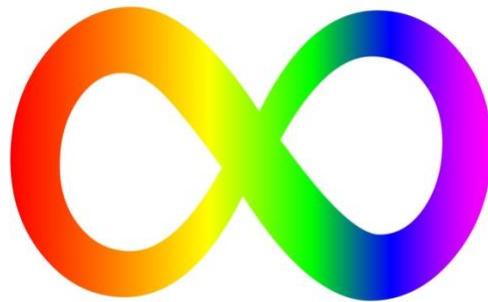


***The New Gold Standard is
Inclusion:***
**A4A's Recommendations for Reforming
Autism Policy in Ontario**



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

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Introduction

One snowy day last March, a group of autistic Canadians walked up the steps at Queen's Park in Toronto to meet with MPP Amy Fee, who graciously welcomed us into her office to talk about autism policy. In that moment, we realized that we were making history. It was the first time that the Government of Ontario had ever consulted with autistic people about autism policy.

It seems unbelievable, doesn't it? After all, hundreds of millions of dollars have been spent on autism programs and services in our province: could it be possible that our provincial governments had *never* asked autistic people about autism policy? It's true. Our former governments had only ever consulted with a select group of service providers and parents, never with autistic people.

We would like to thank our current government for correcting an inequity and consulting with autistic people about the policies that affect our lives. Not only are we key stakeholders, (obviously) but as end-users of services, we have a lot of insight into how existing programs are run and what can be done to reform the system towards a more effective and sustainable model of service, with new paths for care and a new ethos emerging: **inclusion**.

Precedent for Inclusion

While Ontario may be one of the first provinces in Canada to be moving towards inclusion, it is not the only one worldwide. In this report, we will show the example of the UK, Scotland, New Zealand, parts of Canada and parts of the US, who are all moving away from the old segregationist approach towards including autistic people as valued members of the broader society (See Appendix 3, *If Not ABA, Then What?*).

We know that when autistic--and all disabled people--are included, it lifts our entire society. As we explore in this report, universal/inclusive design is good for everyone. Also, inclusion is the right thing to do. (See Appendix 1, *Letter from New Brunswick's Former Education Minister*, for an example of the power of inclusive design.)

A Note on Terminology: We are autistic. As such, you won't be reading hurtful terms like "epidemic", "tragedy", "burden" or "pay now or pay later" in this report. We know that we are who we are and *we like and value ourselves*. We are not a problem to solve (or to shove out of the way): we are a part of society and we strive for inclusion and respect. We want to fully be a part of the broader society and we seek to find the best ways to make that happen.

Overcoming a Legacy of Segregation

The former government's model for autism services was based on segregation of autistic people and the foundations of its funding model were monolithic. All autism services and funding were grouped under **one** Ministry (Children and Youth Services) and all funding was directed to **one** program ([ABA](#), which is built on a segregation model). All funding decisions were made with the input of **one** lobby (ABA providers), without input by end users or any other stakeholders.

Under the old model, autistic toddlers and preschoolers were streamed into full-time, segregated ABA/IBI schools while their peers were playing and getting to know one another at community centres and Early Years programs. By virtue of their geography and ideology, the IBI centres separate the autistic children and stigmatize them as broken versions of normal, not truly a part of their communities.

It is no surprise then that autistic children in Ontario have been starting school at a social disadvantage: they are not a part of their neighbourhood community (because they attended IBI centres, not their local community spaces). It should be no surprise that their peers (who don't have experience playing with autistic kids) likewise lack the social skills to relate to them. No one should be shocked that spending the day racing through mazes for M&Ms and "school readiness" such as cutting up business cards with scissors likewise does not prepare autistic children for the complex social world of a school in which everyone else has known each other for years and has culturally-specific ways of communicating unrelated to the therapist's prescribed lexicon of "no-no" and "good boy".

Without a social context or social bonds, nor the life skills that they could have developed through the normal free play and community activities of early childhood, many autistic students in Ontario primary schools are doomed to be out of place and adults (ever-eager to place them) too often stream them into special education classes and consign them to 13 years of segregation within school. Those students who do remain in the mainstream classroom are typically paired with an ABA aide (and only [ABA](#) aides are allowed in Ontario schools, per the former government's [PPM 140](#)), with districts *still* seeing ABA as the solution --when in our view, it is really the heart of the problem.

Once school has finished, students in special education or those who experience institutionalized stigma within a mainstream class, are less likely to attain any type of post-secondary education and more likely to end up living in segregated group homes and unemployed or working in a segregated workplace. This outcome, also, is completely predictable. By contrast, students who are integrated into the mainstream in a meaningful way are more likely to thrive and achieve autonomous living with or without varying degrees of support.

So why has the IBI system maintained such dominance in public funding in Ontario, when it clearly leads to a life of segregation? This has in part to do with our province's legacy of residential institutions but also with the marketing of the ABA system and the way politics was done in Ontario under previous administrations. [ONTABA](#) is quite simply the most powerful (and until recently, the only) lobby on this issue. Their marketing has hinged mainly on fear – frightening parents with the false claim that theirs is the "only evidence-based" method and providing phony reassurance to policymakers that all they need to do is "pay (tax dollars) now" to avoid having to "pay later" (at the polls).

We hope that, to whatever degree possible, new administrations can push back on this fear and open up our province for choices in service and better inclusion of autistic youth and adults.

Our Background and Resources

We recognize the strengths and limitations within our own knowledge as a group. We **have no paid staff** to prepare this report (nor any financial stake in the recommendations we are giving). Unlike ONTABA, who hired the Pathway group to lobby eight Liberal ministries in 2017, we obviously don't have paid firms doing our lobbying and PR! We are autistic adults, who once were autistic children, and we just want to help make things better.

Our members comprise both verbal and nonverbal/semi-verbal communities, represent a broad range of ethnicities; racialized identities; disabilities; economic class; genders; sexualities; education levels; and level of support. Our group spans the full expanse of political and social views. As an organization, we are firmly non-partisan.

Beyond our immediate group, we also have partners such as our parent auxiliary who are very active and helped with this report. As an international affiliate of the [Autistic Self-Advocacy Network](#), we also have their mentorship and example. And we called upon a broader group of experts on inclusion in schools, housing and employment to inform our policy paper.

Organization of Report

We have organized this report into three sections:

1. RECOMMENDATIONS
 - Administrative
 - School Inclusion
 - Early Years
 - Public Schools
 - Transition to Adulthood
 - Health Care Access
 - Employment
 - Housing
2. OUTLINE OF THE PROBLEM AND POTENTIAL SOLUTIONS
 - Schools: Making Inclusion Work
 - Health Care: Access and Safety
 - Employment Fairness and Economic Security
 - Safe Housing and Housing Autonomy
3. APPENDICES

We appreciate your taking the time to read these sections and look forward to hearing your feedback.

DEFINITION

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

Section 1: Policy Recommendations

We have summarized our policy recommendations in this section. We are making recommendations for:

- Administrative
- Early Years
- School Age
- Transition to Adulthood
- Access to Health Care
- Employment
- Housing

For in-depth discussion of needs and specifics around recommendations, please see SECTION 2, page 17.

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 BCBA's.
 - 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 for Early Years recommendations)

Recommendations: School Inclusion/Children and Youth

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, page 20, 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.

AAC—Flexibility in Services

- Cut wait times for AAC devices.
- 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.

- 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 for School-age recommendations)

Recommendations: School-Age

Universal Design in Schools (the New Brunswick Model)

- For public schools, follow the model of New Brunswick, whose Conservative party 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.

(see next page for Transition to Adulthood 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 for Health Care Access recommendations)

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 for Employment Access recommendations)

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.

SECTION 2: OUTLINE OF PROBLEMS AND SOLUTIONS

Administrative/Policy Considerations

The problem of “feel-good” autism spending

There is an industry around autism services. Unfortunately, many in that industry are unscrupulous in seeking maximum profit by frightening parents into expensive, unsustainable treatments that have no real basis in evidence. It is sometimes easy for them also to convince politicians to rubberstamp investments in such programs because of the “feel good” effect. This kind of spending can make a busy politician feel as though they are doing something to solve a problem without much effort or critical thinking, nor the political will to assess/audit its effectiveness. To put it colloquially, these politicians are throwing money at a problem in hopes of making it go away (or making a powerful lobby go away) until the next election. There is also the potential issue of pork barrel for some politicians who have “treatment” centres in their ridings.

That approach to autism policy is extremely unfair to autistic people and their families, yet it has been a trend in Ontario politics. We are hopeful that our current government can address these problems and, through meaningful audits, create a better way forward.

The silo’ing of autism policy

Under the former government, autism policy was administratively siloed into the Ministry of Children and Youth, meaning little to no policy was focused on adults. The word “autism” rarely appears in provincial or federal government policies other than those targeting children and youth. The former government even used the term “pay now or pay later” suggesting that investments in programs targeting children have more inherent worth than supports for adults, (callously called the “pay later”).

We are glad that our new provincial government is committed to autism services under multiple portfolios, a step in the right direction. This will not only reflect the reality that autistic people well,...grow up and become adulty-people for many decades, it helps to keep an eye on cheques and balances to ensure programs are running fairly, with equity across the demographic spectrum—and that they are economically sustainable.

