I didn't change. My skill set didn't change. My work experience didn't change. The way I look and act didn't change. The only thing that changed was how I communicate. ...I cannot stress enough how big a difference AAC has made for me."

AAC: Recommendations

- **A Communication Charter of Rights** for fair AAC access and accommodations in all aspects of Canadian life, including specific educational mandates for teachers, health care providers and first responders.
- AAC access for all who need it, without delay.
- Education programs for healthcare providers, first responders, teachers and others in the community so that they can communicate directly with their patients/students/clients who use AAC.
 - Programs should be designed and led by disability self-advocacy groups, not autism charities.
- Base funding for new acquisitions on changing communication and developmental needs rather than an arbitrary "5-year" timeframe.

- Teachers and other support workers need training to be effective AAC communication partners.
- Please see our other sections for integrated AAC recommendations as well.

Inclusion: early childhood & school age

Segregation has a devastating impact on autistic Canadians' health and potential. Segregation begins when autistic children as young as 2 or 3 are sent to IBI/ABA centres instead of being integrated into their communities. They are then streamed into special education at school and graduate into segregated lives, in housing, employment and social life.

This pattern of segregation has to end. We need to reform our preschool community options for universal design. We also need to apply accessible design in Canada's public schools. There are many successful models of inclusion (some right here in Canada) that policymakers can learn from. We are happy to share them with the federal government as we did with the Ontario provincial government.

Within Canadian school boards, there is a lot of discussion about *diversity* and *inclusion* but rarely is it applied to disabled students. As Sheila Bennett, Education professor at Brock University states: "Those terms seem to apply to a lot of populations, just not this one." Professor Bennett is the co-author of the excellent 2018 [report](#) *If Inclusion Means Everyone, Why Not Me?* which focuses on the unmet needs of disabled students in our province.

A [report](#) by People for Education from 2014 showed that 1/2 of principals in the Toronto District School Board had phoned parents some mornings and told them to keep their children at home in part because there were not enough support workers that day. In a [2018 study](#), People for Education [reported](#) that 2/3 of their survey respondents report their IDD or autistic children being excluded from field trips and extracurricular activities and 1/3 reported that their child didn't have access to an educational assistant when they needed one.

A [survey](#) by ARCH Disability Law Centre found that many students are excluded from school, with no official tracking or due process. According to Renu Mandhane, Commissioner of the Ontario Human Rights Commission, [in 2017-18](#): "25% of parents reported being told not to bring their child to school, while more than half (54 per cent) said their child had to leave school early on a regular basis."

Canada needs universal tracking for restraint and seclusion in schools. According to a report by the Ontario Human Rights Commission, the province's special education system has not changed significantly [in 40 years](#). Special education classrooms in Ontario have many of the hallmarks of the institutional days: including restraints, isolation and systemic exclusions.

Canadian school boards currently lack meaningful tracking mechanisms to stop abuse. There is no publicly-accessible record of the number and degree of instances of isolation, restraint, sexual assault, exploitation and other abuse in Ontario schools and other institutions. There are also no uniform codes across districts for tracking these. School boards and other agencies also do not tend to share data nor report on general conditions; overall, they lack transparency. We were told by several government departments when we asked for statistics about abuse that “the content of individual complaints are private”; however, this explanation does not in any way address the dearth of general statistical data on this issue.

By contrast, countries such as the UK keep records of complaints and even require workers to report the incidence of events such as the use of restraint. Because they do so, the UK is able to notice trends: for example, the recent spike in the use of restraints there was reported in the media and acted on. Last week in the UK, the National Health Service said that it will stop locking up, isolating and [physically restraining](#) autistic children after an inquiry stated that it was damaging to their health. It has given itself an [18-month timeline](#).

Likewise, in Alberta, when parents got together to self-report the use of restraint and seclusion by creating an independent [survey and report](#) (since the government was not tracking it), they got action from their government. This fall, the government tracked schools’ use of seclusion and [found that](#) it was used more than 700 times in the city of Edmonton’s public schools in just one month. These statistics are essential towards addressing the problem, but in the rest of Canada they are not being kept, so the problem gets swept under the rug.

