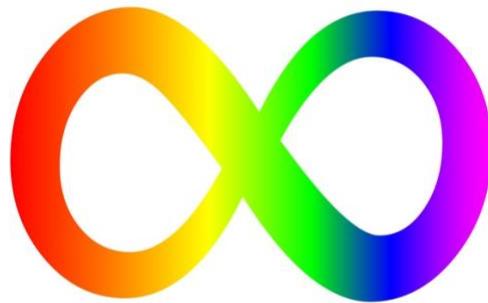


A4A's Recommendations for Reforming Autism Policy in Ontario:

**Adapted from *Inclusion is the New Gold Standard,
a Report to the Government of Ontario***



c 2019 Autistics for Autistics Ontario

Image Description: An infinity symbol, in rainbow colours. The rainbow infinity is the international symbol of the neurodiversity movement

Intro

About A4A

Autistics for Autistics Ontario (A4A) is Ontario's autistic self-advocacy organization. We have thousands of members, both verbal and non-verbal, across a range of service needs, ethnicities, racialized identities, genders, sexualities, economic and employment realities, housing situations and health access needs.

We focus on human rights and inclusion in 4 areas: **education; health care; employment; and housing**. Our work in the community involves public outreach/education initiatives, political advocacy and social activities. While our leadership and most activities are autistic-led and run, we also have a vibrant auxiliary of non-autistic parents who partner with us in advocacy and other projects.

We are a non-partisan group that is all-volunteer. We do not accept donations from corporations, autism service organizations, labour unions or any others who hold interests in specific educational or autism services outcomes. We are ready, willing and able to work on practical solutions for inclusion—and we bring a unique, systems-thinking approach to discussions of policy. We have **all** been through the education system as end-users; some of us have also experienced it as parents of students. We are committed to inclusion and an end to segregation.

Our Report and the Advisory Panel

In early 2019, we authored a report to the Government of Ontario's autism policy advisory panel, entitled *Inclusion is the New Gold Standard*. It outlines many of the issues that autistics in Ontario face, and the ways that institutions, including Ontario's autism service providers, have failed autistic youth and adult. If you would like a copy of our full report, please contact us at a4aontario@gmail.com or visit our website a4aontario.com.

It is our hope that the report, and our recommendations, will inform a shift in policy-- away from the segregationist approach that former administrations have supported, and towards inclusion.

One of our members, Matthew Jason Dever, sits on the Ontario Government's autism advisory panel along with another autistic panelist. This is historic because it is the first time autistic people have ever been a part of an Ontario autism advisory panel! It is promising to see this, and to see the government accessing meaningful data in making decisions. We thank the government for taking a proactive and inclusive approach to consultations.

Recommendations in this document

This document contains our recommendations only, listed under the categories of: General administrative; Early Years; AAC; School-age; Transition to Adulthood; Health Care; Employment; and Housing.

Administrative Recommendations

- 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 skimming, sweetheart deals, pork barrelling, price-gouging, monopoly, pseudoscience and unsustainable service models.
- Create safeguard rules around lobbying and autism service monopolies, so families begin to have flexible options and public funds are no longer funneled to one industry as under [the Ontario Autism Program \(2018\)](#).
- Do not endorse the establishment of a "self-regulating body" of BCBAs.
 - True regulation can only happen via outside oversight entities. Those entities already exist and should be leveraged rather than wasting resources on a new one that will only serve to stymie enforcement.

(please see next page)

Recommendations: Early Years

Funding Flexibility/ End the Service Monopoly

- Fund AAC, OT, PT and SLP for autistics of all ages, as needed.
 - Educate developmental pediatricians in the province on the benefits of these services and where/how to refer for them.
- AAC access for all who need it, without delay.
 - Please see our AAC section, in the full Report for specifics about AAC access support.
- De-fund IBI centres and all ABA in favour of inclusive approaches.

Community Education -- An Inclusion Mandate

- AAC education programs for healthcare providers, teachers and others in the community so that they can communicate directly with their students/clients who use AAC.
- Create a mandatory inclusion education program for Ontario Early Years Centres and other programs for the early years, so that autistic children do not get excluded in these spaces.
- Promote inclusion of autistic and all disabled children in public spaces through a public awareness campaign, ideally in partnership with the private sector.
- Education program/website for parents of newly-diagnosed children, promoting an acceptance and inclusion approach.
- Meaningful consultation with nonspeaking adult autistics and those with high support needs about what needs to change for autistic children with high support needs.

(please see next page)

Recommendations: AAC—Flexibility in Services

DEFINITION of AAC

Augmentative and Alternative Communication (AAC) is any means of communication—aside from verbal speech—that allows someone to use language. AAC is used by people with various disabilities, including some autistic people. It can include:

- Pictures
- Gestures
- Sign language
- Visual aids
- Speech-output devices like phones or iPads

Recommendations

- AAC access for all who need it, without delay.
- Education programs for healthcare providers, teachers and others in the community so that they can communicate directly with their patients/students/clients who use AAC.
- Base funding for new acquisitions on changing communication and developmental needs rather than an arbitrary “5-year” timeframe.
 - If time-limit on AAC funding doesn’t change, allow families to use SSAH funds or other benefits to upgrade hardware or software when communication needs change.
- Train more SLPs that specialize in AAC.
- Teachers and other support workers need training to be effective AAC communication partners.
 - Schools should **not** be introducing an AAC app at school that is different from the one being used at home.
- Provide consistency across the province in terms of SLP clinics: which age group they serve, who can refer, what the diagnosis is.
- Press the federal government to remove HST from iPads prescribed as a dedicated communication device, to improve access.