Who Regulates 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. Some self-regulating bodies can arguably serve to cover up misconduct rather than provide appropriate enforcement and we believe that is what could happen here.

There is incontrovertible evidence that 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.**"*

Any 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.

Oversight in Autism Services

It is crucial to have adequate oversight of funded "autism service" umbrella organizations 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. Unfortunately, some organizations have profited from attaching the words "autism" or "children" to their brand as a way to avoid the type of scrutiny we expect of other businesses. Let's put a stop to it.

On a related note, the government should ensure that all autism lobby organizations who handle money file appropriate financial statements annually, as this is currently not happening. What money comes in, and from whom, is a very important factor in assessing the recommendations of any lobby group.

We know that reforming autism services is, in part, about changing how politics works. We are encouraged by efforts in other jurisdictions, notably Scotland, to ensure that end-users (aka: autistic people) are consulted as a matter of course and measures are taken to curb any conflicts of interest. We are also encouraged by the Ontario government's efforts to offer audits to previously under-audited areas of service. This is a good step towards ensuring that services are relevant, spending is sustainable, industry influence is curbed and conflict of interest reduced.

Recommendations

- Undo the former governments' silo-ing of "autism services" into a single portfolio by integrating the needs and interests of autistic people into all 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.
- Do not endorse the establishment of a “self-regulating body” of BCBAs. True regulation can only happen via outside oversight entities, comprised of individuals *not* working in the profession. Those entities already exist and should be leveraged rather than wasting resources on a new one that will only serve to stymie enforcement.

AAC

Communication is a cornerstone of learning. One of the biggest steps our province can take for autistic children and youth is to prioritize access to [AAC](#) for non-verbal and partially-verbal students. (for a definition of AAC, see page 6).

AAC gives these students an essential tool for communication and regulation, leading to a fulfilled life as a child and in adulthood. It also opens the door to many opportunities and the kind of autonomy that every person deserves.

Unfortunately, studies show that many schools and IBI centres wait far too long to give access to AAC. Ontario should lead the way in removing that barrier to communication.

Testimonials

Below is a testimonial from one of our members who needed AAC but did not get access to it until he was an adult. Derek Burrow now works as an information specialist for a major library in Ottawa:

“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 through ODSP; 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. And, yes, part of that was also being taught how to properly communicate in a job interview. Instead of fighting to make cogent responses, I was able to sit down and just let my brain say its piece with my mind getting in the way. I aced my job interview and here I am now. I cannot stress enough how big a difference AAC has made for me.”

Deanna Shoyer, a Hamilton-based parent of a 12-year-old in Ontario public schools also wrote to us:

“AAC in its broadest sense (including visual supports like calendars for example) has made it possible for my children to thrive in an inclusive school environment. It is an essential element for inclusion to succeed.

“Fostering inclusion is not just the right thing to do, I believe it’s the most efficient way to support disabled people. In education, it lifts the academic performance and happiness of all kids, not just disabled ones. Growing up included in the community and given tools to succeed (like AAC) results in disabled adults who are less likely to rely on public assistance like ODSP.”

A parent from Scarborough, Cathy Wright, wrote:

“I have a 23 year old son, who is a non-speaking autistic man. From early childhood, he was presumed incompetent at school. As parents, we were given very poor professional advice. We were not told that a communication system might change our son’s life. ... At 17, a support

person who had experience with Supported Typing (a form of AAC) offered a letterboard to my son and we began having the first conversations with him ever. We learned that he was a polite, empathetic, sensitive, funny kid who was interested in art, politics, world affairs and travel.

“If you’re inclined to think that a non-speaking autistic person who is discovered to have the capacity to think, learn and communicate in a sophisticated way is a miracle of some kind, know that we have met well over twenty people just like my son, who are using Augmentative & Alternative Communication devices to direct their own lives. Yet the vast majority of non-speaking autistics are trapped inside their bodies with no communication tools. They are institutionalized in high numbers. Their support in school is primarily behaviour management. Why not instead offer communication tools?”

As A4A member Ren Everett, wrote, when assessing a child for autism, professionals should be required to:

“take into consideration whether or not the child is speaking, and if not, communication-based treatment should be the very first thing they receive, as opposed to behavioural therapy.”

Jim Meunier, an AAC user from Coldwater Ontario discussed the need to recognize AAC for inclusion in society:

“Protecting the rights of autistic AAC users to communicate and be heard in the education system, in our workplaces, housing and healthcare, is pivotal to recognizing our full and collective participation in these areas.”

Problems and Challenges

Some parents worry that giving an AAC system to their child will prohibit the development of verbal speech. However, research shows that this is not the case – in fact, the opposite is often true. Access to AAC encourages all types of communication.

Many teachers and staff do not understand AAC and they need education on how to communicate directly with AAC-using students.

Other teachers do not know which type of AAC system is appropriate for a student, or they may not advance a student to a better system because of school administrative/appropriations issues.

Teachers may also implement a different system than the student uses at home, which is a mistake.

Some therapists hold back on providing AAC trying to “force” the child to talk. This is cruel and it must be ended. **Any “therapy centre” taking this approach should be de-funded by our government.**

There are also still preconceived notions that nonverbal people lack basic competencies, so nonverbal children who could thrive in a mainstream classroom with AAC are too often tracked into special education, with lifelong consequences.

Autistic children and adults may not have the type of AAC system that meets their needs, due to arbitrary guidelines based on age/years instead of changing development, needs and technologies.

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.

We hope our province will create a mandate for AAC access, and education to ensure that all people who work with students understand and respect AAC. If you would like to connect with any of our AAC-using members, or members of our parent auxiliary, please contact us.

Early Childhood Program Policy Considerations

Diversity of Services

Sadly, segregation of autistic preschoolers is the norm in some regions of Ontario, where they are streamed into full-time “intensive” ABA centres that remove them from their peers, even as their neighbours are developing the beginnings of lifelong friendships.

When the children go to school, in some sense their lot is already cast. The autistic children, having spent their days in ABA centres, are not familiar with the social world of their peers and likewise the neurotypical children are not used to including autistic peers in play. Segregation in the early years is thus a setup for more segregation in school years, when autistic children are stigmatized as outsiders within their own community.

This is in contrast to countries such as [Scotland](#), who do not generally use segregated facilities for autistic preschoolers and have lower rates of special education referrals in the school years as a result.

Families Who Did it Differently

There are families in Ontario who chose not to put their children in the centres. However, under the former government, there was no funding for alternatives to ABA, such as developmental therapies (e.g., RDI, [DIR Floortime](#)) or programs like the [SCERTS program](#), or even services like Occupational Therapy (OT) and Speech Language Pathology (SLP).

These families were sidelined from funding and sometimes even stigmatized by schools—some paying out of pocket for services that helped their children. Some families also home educate their children because they don’t want [ABA-mandated EAs](#) for their children at school and no alternatives or flexibility are allowed at their local schools.

Although a fraction of the cost of ABA, alternatives to ABA were only available to families with disposable income to pay out of pocket, since the former government did not fund them. Families without the means to pay for these crucial services were left to DIY their children’s services or move to another province.

Testimonial

Two of our parent auxiliary members (married), who chose to remain anonymous, spoke of their efforts to include their son in the community by choosing different services than the IBI centre.

“We were told to send our son to an ABA centre. They said that he would never learn life skills without it. When we visited the centre we didn’t like what we saw at all. Then we learned that there was no funding for the services he did need, like OT and SLP. We were lucky to be able to pay out of pocket for them.

“By the way, he learned all his life skills [without ABA]! We hope the province will understand there are different ways than ABA and they work. I hope they will fund services like OT and SLP for families who can’t afford them. They should be given a chance because they work.”

Problems and Challenges

There are many families in Ontario who have wanted choices other than ABA. They have been wrongly stigmatised for making those choices by being told ABA was the “only evidence-based” method.

Also, many were unable to get enough of the supports they needed due to the funding monopoly of ABA services, where it was the only service covered. Families with wealth had good coverage --and non-wealthy families had to DIY, got patchy service, or even do without.

Some families ended up choosing ABA because it was their only “affordable” option since the government would cover the costs which, ironically, are higher than alternatives to ABA.

Services like OT and SLP typically do not mandate full-time, institutional settings but are done clinically, at far less expense than IBI. It would save parents and taxpayers money to explore alternatives to ABA.

It is also the right thing to do, because families deserve the right to make choices other than ABA.

Solutions

- End the ABA service monopoly and fund AAC, OT 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.
- Explore alternatives to ABA such as the SCERTS model and others (Halton School District has recently done SCERTS training).
- Consult with nonspeaking adult autistics and those with high support needs about what needs to change for autistic children with high support needs.
- Promote community inclusion of autistic children through an awareness campaign in partnership with the private sector.
- Study best practices in Scotland, England, Ireland and other jurisdictions who use alternatives to ABA.

Schools: Making Inclusion Work

Within Ontario 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.