Neglect is also a serious human rights issue that is not tracked. Within the special education classroom, lack of access to the outdoors, free play and physical activity is all too common. As one mom of a 6-year old autistic boy in a Scarborough school reports: “I found out at the end of the semester the teachers had kept my son and his class indoors for recess every day since January, because they didn’t want to do recess monitoring. They gave the kids iPads to play with and never went outside once.”

One woman from Eastern Ontario spoke to us about her daughter (who is physically disabled) being confined for the convenience of staff in her classroom. A fellow student took a cell phone video of the incident and when confronted, school administrators demanded to know the student’s name so they could discipline *her* for having a cell phone in class!

In Peel District (Ontario) a family is suing the School Board for placing their autistic son in an isolation room frequently, sometimes for the entire day. According to an [investigation](#) by *Toronto Life*, his first and second grade teachers “confined him to a small room the size of a walk-in closet, with concrete walls and no carpets or padding. “Teachers would sit on a chair in front of the door to prevent him from leaving, and they covered the small window of the room with construction paper, blocking out the light. ‘If I kept acting up in the room,’ said Christian Thorndyke, ‘they’d add on more time.’ If he had time left over at the end of the day, he was told he’d need to return to the room the next day.

“At a new school in the same district, 9-year-old Christian was also isolated, despite a letter from his therapist asking the school to stop. Christian often begged for food or water, or to use the washroom, and was ignored. Once, he urinated on the floor; he says he was given a mop and told to clean it up. One day, the stress and humiliation became overwhelming. Christian broke down. He wrote on the walls and began choking himself with his hands.”

These are the kinds of stories that we hear from families and they are the reason that advocacy groups are taking legal action. For example, a [lawsuit](#) filed recently by a group including autistic self-advocates alleges that students with disabilities in a Washington DC school district experience unjustified discrimination, psychological trauma, and physical harm from the widespread and improper use of restraint and seclusion and that the district has a pattern of using “seclusion techniques as punishment to silence, control, detain, and segregate students with disabilities.” As our self-advocacy groups grow across Canada, we will also become partners in litigation on these issues.

With parents banned from many special education classrooms in Canada and some teacher groups fighting against proposals to have cameras in the classroom, there is no transparency. Without transparency, more abuse happens. And there are no universal guidelines--access is entirely dependent on the individual environment of a specific district.

Some school districts and unions have balked at the “costs” of transparency, accountability and inclusion mandates. But in reality, inclusion comes mainly from a shift in approach and attitude, towards acceptance and openness to diverse students and the broader community. It is also true that without buy-in from administrators, even the most expensive inclusion programs will not succeed and that when inclusion is rolled out effectively, it is more affordable and sustainable than segregated learning.

Inclusion recommendations: early childhood and school age

Early childhood

- De-fund all IBI and ABA centres and redirect funding towards inclusive approaches.
- Launch AAC education programs for healthcare providers, teachers and other professionals so that they can communicate directly with their students/clients who use AAC.
- Create a mandatory inclusion education program for early years programs, so that autistic children do not get excluded in these spaces.
- Meaningful consultation with nonspeaking adult autistics and those with high support needs about what needs to change for autistic children with high support needs.

School safety and inclusion

- Amend regulations such as the IPRC (O. Reg. 181/98) to require students with disabilities to be placed in a “common learning environment” as envisioned in New Brunswick’s Policy 322.
- Ontario: Remove PPM 140 (2007) and allow families to use classroom support persons other than the districts’ ABA providers.
- Develop a national tool for tracking of school exclusions, to be used universally across districts, using the New Brunswick model, to gather data about the scope of the problem and measure whether it is being addressed.
- Procedural protections for students who are excluded-- *e.g.*, via s. 265(1)(m), giving families similar appeal rights as those available for suspensions and expulsions (see: Part XIII of the Education Act).
- Make existing special education classrooms transparent, to prevent abuse.
 - Have cameras in **all** special education classrooms.
 - Make it **illegal** for a special education program to ban parents from entering the classroom.
 - Incentivize environments where families are welcome as partners in education, not “outsiders”.
- Implement universal systems (*and codes*) for tracking the following:
 - School exclusions (modeled on New Brunswick’s new Attendance Tracking Tool)
 - Use of restraintUse the data to develop better approaches, to prevent exclusions and restraint.
- Review human rights policies for our prisons. **If anything is currently allowed to be used on children in a school that is not allowed on inmates for human rights reasons: ban it.**
- Educate all teachers and staff on trauma-informed care and appropriate de-escalation techniques, per best practices in other jurisdictions.
- Have all students in the classroom provide input into inclusion. They have wonderful ideas and this empowers them.
- National campaign to remove barriers to involvement in in sports/extra-curricular activities at schools for homeschooled kids. Autistic students who cannot currently attend school due to barriers should not face further barriers in being involved in community life.

