



# Not “Special”: Equal Social Inclusion for Autistic People in Canada

A Report by Autistics for Autistics

*submitted in consultation with the CAHS, March 2021*

## Introduction

In this paper, we will outline our vision for social inclusion in the areas of early childhood, education, housing and health care.

For discussion of economic inclusion, please see our second paper in the series, “When Policy Stops Progress: Rethinking Canada’s Approach to Autism Services”.

For discussion of evidence-based services, please see our third paper, “Not All ‘Evidence-Based’ Interventions are Equal: A Critical Look at the ABA Industry in Canada”.

## Our Social Inclusion vision, by 2023:

- **A Communication Charter of Rights** for non-speaking people, for fair access and accommodations in **all** aspects of Canadian life.
  - AAC education mandates for teachers, therapists, health care providers and first responders.
  - AAC funding for all who need it. No wait-times for AAC.
- **Community inclusion** for autistic toddlers and preschoolers.
  - **De-fund ABA** and invest in science-based services such as AAC, SLP, OT, PT and acceptance-based programs and services.
- **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.
  - Ban seclusion and restraint.

- **Intersectional Oppression:** Autistic students who are Black, Indigenous or people of Colour are more likely to be profiled, segregated and streamed into the School to Prison Pipeline. Our Government should consult directly with autistics who are BIPOC on *all* school inclusivity initiatives.
- **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.
  - A government commitment to study and implement best practices in inclusive housing.
- **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.
  - Program instructors and designers should be autistic and include non-speaking autistics in leadership.
- **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.
  - **NO MORE SOLE-SOURCE AUTISM SERVICE CONTRACTS.**
  - Audit of all programs funded by the PHAC under that model and reform to the PHAC operating model!!

## Discussion and policy-specific proposals

### Communication access/AAC

It is estimated that 20-30% of autistic people are non-speaking or partially-speaking. 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.

Sadly, in Canada the average time it takes for an autistic child to receive this essential communication access is 2.5 years. Some people wait even longer. Some of our members were not given AAC access until they were in their teens or twenties. Some non-speaking autistic Canadians are *never* given access to AAC or choices about AAC!

The Government of Canada must begin to adequately fund the services and technologies that allow non-verbal autistic children to communicate. 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 non-speaking autistic people, *not* autism charities.

### **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 de-fund ABA. We need to ban restraint and seclusion. 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.

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. In 2019, 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. These programs should be developed with non-speaking autistics in the lead.
- Create a mandatory inclusion education program for early years programs, so that autistic children do not get excluded in these spaces.
- Meaningful consultation with adult autistics 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 restraint  
Use the data to develop better approaches, to prevent exclusions and restraint.
- 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: Independent supported living NOW**

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 [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.

### **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-led organizations in the lead for developing materials and outreach.

Autistics for Autistics has experience in leading workshops for University of Toronto and Queen’s University medical students and can share its slides and resources with other autistic-led groups across Canada.

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. 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. 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 "biomedical" autism treatments) are traumatic for autistic children and there is [no medical basis](#) for any of them. They can be dangerous and [potentially deadly](#). They [cause](#) psychological damage, including PTSD, to the children who are forced to endure them.

When a parent tries to "cure" their autistic child with pseudoscience, they are physically and psychologically harming their child. Regardless of the parents' intentions, that is the result. Action must be taken to protect victim, whose rights are protected under the law. We must also work on prevention, educating parents away from these abusive treatments.

Right now, there is not enough action being taken to protect children. Sometimes, this is because authorities lack the information to understand and identify the problem. Other times, it is because they lack a clear legal precedent to act.

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 present an education module for health care practitioners (especially ER) on how to communicate with AAC users.
  - These modules should be taught by autistic people with both teaching and leadership by non-speaking autistics.

- Support online tools for autistic youth and adults on communicating with health providers and institutions (Tools should be created by autistic-led groups 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.

#### **Conclusion**

The Government of Canada has a long way to go to ensure human rights protections for autistic and intellectually disabled people. We urge the Government to reach out to autistic-led organizations, such as Autistics for Autistics and Autistics United Canada, to learn from our research and communities. We want to be a part of Canada’s autism policy reform for an inclusive future.