Ontario schools are some of the most segregated in North America for autistic children. This comes at a social cost: kids that are streamed into special ed have less opportunity to live up to their potential and are more likely to end up in segregated living and work settings in adulthood. Inclusion (when done right) creates opportunity for youth as they transition to adulthood. Ontario should follow the example of New Brunswick and break the cycle of segregation.

Problems and Challenges

Ontario’s autistic and IDD students are routinely segregated from mainstream students at lunch, recess and many school activities--and too often they are even excluded from attending school at all. Some autistic and IDD children are denied the right to attend and receive an education for days, weeks or in some cases even permanently.

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.”

Internal segregations—where autistic students attend classes but are excluded from recess field trips or the social environment of schools, is also endemic in Ontario schools.

When a stigmatized student “acts out,” they are often swept into the special education setting instead of administrators making simple, helpful changes to the learning environment.

Simple changes to the design of classrooms, such as a “quiet chill out” area (open to all), changing the lighting and adjusting acoustics in a room make a world of difference to many autistic students. Neurotypical students benefit from these changes as well. Sadly, as of this writing, these kind of accessible design choices are being made on an ad hoc basis by individual teachers, without any broader institutional commitment or planning.

Recommendations

Universal Design in Schools (the New Brunswick Model)

- For public schools, follow the model of New Brunswick, whose Conservative party 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.”
- 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.
- 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*).
- Remove PPM 140 (2007) and allow families to use classroom support persons other than the districts’ unionized ABA providers. Industry bullying and antiquated union provisions should not be dictating whether students can attend school with the right supports for them.
- Assess learning outcome measures and think outside the box. Consider alternative measures of success, per the model of New Brunswick.

- 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).

Special Education: Human Rights

Lack of Transparency Means More Abuse

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.

The Province and 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.

Ontario 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 in our province.

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 could be reported in the media and acted on. This is not currently possible in Ontario.

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."

The use of isolation rooms, which were recently [banned in Alberta](#) and should be merely a nightmare from the past in our province, is [increasing](#). When Sheila Bennett a professor at Brock University in St. Catharines, learned of more school districts in Ontario building more seclusion rooms, [she said](#):

“It really horrifies me... When an isolation room exists, it becomes a viable alternative for behaviour and inhibits our ability as experts and educators and compassionate people to find solutions that work better.”

Testimonial and Case

(cw: child abuse)

There is no excuse for the kinds of abuse that autistic and IDD students face. They are often afraid to tell their parents what is happening and in some cases can't communicate enough of the details for therapists or parents to understand and take action.

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.”

With parents banned from many special education classrooms and some teacher groups fighting against cameras in the classroom, there is no transparency. Without transparency, more abuse happens.

(report continues on next page)

Recommendations

- **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: there is no excuse for abuse or neglect.
- 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.
- 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.**
- 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 or Inclusion BC).
- 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.

Inclusion is an Attitude: Bringing Community into School

Education advocates have (*for decades*) pointed out that schools are healthier when communities and families are involved. This is as true for autistic students as it is for all students.

Yet many parents of autistic children note they are discouraged from being involved or even sometimes being able to enter the physical space of their child’s classroom. Access is entirely dependent on the individual environment of a specific district since there are no provincial guidelines on parent access to school or inclusion of families in schools.

The quality of inclusion is linked to a district’s openness to a parent’s input and involvement. This points to an overarching truth: inclusion is an attitude, not a product. Some districts and unions have balked at the “costs” of inclusion. But in reality, inclusion comes mainly at the expense of a shift in district culture, 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.

Deanna Shoyer, a member of our parent auxiliary, noted a change in her children’s school experience, that will impact their entire lives, when she moved districts:

“From Grade 1 to Grade 5 my children were in the TDSB. They attended a regular school but were in an autism specific class and a developmental disability class. My understanding was that there would be inclusive programming but that never seemed to transpire. I agreed to Owen being in a DD class because I believed they would be more committed to helping him learn to use AAC. On the contrary, despite being supportive of his AAC in person and in writing (his IEP), they undermined its use by taking his talker away from him for most of the day and on the bus.

“From Grade 6 my children have been in HWDSB and I was very insistent that they be mainstreamed. Both boys are now in regular classes for their age and provided with support and accommodations. They are both visibly much happier and excited to go to school. Owen always has his talker with him and he is using it much more. They are extremely popular kids, both amongst the staff and their peers. Oliver is actively mentoring children in lower grades with respect to both play and helping them with reading. Both boys are improving their academic, art and sport skills and strengths at a much faster rate. They are not only happier but more confident in themselves and more comfortable with their peers. I should note that both their classes are mainstream but also include other disabled children.”

Wherever the government can, it should use tracking data to hold schools to high standards for inclusion. At the same time, the government can encourage school/community connections in several ways, outlined below.

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!
- Create a rule prohibiting schools from banning parents from classrooms.
- Consult with [SCERTS](#) and other inclusion models to understand best practices for community involvement.
- Offer incentives for community involvement in schools—never de-incentivize it.
- Provincewide peer (autistic) mentor program with online options in remote areas.

- 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 being involved in sports or other extra-curricular activities.
 - 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.

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Transition to Adulthood

Our province needs to build a useful system 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](#)).

To make a more positive policy environment for transitions to adulthood, policymakers need to do more than extend funding for existing programs (although this is also positive, especially when paired with more flexibility). Policymakers must also audit and overhaul existing programs and develop new programs and partnerships that promote supported autonomy.

Following are some of our recommendations. We hope the government will take the time to assess needs, through data collection. We also hope the government can meet with our core group as well as our Parent auxiliary to discuss the future shape of transition services.

Recommendations: Transition 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 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 & promotes student retention and success.
- Base AAC funding for new acquisitions on changing communication and developmental needs rather than an arbitrary “5-year” timeframe.
- Commit to reforming the “[school-to-guardianship pipeline](#)”, where 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.

Background and Analysis: Access to Health Care

In Canada, health care is a right. Unfortunately, many autistics in Ontario face barriers in access to:

- Basic health care, such as a family doctor.
- Mental health services.
- Dental care.
- Emergency treatment, such as the ER.

AAC Access

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 A4A member Derek Burrow, an adult AAC user, 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. Ontario [Bill 168](#) (2010) which allows health care providers greater leeway in refusing to treat, is also a factor. "I want to share my diagnosis because it could help in my care," says a member, "but I'm afraid it could affect whether I get care."

Inclusion in the ER

Here are some simple ways that ERs can make their spaces accessible to autistic patients.

- Follow our AAC guidelines for communicating with AAC users
 - Acknowledge the AAC, to help the patient feel comfortable.
 - Say "I see you use AAC. I'm glad you can use it to talk to me."
 - Ask for clarification.
 - If you didn't see what the person pointed at, or if you missed some words, ask for clarification. "Sorry, could you repeat that?"
 - Calmly wait. If a patient is using a system like ProLoQuo, it will take some time for typing and having the voice speak the words. Avoid talking over them or starting up new topics; just be quiet and wait till they are done typing.
- Noise canceling or muffling earphones and ear plugs available for use by patients.
- Phone chargers on site so that autistic patients can stay connected to support people.
- Stim toys available -- offer them to patients.
- Never take someone's special object away. If medically necessary, keep it within sight or have a plan of where it goes, so the person feels secure.
- Ask about a special interest.
- Let the person know that they don't need to make eye contact, that you understand.
- Provide written information of everything said, as many of us will not process everything and this can affect aftercare.

- Implement autism education and anti-racism/anti-bias education with related policies.

The Problem of Stigma

Sensory overload, previous bad experiences and PTSD can also create fear of seeking services. For example, past restraint in pediatric dentistry or abusive autism “therapies” can make autistic people avoid seeking health care.

Stigma prevents many of us from acknowledging sensory overload, from explaining our communication methods or sometimes even from giving our diagnosis. We worry about being judged and then treated poorly especially if we’ve had bad experiences in the past. At the same time if we don’t give this information, practitioners may misinterpret important communication, sensory or interoceptive factors among others.

Stigma disconnects us too: for example, some practitioners assume autistic patients aren’t engaged without eye contact, so they only address the patient’s *parents*. Autistic patients may feel stigmatized, left out and are less likely to return for care.

If we can be open about these factors, it can help make it a better experience for everyone. Most helpful is when practitioners meet us halfway, by showing knowledge and acceptance of autistic ways of communicating, moving and being.

Recommendations: Health Professional Education

- 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).

Human Rights and Autism Pseudoscience

Autism pseudoscience (or so-called “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.

Testimonial: Autism pseudoscience

This year, when one of our members, a mom, complained about an MD performing chelation on autistic toddlers in Ontario, the College of Physicians and Surgeons of Ontario (CPSO), the regulating body of physicians in Ontario, [rejected her complaint](#) and took no action. She had shared with them a case where a child had [died](#) from chelation for autism; a case that inspired the UK to reform its regulatory system, as well as stacks of medical evidence from autism experts that chelation for autism has no evidence of benefit and clear evidence of harm, pointing out that **chelation for autism is banned by the FDA and the NHS for these reasons**.