Housing: Empower independent living

Our federal government continues to mainly support segregated housing for autistic and intellectually disabled adults, rather than funding [independent supported living](#). In fact, more than [90 per cent](#) of the federal budget in this sector is for segregated housing. This is completely unacceptable.

Funding for segregated housing should be re-routed towards projects that promote autonomy and community integration (e.g., through groups like [LiveWorkPlay](#) and the [Centre for Independent Living, Toronto](#)). Right now, just 9% of federal funding is for independent living housing projects and that needs to change.

Canada also needs to support a useful systems to help autistic youth transition to adulthood. Too often, youth are tracked by well-meaning school programs into “school-to-guardianship” plans that underestimate their capacity for autonomy. We agree with the National Coalition on Disability (US) on the need for “ensuring that guardianship be a last resort imposed only after less-restrictive alternatives have been determined to be inappropriate or ineffective; and ...recognize the serious implications of guardianship and encourages schools to recognize less restrictive decision making supports,” during the transition from school to adulthood (Read the full [Report](#)).

While Sections 6 and 15 of Canada’s Charter of Rights and Freedoms guarantee the rights of persons with disabilities to freedom to choose their residence on an equal basis with others, the impact of poverty prohibits many autistic, IDD and disabled Ontarians from achieving the dream of independent/autonomous living. Poverty is a health and human rights issue impacting every aspect of life. As psychologist Ajit K. Dalal [states](#): “Disability and poverty tend to go hand in hand, forming a cycle of cumulative causation.”

Group or residential homes in Canada are a vestige of institutional life. The ideal of independent supported living for IDD and autistic individuals, beyond residential homes, is not being pursued federally. And the situation in some group homes is [desperate](#) and [terrifying](#). Between 90 and 120 children and youth connected to Children’s Aid die [every year](#) in Ontario, many living in group home (“residential”) settings. An [investigation](#) by the *Toronto Star* showed that physical restraint is common in Toronto group homes and youth residences. Sexual and other physical abuse by staff is not prevented nor dealt with uniformly, as there is almost no regulation.

As an Ontario government [panel](#) on residential services [concluded](#) in 2016: “At this time, the Panel notes that *there are no universal, or even common, set of indicators, standards or concepts that might lend themselves to the measurements of quality of care in residential services across sectors.*”

Because there is no adequately tracking of abuse within or across systems, perpetrators are able to re-offend. One recent [example](#) from Barrie, Ontario: a teaching assistant was convicted of attacking an autistic student and breaking his leg. He served time in prison and was out on

parole when he was hired by a home care company to care for autistic youth in a group home. Months later, he was arrested for hitting a client across the head and face with a metal water bottle.

Most Canadian jurisdictions currently have no reliable record-keeping or communication system in place to prevent violent offenders from being hired into home care or other settings –nor adequate enforcement policy for agencies who make these placements. To live in residential care here is to feel helpless, much of the time. For autistic residents, this can be amplified by a lack of access to appropriate means of communication and sensory accommodation.

Service providers and social services policymakers must move towards an understanding of autistic realities in residential care, in order to develop trauma-informed care that works for all residents. In addition, we need regulation and enforcement to prevent abuse and recidivist violence.