(please see next page)

Recommendations: School-Age

Universal Design in Schools (the New Brunswick Model)

- For public schools, follow the model of New Brunswick, who led the way in 2010-2013, implementing universal design for learning, integrated services between departments, and a new policy for inclusive education along with modifications to the Education Act, through Policy 322.
 - NB has also transitioned away from the remaining contained special classrooms within schools.
 - **This *Integrated Services* approach received national and international recognition as a model for transitioning to inclusion.**
 - In the words of former NB Education Minister Jody Carr, “Policy 322 ensures that inclusive education is not a simple program or add-on.”
- Remove PPM 140 (2007) and allow families to use classroom support persons other than the districts’ ABA providers. Industry bullying and antiquated union provisions should not be dictating whether students can attend school with the right supports for them.
- AAC access for all who need it at school, without delay. Education for all staff on AAC so they can communicate with the student, not just with their EA.
- Amend the IPRC (O. Reg. 181/98) process to require students with disabilities to be placed in a “common learning environment” as envisioned in New Brunswick’s Policy 322.
 - IPRC should also require school boards to adopt special education plans that are driven by an inclusive philosophy with the goal of placing disabled students in a common learning environment with other students.

School Exclusions: Tracking & Accountability

- Develop an appropriate and comprehensible dispute resolution mechanism for all matters related to the education of students with disabilities, so families are heard.
- Modify the regulatory provision that allows a school board to shorten a student’s school day (O. Reg. 298 s. 3(3)) to require that it only be used when it is in the best interests of the student, with 2-month review to ensure it is still needed.
- Procedural protections for students who are excluded via s. 265(1)(m), giving families similar appeal rights as those available for suspensions and expulsions (see: Part XIII of the Education Act).

- Assess learning outcome measures and think outside the box. Consider alternative measures of success, per the model of New Brunswick schools.
- Remedy the problem of internal exclusions. Autistic children should be included in recess and field trips, with appropriate support persons to ensure they have the same access to these developmentally-enriching activities as other children. (They currently do not).

Human Rights in Special Education

- Make existing special education classrooms transparent, to prevent abuse.
 - Have cameras in all special education classrooms to keep instructors and staff accountable (cameras-in-classrooms program).
 - Make it **illegal** for a special education program to ban parents from entering the classroom (as many programs do now).
 - Create an environment where families are welcome as partners in education, not “outsiders”.
 - Put teachers and aides on notice that the Province is watching for neglect and other abuse in their classrooms.
- 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.
- Ban isolation rooms in schools, as the Province of Alberta [has done](#).
- 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: ban it.**
- Consult with autistic youth in special education and with autistic adult who were in special education about what needs to change in our special education classrooms.
- Educate all teachers and staff on trauma-informed care and appropriate de-escalation techniques, per best practices in other jurisdictions.

(For data and helpful resources, contact [Inclusion Alberta](#) and Inclusion BC).

Community Involvement in Schools

- **Inclusion is an attitude, not an out-of-the-box program.** While mandates are essential, so is education to meaningfully change the environment.
 - Have all students in the classroom provide input into inclusion. They have wonderful ideas and this empowers them.

- Allow families to get to know each other and be a part of inclusion. Community-based schooling leads to better success socially and academically.
 - Inclusion lifts the whole community: celebrate it!
- Province-wide peer (autistic) mentor program with online options in remote areas.
- Consult with SCERTS and other inclusion models to understand best practices for community involvement.
- Education about self-regulation and autistic ways of moving, to reduce stigma and improve classroom success.
- Education about AAC so that school social workers, staff and other parents are comfortable communicating with students who use it.
- Helpful supports for families who home educate.
 - Remove barriers to involvement in in sports/extra-curricular activities at schools.
 - Online tools to modify and provide feedback on the Ontario curriculum.
 - Educate community centres on ways to include and welcome this growing population during school hours.
 - Autistic students who cannot currently attend school due to barriers should not face further barriers in being involved in community life.

(please see next page)

Recommendations: Transitions to Adulthood

- Cut wait times and other restrictions on Special Services at Home (SSAH).
- Offer flexibility in Passport funding plans and options.
- 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 less restrictive decision-making supports.
 - Implement these practices to increase autonomy for autistic adults.
- Please see our “Employment” and “Housing” sections for more specific recommendations.

(please see next page)

Recommendations: Access to Health Care

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).

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 (see Health Care section for case law).

(please see next page)

Recommendations: Employment and Economic Security

Life Transitions: Employment

- 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 ODSP to ensure people are not being economically penalized for going from unemployed to part-time, which has happened under other governments.
- Flexibility in service support for disabled employees who need to transition between unemployed and employed throughout their lives.
- Include autism in all disability support and funding policy.

Job Searching and Employee Retainment

- Online how-to information for autistic job-seekers on how to navigate disclosure and requesting accommodations.
 - Can be built from existing resources in other jurisdiction, with consultation from local autistics.
- 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, Microsoft's hiring and accommodation protocols).
- Mentorship between working autistics and job seekers.
- More partnerships with the private sector
 - Leverage the knowledge of the private sector in creating accessible workplaces.
 - Learn from the best practices in private sector for the job interview process (example: Apple).
 - Encourage private sector to hire autistic employees at competitive wages.

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.

Recommendations: Housing, Safety and Autonomy

Safety in Group Homes

- Government standardized regulation for vetting and hiring of privately-run group home staff, to prevent abuse and recidivist violence (see Housing, page 41).
- 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.

Towards Maximum 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.
 - LiveWorkPlay offers 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.

Thank you for reading these recommendations. We hope you will read our full report, available on our website: a4aontario.com or by email: a4aontario@gmail.com