Nevertheless, the CPSO gave its endorsement for chelation to be performed on autistic children, stating that chelation for autism was a “valuable and evidence based” form of complementary medicine that fit within their guidelines. The physician, who has sat on several CPSO committees, continues to practice chelation on autistic children today, despite universal condemnation of the practice by autism experts, the FDA and the NHS. The complainant, Anne Borden King, told us:

“I thought I would get a letter back saying they would stop him from doing this. I am still in shock that they have done nothing.”

This case demonstrates the need for provincial oversight into autism pseudoscience. Self-regulating bodies are not taking action to stop pseudoscience on children. Policymakers must

reconsider our province's overly-broad definition of proxy consent, in the interest of child health and safe.

Recommendations: Regulate Autism Pseudoscience

- Genuine government oversight of medical professionals 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.

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Background and Analysis: Fair Employment and Economic Safety

A 2008 [study](#) of Toronto autistic youth by the Redpath Centre and University of Toronto showed that just 16.5 per cent of respondents were working full or part time. Without employment, it is not possible for most autistic people to live independently. With employment that has marginal pay, it is also impossible. Autistics who can't live independently are at risk of abuse and many lack the freedom of movement to break free of abusive situations. Safety is a serious issue in some households and [in group home settings](#).

There are some simple steps that the public and private sector can take, to make employment more accessible for autistic Ontarians. We outline them below in our recommendations.

Testimonials

One challenge we face is assumptions based on functioning labels: where we are either deemed too 'low-functioning' to live/work with the degree of autonomy we deserve or deemed so 'high-functioning' that we don't need **any** supports. In reality, our support needs vary and can even fluctuate according to life events and other factors.

The best way to understand what we need is to ask us. One of our members put it this way:

“Many people believe that the autism spectrum has two ends with the two ends considered to represent IQ. However, this is not an accurate reflection of how autism presents in individuals; it is a generalization based on observations of outsiders. Autistic people experience varying degrees of issues with motor coordination, understanding nuances of language, ability to filter sensory information, and executive functioning skills.

“I have good language and motor coordination skills, but very low executive functioning skills. Yet, I am still considered 'high-functioning' despite years of continuing struggle with employment and relationships.”

Another member wrote:

“I cannot stress enough just how much of a problem the current hiring process is for disabled people in general, but particularly for autistics. 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, and when it's something you have to work at.

“I wound up working jobs that were terrible for me, for awful pay, in bad conditions, because they were jobs that only cared about physical skills. People got that I was smart, and no one could figure out why I was doing work I obviously hated, but I could never manage to say all the things that explained myself.

“AAC changed my life. I was able to get employment supports through ODSP. 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.”

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.

Sheltered Workshops

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.

Last year, the provincial government [decided](#) to close all sheltered workshops, following the lead of many communities in the United States.

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: 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.

Background and Analysis: Housing: Safety, Security and Autonomy

Housing –The impact of poverty

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.”

We do not have statistics on how many autistic Canadians live in poverty because no one is keeping track. As well, autistic adults are not mentioned in Ontario government benefits legislation. Some benefits require an IQ test, which some autistics can “pass” while still needing assistance and thus end up without needed benefits, left in bureaucratic limbo.

The Ontario Disability Support Program (ODSP) monthly amounts for food, shelter and other basic needs for recipients of ODSP were frozen from 1993 until 2003, and the subsequent increases do not correspond with inflation and the cost of living, especially in cities, so current ODSP rates [do not cover](#) average basic needs. Some disabled recipients who work part time or are starting back in the job market also feel they are penalized for working while on ODSP. We are hopeful the new government will revise the ODSP system for more fairness in this and other areas.

Housing: Abuse in group (“residential”) homes

Group or residential homes in Ontario are a vestige of institutional life. The ideal of independent living for IDD and autistic individuals, beyond residential homes, has not been fully realized in our province. And the situation in some Ontario 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.

Our Province currently has 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 Ontario residential care 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. The needs of autistics in residential care has not been studied in any depth, nor have Ontario’s autistic group home residents *ever* been surveyed as a demographic to understand their communication and sensory needs in the group home setting.

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 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.
- 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 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.
- Look to the best practices of Ontario service organizations (beyond “autism services”). Study the work of agencies 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.

(report concludes on next page)

Afterward: Inclusion is the New Gold Standard

Autistic Self-Advocacy and the Neurodiversity Movement

Autistic self-advocacy can be summed up in the phrase *nothing about us without us*. Put simply, we reject the segregation and barriers that still exists in schools, employment, housing and public life.

The autistic self-advocacy movement is based on a few facts:

- We will always be autistic.
- **We want to like and feel good about ourselves, not be told we're broken, toxic and wrong.**
- With simple accommodations, we can be included in school, work and all society.

A4A is an international affiliate of the Autistic Self-Advocacy Network (ASAN), which was formed in the US in 2006. Now based in Washington DC, ASAN plays an active role in the development of services, programs and policy. They consult with media (for example, members of ASAN consulted in the development of the autistic character, Julia, for *Sesame Street*). They are also activists, able to mobilize in the thousands around human rights issues. Globally, autistic self-advocacy groups are taking on a greater role in government advising and consulting, especially in the last 5 years.

Like biodiversity (our interconnectedness across biological differences in the ecology of our earth) *neurodiversity* points to the reality of “all kinds of minds” and their necessity for our survival as a species.

- Neurodiversity is a scientific, biological fact, not a “controversy.”
- The neurodiversity movement is about pride, inclusion, access and human rights.
- The logo of the international neurodiversity movement is a rainbow infinity symbol.

The Autism Industry: Due for a Disruption

As we've outlined in this paper, there is an industry around autism—and much of the industry is based around old, segregationist ideas that harken back to the era of residential institutions. We disagree with Coker Capital group, which [describes](#) the autism industry as “poised for consolidation” (into large ABA providers). As it stands, the autism industry [generates billions](#) for companies worldwide, but attempts at consolidation (as was [happening in Ontario](#)) have led to disastrous breakdowns in useful supportive services.

The autism industry has largely maintained the idea of us – autistics – as an abstract: a gene to splice, a set of behaviours to correct, our entire childhoods a measurable outcome in a Gantt chart. But life isn't really like that. The Coker report states that the “fragmentation” of autism services is a problem for investors. Yet what the consolidation proponents call *fragmentation* is

often actually flexibility, essential to keep (or make) services workable for us. As most parents can attest, services for autistics need to be flexible and diffuse.

The autism industry is facing a disruption because it has been based on segregation and people want inclusion. Think of recent innovations such as inclusive design in classrooms, sensory-friendly spaces, improved workspaces for retention, de-escalation alternatives & shifting policy priorities towards autonomous living. Where can the ABA/IBI model even place itself within this new schema? It can't. That's why it fights with inclusion movements, because it can't come to terms with its own obsolescence nor the fact that policymakers have begun to diversify services, to engage *less* with the old autism industry and *more* with new models and ideas.

We are all stakeholders in this change. Inclusion involves the whole community. Policymakers can foster and encourage this by continuing to consult with end users and drawing upon community partners outside of "autism services" for programs. Part of the work of policymakers now is to identify the best community organizations that prioritize inclusion, and put in systems of accountability for schools, employers and service providers.

Inclusion in Ontario means we do things differently than before. We let go of old systems. We let go of old methods that are obsolete or counter-productive. We bring in new people and new energy. We redefine the gold standard of autism services, away from the segregation model. Now, the gold standard is inclusion. The gold standard is connection. The gold standard is community.

Thanks for reading and considering our recommendations!

--The A4A Team

a4aontario.com

APPENDIX 1: Memo from Jody Carr, former Minister of Education, New Brunswick

**Dynamic Inclusive Learning - New Brunswick, Canada
Jody R. Carr * June 7, 2019**

Canada has a decentralized education system devolved to each of the 13 individual provinces and territories. The federal government has no responsibility for education, the individual Ministries of Education voluntarily collaborate through the Council of Ministers of Education.

In New Brunswick, schools embrace **DYNAMIC, INCLUSIVE LEARNING** where all children of all abilities and backgrounds form relationships by learning together within their neighbourhood schools and are supported to achieve success in common learning environments.

Dynamic, Inclusive Learning, when properly supported and implemented, ensures **HI-QUALITY** and **E-QUALITY** learning for all children. Moreover, every student has equal access to high quality classroom teaching. Accommodation for learning is provided in the common learning environment and only when intervention is not able to be provided in this common environment, then alternative and individualized settings with properly trained professionals are provided outside the classroom. New Brunswick began with basic legislation in 1986 that integrated all children and ‘special’ educators within mainstream schools. Small private special education schools were closed, and all children were integrated within mainstream schools.

Much progress was made over 25 years transitioning from special self-contained classrooms in mainstream schools by providing inclusive and adaptable curriculum, assistive technology, and robust assessment.

In 2010-2013, the New Brunswick education system began implementing universal design for learning, integrated services between departments, and a new policy for inclusive education along with modifications to the Education Act. The province also invested in additional practicable education support that allowed for transitioning away from the remaining contained special classrooms within schools. Integrated Services received national recognition and Policy 322 – inclusive education received international recognition.