Recommendations: Housing

Safety in Group Homes

- Government standardized regulation for vetting and hiring of privately-run group home staff, to prevent abuse and recidivist violence.
- A **Bill of Rights** for all group home residents in public or privately-run group homes.
- Standardized training for all group home workers on de-escalations and safety.
 - Restraint is currently the “first resort” for too many group homes.
- Universal record-keeping on incidents of restraint in group homes, modeled on the United Kingdom’s tracking tools for this.
- Audits of private group home corporations to ensure fairness and transparency in their rules and policies, with oversight by community members and independent living experts.

Housing Autonomy

- Consult with experts on independent/autonomous living to create a *Framework for Autonomous Living*, to empower more autistic and IDD individuals to achieve supported autonomy.
- Look to the best practices of Ontario organizations such as [LiveWorkPlay](#) for models of fostering housing autonomy by offering support in areas requested by individuals such as financial management; meal planning; social gatherings; and co-ordinating supports.

- Look at best practices as well as pilot projects in other jurisdictions and communicate with our federal government about new ideas and potential partnerships in working towards more autonomous living.
 - The [Money Follows the Person](#) pilot project in the US is one promising example.

Employment and support

Poverty and unemployment are a major crisis for autistic people in Canada. Our government should include autistic adults as a category in its next Census and study our rates of employment and income, because these have never been studied.

Flexibility is key for our employment. We recommend that federal and provincial/territorial governments review their disability funding programs to ensure that autistic Canadians can work part-time, or move between unemployment and employment, without being penalized.

The best way to understand what we need is to ask us. One of our members put it this way: “I cannot stress enough just how much of a problem the current hiring process is. Interviews don’t make sense, and are less based on your actual ability to do the job than your ability to talk yourself up...which, again is difficult to do when speech isn’t always easy.”

The private sector has begun to adapt the interview for autistic candidates (for example, Microsoft and other IT companies do project-based interviews) and autistics working in IT and a range of other sectors are being chosen by the private sector and non-profits to be mentors to other autistics. These are all amazing initiatives that should serve as a model for our federal and provincial governments.

However the Government of Canada does not fund a single one of these programs, [preferring to](#) squander \$600,000 on a “mentorship” program through an “autism centre” *where the mentors are not themselves autistic*, but rather are non-autistic volunteers such as social work students. A social worker is not the same as a mentor and autistic people in the workforce are ready, willing and able to be real mentors. It doesn’t make sense. Further, Canadian and provincial/territorial governments continue to fund big autism agencies’ “employment” projects, without independent data and reporting, rather than the [local non-profits](#) and programs that are bringing real change to hiring and employment for autistic Canadians.

As well, the government should transition sheltered workshop workers out of that isolated, [exploitative](#) environment and into community-based supportive environments and living wages.

In the late 20th century, as part of de-institutionalization in both the US and Canada, many communities opened up sheltered workshops, where workers with intellectual or other disabilities were placed in factories and other workplaces to do jobs for sub-minimum wages, often just a few dollars a day. The low wages were often accompanied by the myth that it was “training” for future employment at a living wage. But it turned out sheltered workers weren’t being trained; they were trapped. “Training opportunities” translated over the decades into

dead-end jobs for low wages. IDD workers were not learning skills for the paid workforce and remained unable to earn enough to live independently.

In 2017, the Ontario government [decided](#) to close all sheltered workshops, following the lead of many communities in the United States. Unfortunately, with a new government, it has not followed through on that promise. We've authored a [statement](#) with Community Living about the closures, supporting the transition away from sheltered workshops towards including community participation supports and employment opportunities at and above the minimum wage. The Canadian Down Syndrome Society also [supports](#) the closure of sheltered workshops and the development of new alternatives and leveraging of existing partnerships and programs.

Employment: Recommendations

- Make the successful transition from school age to adulthood a priority in autism funding.
- Create employment-search support for those who want to work part time but can't do full time due to disability.
- Audit provincial disability support programs to ensure people are not being economically penalized for going from unemployed to part-time.
- Incentivize employers offering flexibility in service support for disabled employees who need to transition between unemployed and employed throughout their lives.
- Include autistic people in all disability support and funding policy; de-silo autism policy. Abandon segregated initiatives like the proposed National Autism Strategy.

Job Searching and Employee Retainment

- With autistics in the lead, develop online how-to information for autistic job seekers on how to navigate disclosure and requesting accommodations.
- Education for employers on workplace accommodations, to ensure more retention of autistic employees. Can be built from existing resources already in place by the private sector (for example, Apple's hiring and accommodation protocols).
- Mentorship between working autistics and autistic job seekers. Do not fund "mentorship" programs where the so-called mentors are not autistic!!
- Leverage the knowledge of the private sector in creating accessible workplaces.

Dignity and sustainability

- Follow through on the provincial ban on sheltered workshops.
- Replace sheltered workshops with meaningful options that maximize opportunities for autonomy and dignity.

Youth transitions

- Ensure that autistic youth are specifically included in the language/materials of all job program opportunities for IDD youth, so resources are clearly available and accessible.
- Work in partnership with colleges and universities to develop a framework for inclusive post-secondary education that includes AAC and accommodations that promote student retention and success.
- Commit to reforming the “[school-to-guardianship pipeline](#)”, where too many youth are placed under guardianships from their earliest years of majority.
 - Research best practices in least-restrictive decision-making supports.
 - Implement these practices to increase autonomy for autistic adults.

Access to Health Care

We advocate for a national education program for health care professionals to train them on AAC and communicating with autistic patients, as well as simple steps to make hospitals, clinics and the dentist more accessible for autistic people. This education program should have autistic self-advocacy organizations in the lead for developing materials and outreach.

Like everyone else, autistic people need health care. Unfortunately, communication barriers and sensory differences limit our access to health care. This can affect our ability to seek care and the quality of the care that we receive, especially in the ER.

Many providers do not understand how to communicate with AAC users or assume “incompetency” when they meet an AAC user. This creates a barrier to care and can prevent someone from seeking health care when they need it. As one of our members notes: “I have had medical staff look at me using my device, and then ask if I needed a guardian to sign it a form for me. Despite me walking in, by myself, and advocating for myself.”

We recommend teaching incoming and established health care practitioners:

- to understanding the broad communication capacities of AAC users;
- how to communicate with an AAC user (such as waiting for them to finish typing, rather than talking over them); and
- the need to keep AAC accessible during any medical care visit.

The Emergency Room

Because some practitioners don't understand AAC or other autistic communication methods, autistic people may receive sub-standard care in emergency medical situations.

The environment of the ER is very stressful to autistic people, because we take in every single sight, sound, word/click/beep/door slam/yell/sob/whisper, smell and feeling (often including others' emotions) when we enter the ER. We have heard that NTs can internally block these things out (seems weird, but ok) and many of us have our own external methods for helping to block these out so we can function in this over-stimulating environment. These include:

- Noise canceling or muffling earphones and ear plugs
- A stim toy to stay grounded (usually held in our hands or kept close)
- Talking about a special interest
- Echolalia
- Rocking jumping or spinning, as a form of self-regulation
- Our phones, to connect with other autistic people and friends/family

When these are not available to us, or if they are and things are going badly, we may go into sensory overload. This can look like:

- Shut down: going selectively mute, not looking up, seeming unresponsive, being unresponsive.
- Meltdown: crying, yelling, screeching, flailing, falling, swearing (Note: some of us also have Tourette's)
- Leaving.
- Any versions of the above and others.

These responses could usually be prevented with sensory considerations and communication. They are frequently misunderstood. As one of our members, who had reached the breaking point, recalled "The EMTs thought I was having a meth withdrawal." Autistic people are vulnerable to abuse, systemic violence or denial of care in these situations, especially those who are Black, Indigenous, People of Colour or Trans. We heard from members that some are afraid to give their autism diagnosis when receiving EMT care or even decline to seek care because of stigma and fear.

The results can be deadly, as in the case of [Oliver McGowan](#), an autistic teen who was in the ER following a seizure and was given a powerful anti-psychotic to which he did not consent and which his parents repeatedly told doctors he had previously had an adverse reaction to. He died from Neuroleptic Malignant Syndrome, brought on by the medication. As Oliver's mother has [said](#): "We strongly believed that doctors were misunderstanding Oliver's normal autistic behaviours."