Policy 322 imports a consistent human rights framework based on the principles of equitable access and the duty to accommodate found in the Convention for the Rights of Persons with Disabilities. The requirement to provide teacher training and classroom support and the principles of Universal Design for Learning are also outlined in Policy 322. Universal Design for Learning (UDL) recognizes that variation in learning is based on multiple means of representation, action and expression, and engagement. Policy 322 is not just about disability but about all children across the wide variety of differences in society.

There is a common general understanding and belief by educators that all children, regardless of differences, can learn literacy, numeracy and competencies – together within age similar groupings. Schools include all children in the mainstream classroom as much as practically possible. Any individual pull-out from class is normalized and fluid. Policy 322 stipulates that when a child leaves

the classroom, it is for individual intervention and learning and usually temporary and can be in small groupings of up to 3 children.

The principal of the school provides assertive leadership and sets the tone for a positive, inclusive environment. Teachers embrace the concept of building capacity within their students to self-regulate their behavior and learning. The teacher is more of a facilitator of learning rather than lecturer.

Inclusive education goes beyond diagnosis and labels and includes all diversity and differences. There is one approved curriculum that is adapted for the individual learning needs of the students.

Inclusive school-based support for educators is the responsibility of all professionals in the school and outside professionals. Policy 322 ensures that inclusive education is not a simple program or add-on. There are no special classrooms or special schools, and there is no longer mention of special needs in legislation. Students attend their neighborhood school based on their age and geographic location. Each child is promoted from grade to grade based on their age grouping. A child is held back from promotion very rarely and only after very careful consideration and consultation. All children of the same age graduate together in an inclusive year end ceremony. All graduates receive the same certificate.

The classroom teacher works with the school-based Education Support Teacher – Resource and other specialist teachers. This inclusive education resource teacher works mostly with classroom teachers to assist and coach them on how to improve their UDL practices, to help co-teach or help address particular learning and behavior needs. They also assist in obtaining additional support for educators and students from internal school specialists and outside agencies for physio, psychological, numeracy, behavior, literacy, etc. When required, support requests can be elevated to the regional and provincial integrated services teams.

If a child cannot be universally accommodated the classroom teacher and resource teacher would develop individual accommodations and a student may eventually have a modified program. Their learning is still based on the curriculum but at the level the student is at, with set goals and progress being measured by the classroom teacher and resource.

The availability of a Personal and Individual Learning Plan is guaranteed in legislation which must be a living document that is updated and evaluated on a regular basis.

In terms of measuring learning in New Brunswick, all students, not just those with identified disabilities, are encouraged to demonstrate their learning in a variety of ways, offering an alternative to the typical paper and pencil testing. For example, in a system like New Brunswick where UDL is embedded in policy, students may show what they know through oral presentations, student-led conferences, video creations, artistic expressions and other means. This acceptance of varied ways to demonstrate learning ensures students still meet expected learning outcomes, while respecting individuals' strengths and capacities.

Our school system recently implemented a new attendance tracking tool that is used by schools to monitor when and how often a student is excluded from learning due to their disability or behavior.

Jody R. Carr, BBA, JD
Jody.r.Carr@gmail.com

Jody R. Carr

Mr. Carr is a lawyer with 25 years' experience in politics, government and legislative policy making. He is a former Minister of Education and Early Childhood Development in New Brunswick Canada holding that position between the years 2010-2013. He initiated an internationally recognized inclusive education improvement plan across the provinces' schools that included policy, systems integration, universal teaching strategies and practical educational support. He will be called to the NB Bar on June 18, 2019 and will have a private practice in Fredericton. He is an Associate with Inclusive Education Canada and Expert Advisor to Inclusion International's Catalyst for Inclusive Education.

APPENDIX 2: Memo from Arch Disability Law

Dear Autistics for Autistics:

I am writing you with respect to your June 10, 2019 request regarding ARCH Disability Law Centre's position on inclusive education as it applies to Ontario's education system.

It is worth noting at the outset that ARCH believes that an education system which emphasizes inclusivity for all students, of varying degrees of ability, will be best placed to maximize student performance and ensure that the goals of the *Education Act* are met – namely that students become highly skilled, knowledgeable, caring, and contributing citizens. In order to achieve this goal, the education system must abide by its obligations, under the *Human Rights Code* and the *Convention on the Rights of Persons with Disabilities*, to educate students in a non-discriminatory manner and to remove the barriers that prevent many students from accessing a meaningful education.

As you know, the legal framework that currently exists in Ontario is still rife with systemic barriers and there are a number of changes which could be made to our education system to better promote the rights of students with disabilities. Some of these recommendations have been previously outlined in our prior [publications](#), but for convenience sake, I will reproduce some of these recommendations below.

Student Consultation

It is of primary importance that students, to the extent that they are able, be consulted on all matters related to their education. True inclusive education means ensuring that there is a role in the decision making process for students with disabilities. As it stands, students with disabilities have limited rights under the *Education Act* with respect to decisions about their education. Those rights which do exist, under O. Reg. 181/98, limit student participation to those over the age of 16 and limit the types of decisions which they have a right to participate in. The *Education Act* should be revised to provide *all* students with disabilities with a greater role in decision making process.

Preventing Exclusions

As ARCH has [reported](#) on in the past, the outright exclusion of students with disabilities from our education system remains an ongoing problem in Ontario and it is obvious that this type of exclusion has a negative impact on student attendance and achievement. In light of this troubling trend, we believe the following policy changes would be helpful to address this problem:

- The Ministry of Education should develop reporting requirements designed to track all forms of exclusion, both formal and informal. These requirements should ensure that all withdrawals, absences, and exclusions, voluntary or otherwise, are recorded and forwarded to the Ministry of Education, which would publish statistics for each school board. Tracking should include instances where students are informally asked to stay

- home, where they are excluded via s. 265(1)(m) of the Education Act, where their days are ‘modified’, or where they are sent home due to a lack of appropriate supports.
- The Government should modify the use of s. 265(1)(m) (the ‘exclusion clause’) to preclude its use on students.
 - o In the alternative, the Government should develop and implement a series of procedural protections for students who are excluded via s. 265(1)(m). These procedural protections would afford families similar appeal rights as those available for suspensions and expulsions (see: Part XIII of the *Education Act*) and would require a principal to explicitly consider the mitigating factors outlined in s. 2 and 3 of O. Reg 472/07 when making a decision about whether to exclude a student with a disability.
 - Finally, the Ministry should modify the regulatory provision that allows a school board to shorten a student’s school day (O. Reg. 298 s. 3(3)) to explicitly require that it only be used when it is in the best interests of the student. It should also require that a decision to invoke this provision be reviewed every two months to ensure that a shortened school day is still appropriate for the student.

Promoting Inclusive Classrooms

Although the Ministry of Education encourages the inclusion of students with disabilities across the province, via its *Equity and Inclusive Education Strategy*, there is no policy that requires education services for students with disabilities to be delivered in a fully inclusive manner. Ontario largely deals with the issue of placement in the regular classroom through the IPRC process (O. Reg. 181/98) and leave school boards broad discretion to determine the structure and philosophy of their special education programs (O. Reg. 306). The result is that a large number of boards have implemented ‘special education plans’ that segregate many students with disabilities and prevent them from learning in the regular classroom.

To remedy this situation, the Government of Ontario should amend the IPRC process to require students with disabilities to be placed in a ‘common learning environment’ as envisioned in New Brunswick’s Policy 322. It should also require school boards to adopt ‘special education plans’ that are driven by an inclusive philosophy and that are designed to provide appropriate support to students with disabilities in a ‘common learning environment’.

In order to facilitate proper implementation of this policy, it would be necessary to implement a phased transition from the current system which ensures that a) teachers receive the necessary support and training they need to create an inclusive classroom and b) that resources can be effectively transitioned from segregated environments to support inclusive ones.

Conflict Resolution

One of the most persistent problems, with the potential to hinder inclusive practices, is the chronic conflict that often exists between families and school staff. Cooperation between families and school staff is crucial if appropriate services are to be made available. While many families and school boards make significant efforts to maintain a productive relationship, these efforts do not always succeed. In these cases, proper conflict resolution mechanisms have

significant potential to help address this type of relationship breakdown. Unfortunately, there is no impartial and expeditious conflict resolution process available within the school system.¹ Feuding parties are often left to their own devices to try to resolve disputes. Many families often turn to litigation in these circumstances, further souring an already contentious relationship.

With this in mind, the Government of Ontario should make efforts to develop an impartial, accessible and expeditious dispute resolution mechanism for all matters related to the education of students with disabilities. The *Centre for Appropriate Dispute Resolution in Special Education* has outlined a number of different models for such a process – many of which have achieved demonstrated success. Many of these processes start with independent mediation and eventually transition to independent adjudication of special education matters.

Proper Accommodation

One of the primary barriers in Ontario preventing greater inclusion is the existence of barriers to accommodation. The source of these barriers are various and unfortunately they do not lend themselves to concise description. However, in order to address the prevalence of these barriers, a review should be conducted to identify common accommodation failures and to trace their source. The results of this review should be used to identify further policy changes that could be made to better support students with disabilities.

Conclusion

I should emphasize that the above proposals do not constitute the entirety of ARCH's position on inclusive education and that a number of details related to specific policy proposals have been left out for the sake of brevity. However, the issues outlined above do broadly encompass some of the key issues that government would need to address in order to move towards a fully inclusive education system.

Should you have any further questions about any of the above, please do not hesitate to contact me.

Best Regards,

Luke Reid
Staff Lawyer
ARCH Disability Law Centre

¹ Although there are two possible resources that parents can access to resolve *some* disputes, the Ontario Ombudsman and the IPRC Process, both of these have significant jurisdictional limitations and are not necessarily well placed to deal with the full range of issues experienced by students and families.

APPENDIX 3

If Not ABA, Then What?: Best Practices in Other Jurisdictions

by Autistics for Autistics Ontario
March 2019

Over the past few months, we've been asked by parents, policymakers and concerned Ontarians: *What are the alternatives to ABA? Are there other alternatives?*

Before we answer (below), we'd like to reframe the question and ask: why would anyone think that ABA is the only way...or that there *is* only one way to provide supports and services to autistic people? We know that for almost any challenge there are multiple solutions, and that creativity and imagination drive the best approaches. Why would it be different for raising autistic children?

There are many places where ABA is not used and yet children learn life skills and benefit from inclusion. We know that inclusion is associated with positive life outcomes and that by contrast ABA fosters segregation, from the moment a child enters the closed setting of the intensive early intervention centre. Ontario's former autism policy was an ABA-based plan. We don't see evidence that this was an informed decision. It appears to have been an appeasement decision—one that promoted segregation and diverted funds for much-needed services. Moving forward from the mistakes of the past, our new government can make change by:

- Assessing data on community needs;
- Reviewing independent research on autism services;
- Analyzing best practices for school inclusion from other jurisdictions;
- Continuing to consult with autistic Ontarians;
- Using the above information to inform policy.

Making good autism policy in Ontario is not a matter of #pausingtheplan and then going back to the same old thing. We've needed a change in our province and it's finally happening. This article is a start of a broader conversation on how to change autism services and unroll inclusion in Ontario in the best way possible.

What Do Other Places Do?

A good question to ask when making public policy decisions is: what are other places doing, that works better?

We will give two brief examples for now: Scotland and England. (The inclusion team we are on will detail others in its upcoming report.)

Neither the UK's National Institute for Health and Care Excellence (NICE) nor the Scottish Intercollegiate Guidelines Network (SIGN) endorse or recommend ABA. The NHS of both countries do not recognize ABA as a science. ABA is used in a handful of specialized centres in England, having served around 2,000 students and is viewed as a "last resort". Local health authorities in England and Scotland also do not fund ABA.

What this means is that the vast majority of autistic children in these countries do not have ABA, yet they are still able to learn life skills, be included in society and have positive outcomes.

Mainstream offerings for autism in these countries are determined by local authorities, but generally include funding and support for **speech language pathology (SLP)** and **occupational therapy (OT)**. Increasingly, these services are not about taking the child away for 1:1 sessions, but to educate those around the child in terms of their interactions to foster communication and support self-care skills, *together*.

Augmentative and alternative communication (AAC) for non-verbal or partially verbal students is a part of SLP there. Whereas it would be standard for a Canadian ABA-trained SLP to wait 6-12 months before introducing AAC, a non-ABA SLP will likely include AAC from the start as needed, not wanting to sacrifice a child's need to communicate in the quest for immediate speech.

Newer [types of programs](#), such as **SCERTS**, are being rolled out in Scotland and the UK (as in the US and other countries). Governments there are investing in piloting models such as SCERTS, which focuses on: Social Communication, Emotional Regulation and Transactional Support, emphasizing the role of the family and community as partners in communication and implementing accessible design and supports.

Programs such as these proactively prioritize **inclusion**, a crucial part of autism services that was not a part of the former autism plan in Ontario. Inclusion may be more intrinsic to programs in Scotland and the UK because the culture takes a less segregationist approach to autism than Canada has (to date). For example, the concept of "early intervention" (autistic toddlers getting 25-40 hours per week of therapy away from family/peers) does not reflect the fabric of social life there. Instead, autistic children are included in community life from the start.

The idea that children would be removed from the community and sent to "early intervention centres" isn't the normative response to a diagnosis there, nor is it in [New Zealand](#) or a range of other countries, which instead use non-intensive, family-centred therapies. The Maori term for autistic is *takiwatanga*, meaning "his or her own time and space," signifying a respect for the timing, spacing, pacing and life-rhythm of autistic Maori. The term has taken on a broader meaning throughout Australian culture as they work for inclusion, fairness and autistic acceptance.

By contrast, as we noted in our [Human Rights Report](#) to the United Nations, Ontario's approach to autistic children has typically reflected the older, residential-institution approach to autism.

Removing children from their peers at an early age sets the stage for a lifetime of segregation. Some argue that this segregation is “the only way autistic children can learn life skills,” but that argument doesn’t hold up when we compare with places such as Scotland and the UK, where children learn life skills without being segregated.

We can then see that segregating autistic children doesn’t represent a therapeutic need at all: it just represents tradition—a tradition we need to end.

The government of Scotland [recently committed](#) to meaningfully involving autistic people in all decision making about autism policy. In this commitment, it will be heading off many of the problems that exist when institutions try inclusion but lack direction. Their proactive, positive approach is summarized in this [statement](#):

“Autistic people contribute much to Scottish society and with the right support many could contribute much more.”

All countries and regions seeking to make change need to be communicating with each other and consulting with students and self-advocates. There is room for improvement in all inclusion-based programs. Our governments can learn from other jurisdictions what has worked and what hasn’t, and let that inform its policy decisions.

What about Ontario?

Autism policy in Ontario is heading away from older segregation models and towards an inclusion model:

- Under the new autism plan, OT, SLP, and AAC supports are funded;
- School districts in Ontario are learning newer models such as SCERTS (for example, its founder will be presenting to the Halton Region School District this month);
- We have a government commitment to move towards more inclusive schooling;
- Autistic people are being consulted in policymaking, for the first time in our province’s history.

Segregation has historically defined the experience of many autistic students in Ontario. From the moment of diagnosis, autistic children are tracked into intensive therapy centres, while their peers are getting to know each other in their neighbourhood preschool and Early Years Centres. When autistic children leave the ABA centre to enter primary school, they often have no friends because they were removed from their community at diagnosis; likewise, their peers don’t have experience with autistic children.

Although many teachers have good ideas and intentions for inclusion, their efforts to connect can often fall flat because our education system is still entrenched in the notion of 2-tier education. With no umbrella of accessible design in our school districts, autistic students are often re-routed into our [troubled special education system](#)—despite advocacy by their parents—or are even [excluded](#) in part or wholly from the education system.

Some may push back that “ABA promotes inclusion,” but there’s no evidence to support that claim. While accessible design as well as inclusion programs like SCERTS involve all children and adults in making spaces welcoming, the ABA model focuses only on the individual “pathology” of the child, targeting behaviours (such as special interests or flapping) and trying to eliminate them. That focus is incompatible with our society’s values about diversity and the collective role we play in accessibility, making ABA an [unsustainable](#) approach to disability.

It is a significant step forward that our government is funding OT, SLP and AAC and consulting on comparative approaches to autism policy. With the right tools and a spirit of bipartisanship, our province can become a leader in Canada on inclusion.

This is an important moment in Ontario. What happens here reflects a national policy conversation as well. It is following in the direction of the broader society: the understanding that **neurodiversity is part of diversity**. Reforming the autism services paradigm opens up broader inclusion throughout society. With this shift, we hope that there will soon come a day when people will no longer ask, “what will we do without ABA?” but instead ask, “why on earth were we doing ABA for so long?”

APPENDIX 4: Personal Testimonies

(1 of 3)

AAC Access – modified from a presentation on inclusion

My name is Derek Burrow. I am 35, and I work for The Ottawa Hospital as the administrator for our learning management system, a clear language editor for our patient education documents, a videographer for our Medical Education department, and basically whatever else I am needed to do. I am an American Library Association certified librarian, with a Masters in Information from the University of Toronto. And somehow, on top of that, I also work as a technical writer for AssistiveWare, and wrote the help and support documentation for Proloquo4Text and the latest version of Proloquo2Go.

I am autistic. I paused over how to say that. I was tempted to say “also” autistic, as if it were some sort of big revelation, or something secondary to me. But it is neither. It is a fact and an integral part of who I am. My case is a bit complicated because it is mired in some very old school thinking and poor record keeping.

BUT WAIT!

At this point, some of you probably are starting to tune out, because you are here to learn how to help your kids, and I seem pretty far from that. Well, to be fair, I am, but bear with me, because there is something you really need to hear:

Yes. I am absolutely different from your kids, and from the people you work with. A large part of that is that I am an adult in their mid-thirties. I have been living with this brain for a long time, and that’s led me to figure out ways to do things. I had a lot of help learning some of those things, and to learn ways of dealing with them. Some of that hasn’t been super healthy, because some of it meant fighting the way my brain works.