Autism pseudoscience

Autism pseudoscience (or so-called “alternative” or “biomedical” autism treatments) do not have any positive effect on autistic children and there is [no medical basis](#) for any of them. They are [dangerous](#) and [potentially deadly](#) to autistic children. They [cause](#) psychological damage, including PTSD, to the children who are forced to endure them.

All autism pseudoscience causes psychological damage to the children who are forced to endure them. Also, the myth that autism can be removed from a child leaves no room for parents to accept their child for who they are. A child who is being told they will be “detoxed” until no longer autistic, is not given the opportunity for healthy self-acceptance. When the miracle cure doesn’t arrive, it can have devastating consequences for the child and family.

As the Westminster Commission on Autism (UK) [writes](#) in its report recommending improved policy and practice on autism pseudoscience: **“Health care fraud is big business and autism is one of its many targets.”** The United Kingdom has recognized the problem of autism pseudoscience and is working to create more regulations around it. (We encourage you to read their informative and engaging [report](#)). Canada lags behind, still largely relying on so-called “self-regulating” colleges to keep practitioners in check. The problem is, this doesn’t work and children are in danger.

Our federal government needs to follow the UK’s lead and take action. Please read our [Physicians' Guide to Autism Pseudoscience](#) for more information.

Recommendations: Health care

Practitioner training

- Training for both homecare support workers and staff in long-term care facilities for understanding how to best support autistic people as they age.
- Partner with medical schools to create an education module for health care practitioners (especially ER) on how to communicate with AAC users.
 - Alternative: support and promote [independent efforts](#) at these education modules.
- Recommended unit for medical schools: “Ask an Autistic,” where autistic people discuss their end-user experiences to educate incoming professionals on communicating with autistic patients.
 - Alternative: support and promote [independent efforts](#) at these education modules.

- Recommended education unit for dental students: trauma-informed care for autistic patients. Evaluate and update existing programs.
- Support online tools for autistic youth and adults on communicating with health providers and institutions (Tools should be created by autistic individuals in partnership with medical institutions, not by “autism service” providers).

Recommendations: Regulating pseudoscience

- Genuine government oversight of self-regulating colleges (chiropractic, CPSO) to ensure that autistic children are not exposed to dangerous quack treatments.
 - A provincial “do not use” list of autism “cures” such as chelation:
 - This can be modeled on the NHS’s Do Not Use For Autism list and the FDA’s list of banned autism “treatments”.
 - Right to consent laws that protect children from harmful autism pseudoscience like chelation.

Community education

Canada has little in the way of community education programs to keep autistic people safe and allow us access to necessary services. As mentioned, 99% of Canadian medical students are not trained in speaking with someone who uses AAC (and 25% of autistics are nonverbal or semi-verbal). As well, two thirds of all first responders have no training in communicating with autistic people. These barriers, as well as other communication and sensory barriers, prevent us from getting the care we need and can even lead to deadly results.

Recommendations: Community Education

- Education on autistic- and trauma-informed approaches to first responder services, medical care and other areas of life, so that we can be included and have the access to keep ourselves healthy and safe.
- ALL community education programs MUST BE informed by autistic educators and overseen by government and autistic self-advocacy organizations, NOT autism service organizations or charities.

Reforming how autism policy is made

As end-users of services, autistic people are the major stakeholders in all autism policy. **We must be consulted nationally.** Our government also must consult with inclusion experts and other disability organizations within and outside of Canada to understand new models that value inclusion.

We are asking the Government to craft policy that is informed by real inclusion experts, globally, who are making access happen.

Oversight in Autism Services

It is crucial to have adequate oversight of funded “autism service” organizations and charities to detect conflicts of interest, misuse of funds, sweetheart deals, pork barrel and service monopolies--as well as to assess the relevance, utility and fiscal responsibility of the programs our government is funding.

We are asking for reasonable standards including tendering/RFPs on ALL new contracts. We are also asking for **financial audits of every autism service organization receiving government funding**, as well as reviews of how previous federal funding was undertaken, both for transparency and to learn from past mistakes (*e.g.*, where bidding/RFPs were wrongly bypassed and project decisions made based on weak industry data).

Start using good data

It’s a problem when governments give hundreds of millions of dollars to “autism service” projects without robust demographic data about the needs of the targeted population. It’s also a reflection of an antiquated, patronizing approach where non-disabled people make decisions that impact our lives based on tiny selected samples and random theories about how our minds work. That approach doesn’t solve problems; in fact, the service providers that use this model only profits when the problems *aren’t* solved.

Let’s solve problems instead. Have the government collect its own data, using multiple databases (or a broad platform like a Census) to collect demographic information and determine gaps in service, areas of need and the (in)efficacy of existing approaches--as they develop new and creative approaches that are also built around data... the data being case studies and pilots from other jurisdictions who have had successes using new and novel approaches. Autistic-led groups can provide leadership in the data collection process.

De-silo autism services and integrate autistic/IDD Canadians in broader disability policies

Federal autism policy is currently administratively siloed in the Health Ministry, kept apart from other disability policy. That is a very poor decision that should be reversed.

By keeping autism policy silo’d away from other disabilities, policymakers have created a false impression that autistic people’s fundamental needs are different from other disabled people. They’re not.

We *all* need access, human rights, dignity and self-determination in housing, employment, education and health care. Many specific issues, such as communication rights and access for non-verbal people, also apply across disabilities. Autistic self-advocacy groups, universally, identify with the broader disability self-advocacy movement. National policy should reflect that.

Canada deserves robust accessibility legislation that includes autistic people. Our government

must include autistic Canadians in its disability policies, across portfolios—and to do a serious audit of autism service providers and how they have gained government contracts—in order to reform that system. The Government of Canada must also meet with autistic self-advocacy groups to hear our ideas and discuss our resources and policy recommendations.

De-fund ABA

We have grave concerns over the suggestion that BCBA's strike a "self-regulatory body" to keep an eye on other BCBA's. This is equivalent to the foxes guarding the henhouse, in our view. The profession of ABA doesn't just ignore abusive practices among its own members—it endorses them. For example, the Judge Rotenberg Centre, an ABA-designed- and-run centre, has been using shock torture on autistic and IDD people, a practice which has now been banned by the FDA and is classified as torture by United Nations watchdogs. Yet the Association for Behavior Analysis International (ABAI) decided to feature the Judge Rotenberg Center (JRC) at their 2019 annual conference. As the Autistic Self-Advocacy Network [writes](#):

"ABAI's decision to give JRC a platform at their conference reflects a [continued pattern](#) of complicity in the torture of the very population that they claim to serve. Furthermore, the JRC's presentation at this conference specifically focuses on the 'merits' of the electric shock device. This means that ABAI is more than complicit in the abuse taking place at the JRC: they are actively endorsing these practices."

ABA should be completely de-funded. However, if the government lacks the political will to do so, then new regulatory bodies for ABA should be completely independent and arms-length from the industry, with **no** members of the industry represented in any advisory or decision-making capacity. Like other autism pseudoscience, ABA needs to at least be strictly reviewed by our government through an independent oversight body to regulate and stop abusive practices—until lawmakers recognize the need to ban it altogether.

Recommendations: Policymaking

- Autistic leadership. Federal government meets with disability self-advocacy groups, including autistic-led groups, to plan policy, using *independently* collects data and studied best practices in other jurisdictions.
- Undo the former governments' silo-ing of "autism services" into a single portfolio. Integrate the needs and interests of autistic people into multiple, relevant portfolios.
- Follow the lead of Scotland, who has made it **law** that autistic people be consulted when the Government crafts autism policy, in perpetuity.
- Financial auditing and oversight of all organizations offering "autism services" to prevent price-gouging, monopoly, pseudoscience and unsustainable service models.

- Do not endorse the establishment of a “self-regulating body” of BCBAs. De-fund ABA or work towards the goal of de-funding ABA.

Conclusion

We all know that autistic people deserve better than the policies Canada has been delivering via the PHAC and Health Ministry. We know that we don't have to live segregated lives. Just because Canada has “always done things this way” doesn't mean it has to. There are better ways and best practices elsewhere that our federal government can learn from. By setting inclusion as the standard, the norm, our government can begin to move Canadian autism policy into the 21st century.

Government of Canada: Start now.