However, none of that changes the fact that I am autistic. That the world is constantly too loud and too bright. It doesn’t change the horrible levels of social anxiety I feel, or how small changes in routine can bring my brain to a screeching halt. It doesn’t change that if I expect something to happen, and something different occurs, that my mind just sinks into a great fog of confusion where nothing really makes sense.

Funny story, I didn’t learn to read until I was almost 10 years old. I went through grades 1 and 2 with a pre-kindergarten reading level. If you tried to make me read something I would stare at a page of meaningless garbage and melt down. I hit myself, hit other people, ripped up papers, flipped desks, screamed, ran away...if you have an autistic kid, or work with autistic kids, you know the sort of meltdowns I’m talking about.

At around this time of year, twenty six years ago, I was functionally illiterate. Now I’m a librarian. I write product documentation. I do copy editing for lengthy fiction stories, and for high level medical documents. How did I get there? I got older, I learned how my brain worked

with a lot of help from some very dedicated special education teachers. Sometimes reading still gets a bit weird for me, but I know how to handle that.

Everyone's disability is different, and everyone will progress and develop differently. Just because an adult looks like what you would use the term "high functioning" to describe doesn't mean that they have always been like that, or are always like that.

Schooling

I hope I have piqued your interest here. Let me just explain where I am coming from.

I didn't speak until I was 3. I spent 3 years in a segregated special education classroom, then another 3 mainstreamed with special education support and an educational aid. My special ed classroom from grades 1 to 3 was up a flight of stairs, around a corner, at the back of the school. We had separate recess and lunch periods...we rarely saw anyone else who went to school with us. It was a mixed grade class. I did speech therapy from grades 1 through 3. After grade 3 it was felt that I should be mainstreamed.

I was mainstreamed for grades 4 through 6 at a different school than where I had my special ed classes at. I had a resource room as my home room class, and had probably about half my classes each day there. I had an E A for my other classes, though truth be told I seem to remember that they were more there to help me deal with meltdowns and weren't overly helpful with my anxiety around being in regular classes.

Speech

Speech didn't come naturally to me, but frustratingly it was the only thing that people around me would respond to.

It was stressful, it was tiring, and I was not able to say the full sum of what I wanted to say. Sometimes I couldn't say anything at all. It felt like there was a pressure to speak.

But this was in the 80s and early 90s, and no one bothered to actually TELL me that I was autistic. I knew I was different, but at the same time there were things about myself that I had to sort of...extrapolate...and assume were the same for everyone. Speech, for example. I cannot stress enough the importance of telling kids that they are disabled. Not telling them about their limits, but telling them that there is a reason their brains or bodies work differently, and that this difference does not make them wrong or bad.

Moving

For a variety of reasons, my records and diagnosis did not transfer schools when I moved to Ontario to live with my father in grade 7. Suddenly I hit mainstreaming with zero supports and a dad who didn't know what the heck was going on with me. For the most part I had to figure things out on my own. In high school I was allowed to write tests on computer, which helped a lot because it turns out I also have dysgraphia on top of everything else. I got some extra help with math, but mostly just had to sort of muddle along.

I made friends. I found a hobby, tabletop roleplaying games, as a kid that presented an environment where I could express myself better. I worked hard with that. I made most of my friends that way, and it helped me in some very big, very real ways, including with speaking and expressing myself. But that didn't change what was still going on behind the scenes in my brain.

I could go into a very long discussion on that subject, but I actually wrote an article about it last June on the AssistiveWare website. I will make sure that you get a link to that at the end of this presentation.

Speech Issues

I am not really sure how to describe the feeling of having a ton of words in your head but your mouth stalwartly refusing to say them except in specific situations. How there are times when you are fighting to say what you want, but just give up and don't say it.

All the sentences that just become a single word: Never mind. Forget it. Whatever.

And other times when you have to focus to line the words up, organize what you are saying, and then remember what you just said.

You have to talk around things...just like, really, I am talking around this subject, because our language isn't designed to discuss the opposite of speech not always being silence, but instead an absence of words which could potentially be spoken, but cannot. Start a sentence, then try to see where it's going to end...then look back from the end at the start. Can you see where you started?

So what I'm saying is that it's a weird feeling.

University and Work

I got through university, got my degrees, and promptly found myself running into all kinds of problems finding work. Because I couldn't properly express what I knew. Because I couldn't deal with all the precise structures, all calibrated to be the opposite of accessible for autistics. I cannot stress enough just how much of a problem the current hiring process is for disabled people in general, but particularly for autistics. 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, and when it's something you have to work at.

I wound up working jobs that were terrible for me, for awful pay, in bad conditions, because they were jobs that only cared about physical skills. People got that I was smart, and no one could figure out why I was doing work I obviously hated, but I could never manage to say all the things that explained myself.

And, over time, the frustrating, the stress, the burn out built, and speech became harder than it was before. And harder. And harder, till it was like fighting every syllable. I cannot stress how

much of a toll it takes to be fighting with your own brain just to fit in, because you don't know there are any other options. It finally forced me to face just how difficult this whole speaking thing was, no matter how much I might pretend it wasn't or force it as much as I could anyway.

AAC

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 through ODSP; they set me up with an employment support worker who helped me find and apply to jobs, helped handle important phone calls, and kept me motivated. I cannot stress just how much help this program was for me. It was easier than applying for ODSP financial supports, and the types of organizations involved, like Causeway Work Center in Ottawa, are just phenomenal. 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. And legitimately?

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. And, yes, part of that was also being taught how to properly communicate in a job interview. Instead of fighting to make cogent responses, I was able to sit down and just let my brain say its piece with my mind getting in the way. I aced my job interview and here I am now.

I cannot stress enough how big a difference AAC has made for me. I am able to say things now that I never could before, and in situations that I have never been able to. The connection between my fingers and typing is far superior to the connection between with my mouth for speaking. It is effortless. There is no stress to it. No exhaustion. I just think, type, and what is in my head comes out. Organized. Effective.

Presuming Competence

And this, right here, is where I start talking about not just the presumption of competence, but the understanding that there is always more going on inside us that meets the eye. That is to say not just that we presume competence, but that we should seek to understand that difficulties can exist even when competence is apparent. I have a hard time imagining what my life would be like if I had AAC back in high school, or in university. Would that have helped me? I honestly think that it would have...but I'm also 35, and this technology just didn't exist in a form as accessible as this one when I was in school.

Thankfully, however, it does exist now. It is something that can benefit anyone, regardless of age. But the first step is accepting that it can be useful even to people who have speech, who have been speaking for a long time. That speech does not exist as a binary on, off, state, but rather flows along a spectrum. Which is in keeping with every disability, really, and in fact most things in life.

Think about it this way: If you make communication supports and AAC available to kids who are seen as having functional speech, and they don't need them...then you have lost nothing but a bit of time. However, by destigmatizing alternative communication, and offering it as being

just as valid as verbal speech, you open it up to kids who do need them but may not be a priority for receiving them. And many of those kids are already using AAC in other forms.

Destigmatizing AAC

Texting, instant messaging, drawing pictures, even just picking a specific shirt or hat or toy that fits their mood. These are all alternative ways of communicating which we find surprisingly acceptable in our society. So...using a communication device, or any other aid, should also be seen as acceptable and normal.

But that also means destigmatizing all AAC.

I use a text to speech program to communicate. I type, it speaks. Other people use programs that let them build sentences with symbols, or use physical communication books and point to symbols. Some people just write on paper with a pen, or use sign language.

We need to not see a hierarchy where text to speech is seen as innately superior and indicative of greater intellect or ability than symbol based AAC systems, whether those are high or low tech. One does not mean that someone has more to say than the other. Or even that one method is faster than the other...but there, again, we also run into the issue of establishing a hierarchy of disability that says being a faster communicator makes me superior to a slower communicator.

Erin Sheldon [inclusion advocate] mentioned some interesting statistics: Even a 2 second pause in communication can make someone think you sound less intelligent. A 5 second pause becomes uncomfortable and makes people seriously question your abilities. So what happens when there is a thirty second pause, a sixty second pause? What must people think when it takes you two whole minutes to respond to their question because you have to get your words lined up in your head and find the right symbols to represent them?

We need to challenge assumptions about communication, especially as technology moves forward. As we get more and more options for how we can communicate, we need to understand that people will find some of these methods easier than speech...and that that is OK. Problems speaking do not indicate a lack of intelligence, they just indicate problems matching the words in your head to the words coming out of your mouth.

Closing thoughts

I am lucky. I don't run into as many situations when I am out and about where people don't presume my competence. It's happened a few times, and it is the most frustrating thing in the world to be infantilized by complete strangers. To have difficulty with communication translate into people assuming you don't know what's going on, or assume that they know more than you. To assume that verbal speech directly correlates to awareness, competence, and decision making capabilities.

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. ...I was tagged as

being “low functioning” by people who I was directly communicating with. I was seen as lower on that hierarchy.

But that just goes to show that individual presentations of our disabilities do not indicate a lack of competence. This is especially important where speech is concerned, because, as noted, so often problems with speech are immediately related to reduced competence, and from there to how teachable someone is.

We associate certain traits with being teachable, or that some presentations represent someone who may be less able to learn than others. We associate being nonverbal with being less able to learn, less able to develop, less able to be independent. But in doing so it is very easy to communicate to a disabled person that things about them make them less valuable as people.

Thank you and I hope that I have offered some things to make you think.

Derek Burrow, Ottawa

APPENDIX 4: Personal Testimonies

(2 of 3)

To the Government of Ontario:

The rights of Autistic people to dignity, autonomy and freedom are protected by the UN Convention on the Rights of Persons with Disabilities, a convention which Canada ratified in 2010. According to its guiding principles, "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity" underlies the spirit and letter of that important framework.

What we, as Autistics people, are recommending to the current provincial administration is not only to listen and respect the voices, experience and best practice that we ourselves are presenting in this document, but for made-in-Ontario policies that enthusiastically support the highest global standards of acceptance. We believe that this province already has the capacity to implement inclusive policies, end the segregation of Autistic children, youth and adults and move Ontarians of all abilities into a more sustainable and supportive future.

The UN Convention of the Rights of the Child also requires that all actions concerning children should primarily consider the best interests of the child (Article 3), which is supported by Canadian federal, provincial and territorial law, as well as case law.

We have witnessed the effects of historic laws and policies which allowed for an overarching idea of conformity to dominant "ideals" of the time, to supersede the primary interests of children. Today, it is critical that children of all ranges of abilities, particularly within marginalized and oppressed peoples, not be subjected again to laws and policies which prioritize the regulated imposition of behavioural techniques targeted specifically to eliminate autistic movement and characteristics, over the health and wellbeing of autistic children, youth and adults.

There is no group of people, especially children, who are an exception to the above international and Canadian legislation and policies, including those of who are autistic. We too, are people whose rights and freedoms deserve consideration and protection. We too, deserve to live in an Ontario which respects the whole of our personhood, including our unique neurodiversities and to have a voice in creating the policies which impact our everyday lives.

This means practical, integrative changes to the landscape of autism services which have traditionally been funded with very specific and narrow interests in mind, those that have never before benefitted from substantive contributions from autistic people. These recommendations from and by autistic people, families, professionals and community members, represent a hopeful shift in a more promising direction and a more practical, proactive approach that centres real needs: education, employment, housing and access to healthcare.

Almost entirely absent from previous, more segregated reports from autism organizations which often do not speak for autistic people ourselves, is the conversation on diversity of

communication. Many autistic children, youth and adults use alternative forms of communication (AAC) to be heard but there is a long way to go before these are respected in public and private spaces alongside, for example, ASL and signed language.

Deaf, deafened and hard of hearing (DdHoh) people and organizations have championed Deaf languages are integral to the values, traditions, norms and identities of Deaf peoples. In 1997, the Supreme Court of Canada found that the failure of hospitals to provide sign-language interpretation "where it is necessary for effective communication" (*Eldridge v. British Columbia*) was a violation of the Charter rights of Deaf persons and therefore, unconstitutional. However, provincial and federal law does not distinguish between disabilities. Constitutionally, it could be argued that the routine violations of AAC users' rights to be provided communication methods which prioritize our freedom of expression, rather than methods narrowly advocated within ABA/IBI programming, represent an unequal 'hierarchy of disabilities' which disenfranchise autistic people from a very early age, onwards.

The services accessible to us as autistic people have never been determined and prioritized by us, and so for the current and coming generations of autistic people, we are determined that our voices be integrated into national and provincial conversations about autism and autistic life and wellbeing. Protecting the rights of autistic AAC users to communicate and be heard in the education system, in our workplaces, housing and healthcare, is pivotal to recognizing our full and collective participation in these areas.

In the education system, from pre-school to post-doctoral, autistic students (and also autistic teachers, instructors and faculty as well) must be accommodated by education providers, in compliance with human rights law in Ontario.

In workplaces, employers must recognize the inherent value of hiring autistic workers and employees, beyond the outdated stereotypes of autism which limit our participation to lower-paid and lower-valued forms of labour. Autistic workers and employees' rights are encoded into the same labour and employment laws that protect every other Ontarian. In today's changing times, some of the most highly valued traits of employability overlap with the same diverse aspects which behavioural therapies seek to eliminate in autistic people, potentially jeopardizing the availability of diverse employees to the Ontario labour market. Access to well-compensated, safe and healthy work environments for autistic people, regardless of the methods by which we communicate, is both highly necessary and highly sustainable.

In the area of housing, there are so many original and innovative solutions which have quietly been put into motion by autistic people, supported by our families and communities. The lack of affordable, geared-to-income or subsidized housing accessible to Ontarians across a range of abilities, creates an unnecessarily precarious ground from which to build a healthy and productive life.

Like the Housing First initiative, a "rights-based intervention rooted in the philosophy that all people deserve housing", autistic peoples' rights to appropriate and accessible housing is fundamental to ensuring our ability to contribute to society across the lifespan. This includes access to housing for autistic parents and families, autistic people who require higher levels of

support and autistic people who encounter barriers which may complicate their access to housing, such as substance use, mental or physical health diagnoses. Autistic people seeking access to housing must not be discriminated against based on their method of communication, nor their choice and self-determination be limited based on similarly ableist criteria. Projects initiated by and for autistic people in the area of housing, should be given at least equal consideration alongside projects initiated by autism service organizations steered by non-autistic members.

We are hopeful about the future, and recognize the long road ahead as we look to a more inclusive Ontario. We are advancing these recommendations in a cooperative and positive spirit, and believe that listening to and respecting the voices of autistic people ourselves had the power to transform what has become a fractious cacophony, into a truly broadminded spectrum of diverse autistic voices.

Jim Meunier, Clearwater, ON.

APPENDIX 4: Personal Testimonies

(3 of 3)

To the Government of Ontario:

This letter addresses the Communication Rights Crisis in non-speaking autistic children and adults.

I have a 23 year old son, who is a non-speaking autistic man. From early childhood, he was presumed incompetent at school. As parents, we were given very poor professional advice. We were not told that a communication system might change our son's life.

The majority of non-speaking autistic people have no access to communication tools. The majority are presumed to be intellectually incompetent. Presumed by professionals, their teachers, and even their families to be incapable of thinking, learning, and directing their own lives. We live in an ableist society that makes assumptions about people based on their support needs. They are labelled low-functioning or severely autistic because they often need support with the basics of daily functioning and because there are sometimes behaviours that are not well understood, like meltdowns. And rather than providing communication tools such as Augmentative & Alternative Communication (AAC) systems, the focus ends up being on behaviour.

Although this is a huge issue, affecting all areas of life, I'm going to focus on the education system, where the opportunity is greatest to make needed changes.

In a psych test at age 14, my son scored less than the 1st percentile. At 17, a support person who had experience with Supported Typing (a form of AAC) offered a letterboard to my son and we began having the first conversations with him ever. We learned that he was a polite, empathetic, sensitive, funny kid who was interested in art, politics, world affairs and travel. He desperately wanted to be provided with an education but that didn't happen.

Although his school embraced his communication system and recognized his intellect, he still had very high support needs. He still needed help using the washroom, eating, sitting in a classroom and managing sensory issues and the only place they provided support staff was in special education classes where he couldn't receive high school credits. When we tried to provide a support worker for him to attend credit earning classes, we were prevented from doing this due to collective bargaining agreements. He attempted to use the PLAR system to be awarded a credit, but it wasn't an accessible system. I fought with a school superintendent over that, who just stopped responding to my emails as a way of dealing with me.

My son left high school at age 21 with no credits and at 23, still hasn't been able to access the education system in a meaningful way. He is taking a math course right now at a local college but ended up changing his status to audit because his school offered him a comprehensive accessibility plan and didn't follow through on the plan. My son would rather be in a learning environment, even under those circumstances, than not be learning so that's what he's doing.

Incidentally, there are a number of colleges in the United States that admit students who use AAC. Canada lags behind in many ways.

If you're inclined to think that a non-speaking autistic person who is discovered to have the capacity to think, learn and communicate in a sophisticated way is a miracle of some kind, know that we have met well over twenty people just like my son, who are using Augmentative & Alternative Communication devices to direct their own lives. Yet it remains that the vast majority of non-speaking autistics are trapped inside their bodies with no communication tools. They are institutionalized in high numbers. Their support in school is primarily behaviour management. Why not instead offer communication tools?

Our schools lack the capacity to support communication in non-speaking autistics. They have staff they call autism teams who don't have a clue about AAC and this is even true of Speech Language Pathologists. Similarly, their psychologists will proceed with testing on students who have no communication tools, and declare them intellectually incompetent. Most parents don't know any better because we look to these professionals for information. This is a chronic problem that has its roots in the ableism that permeates training.

School systems blame lack of funding and other resources, but they are not even providing the most basic support to their non-speaking students. Communication is a basic human right. When communication rights are denied, of course the result is students who are perpetually in a fight/flight state, who get labelled incompetent.

Even when parents who do know better advocate for their children, school push back hard and gaslight us.

It's past time to recognize that we have a communication rights crisis. Schools must be mandated to provide communication systems to their non-speaking students and this must happen now.

Catherine Wright
M4K2L3 catherinemaewright@gmail.com