



When Policy Stops Progress: Rethinking Canada’s Approach to Economic Inclusion and Autism Services

by Autistics for Autistics, Canada

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Introduction

In this paper, we discuss the failures of Canada’s autism policy and outline our vision for economic inclusion for autistic Canadians.¹ Our vision includes changes to childhood autism policy, housing, disability funding and employment policy. It also involves getting rid of the federal government’s obsolete approach to autism policy and adopting a new operating system, so to speak.

Our economic inclusion vision, by 2023:

1. Respect autistic students

- De-fund ABA and replace it with inclusive programs that empower autistic children to attend mainstream classrooms safely and successfully.
- Ensure Augmentative/Alternative Communication (AAC)² access for every student who needs it, without wait times.
- Recruit autistics to become educators and make schools accessible for autistic teachers so that children have role models/mentors like themselves in teaching/leadership positions.

¹ For discussion of social inclusion, please see our first paper in the series, “Not ‘Special’ Equal: Social Inclusion for Autistics in Canada.” For discussion of evidence-based services, please see our third paper, “Not All ‘Evidence-Based’ Interventions are Equal: A Critical Look at the ABA Industry in Canada”.

² *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; and more.

2. Empower recent graduates

- Commit to reforming the “[school-to-guardianship pipeline](#)”, where too many youth are placed under guardianships from their earliest years of majority. Research and implement best practices in least-restrictive decision-making supports.
- 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.
- Ensure that autistic youth are specifically included in the materials of all job program opportunities for intellectually disabled (I/DD) youth.

3. Educate employers

- Fund mentorships between working autistics and autistic job seekers.
- Leverage the knowledge of the private sector in creating accessible workplaces.
 - Educate employers on workplace accommodations and hiring/retention of autistic employees.
 - Can be built from existing resources already in place by the private sector. (See further in this report for a list of employers.)

4. Support disabled people

- Audit disability support programs to ensure recipients are not economically penalized for working part-time.
- Incentivize employers offering flexibility for disabled employees who need to work part time or from home.
- Enact a federal ban on sheltered workshops. Replace sheltered workshops with meaningful options that maximize opportunities for autonomy and dignity.
- Harmonize disability supports so that all people on disability supports receiving a livable level of support for independent living and don't end up trapped in “autism homes”.

5. Build a new operating system for federal autism policy

- De-silo autism policy. No “National Autism Strategy”.
 - End the idea that there is an “autism strategy” or “autism portfolio” to assign to one or two ministries. Policy should be dispersed broadly and overseen by area (employment; health care; housing; education, etc).
 - Integrate services for autistic Canadians into existing policies that serve other disabilities (e.g., employment protections), recognizing we have the same rights as other disabled people in Canada.

- Audit all organizations currently under federal contract for “autism services” to end price-gouging, monopoly, pseudoscience and unsustainable service models.
- The PHAC should no longer be in charge of any autism funds, discretionary or otherwise.

There is no way to reform or redeem the Agency’s mistakes, which have squandered billions of tax dollars. **The Government of Canada must simply delegate autism policy responsibilities elsewhere.**

A legacy of failed policy in Canada

Autistic people in Canada are living with an unmitigated crisis of poverty and disadvantage. We face high rates of unemployment and precarious housing. We often face exclusions, stigma and abuse in schools. Many of us do not receive health care and other services because of communication access barriers. Our suicide rates are nearly 9 times that of non-autistic people.

These are all major social problems--and it isn’t “living with autism” that causes them. In large part, these crises are directly caused by Canadian policymakers lacking the awareness or political will to break out of a historically pathologizing, segregationist approach to autistic and intellectually disabled (ID/D) people.³ Instead of reaching out to autistic-led groups, the Government of Canada continues to engage with the same charities offering the same old “solutions” that don’t work.

The Government of Canada should be studying best practices in other jurisdictions for autistic inclusion for schools, housing, employment and economic justice--while creating competitive RFPs for programs and services and engaging directly with innovators. But that is not currently happening. Rather, the Government has given control of projects to the Public Health Agency of Canada who has grossly mismanaged autism funding for years by giving the same 5 or 6 “autism” organizations and individuals **wasteful sole-source contracts⁴ in the hundreds of millions.**

If you were shocked by [the WE scandal](#), you will be even more shocked that a search of all publicly-available databases of government contracts shows that **federal autism-related projects have not been put to tender in years. They are all controlled under a “discretionary fund”. Most of these sole-source contracts do not even appear on the government’s funding transparency public databases at all.** They were granted without any study to determine whether the service was needed, nor any independent standards and practices to measure program efficacy or outcomes.

An example of this is **the \$10 million website**--known as the “AIDE project”. It is a sole-source

³ Please see Report 1, “Social Inclusion” for background on the residential institution model and its impact to the present day in Canada.

⁴ A sole-source contract is when the government allocates funding directly to a specific supplier, without inviting/allowing other organizations to provide competing bids.

contract for \$10 million that the government granted to Pacific Autism Family Network and the Miriam Foundation in 2019 [to make a website](#) that is nothing more than a bit of general content, a provider list and links to online articles on autism, with the belief that Canadians are going to access the out-dated clearinghouse platform instead of Googling for the info they need.

In that same package is **the \$10 million “hub”**, where \$10 million was given to the PAFN to use for [mini-grants](#) to itself, to the Miriam Foundation and 4 other non-profits that run and [promote segregated ABA centres](#) for children and [segregated residential institutions](#) for adults. This colossal expenditure was to set up “information hubs” in existing autism service centres— *and no other information about what the \$10 million hubs are has been made available to the public.* (For more sector-specific boondoggles, keep reading).

Given the amount of unregulated funding they get from the Government, it is unsurprising that the autism charities have their own lobby in the form of the Canadian Autism Spectrum Disorder Association (CASDA), whose stated goal is to “coordinate national conversations about autism – bringing community voices to the federal government to guide their development of a National Autism Strategy.”

It doesn’t seem to matter to CASDA, nor the handful of MPs who champion the lobby’s interests, that the community voices of **every autistic-led organization in Canada opposes the “National Autism Strategy”**. In a joint statement, all chapters of Autistics United Canada and Autistics for Autistics Canada, as well as ally groups across Canada, [wrote](#):

Canada’s national autistic self-advocacy organizations are united in opposing CASDA’s “National Autism Strategy”. An Autism Strategy led by CASDA and Autism Speaks would maintain the current broken system of autism services in Canada. The Government of Canada has been giving [contracts] to selected service agencies and charities like Autism Speaks with no real data to justify spending, no transparency and net negative results. The money, quite simply, has been going down a hole. ...It is time for a culture shift in federal autism policy.

Interestingly, the [Vice Chair](#) of the Executive Board for CASDA is also the President of Autism Speaks Canada. [Autism Speaks is a Capital Lead Partner at PAFN](#) and a [Collaborator of CASDA](#). It is concerning that Autism Speaks is so closely tied with CASDA and that it could establish dominance in autism funding. The charity has [one of the lowest rankings among autistic people in the world](#) due to its support of eugenics and its problematic use of donations, which mostly go towards eugenics and other “research” rather than supporting autistic people. In the words of tens of thousands of autistic advocates: “Autism Speaks is a hate group.” ([Learn More Here.](#))

The CASDA lobby is also presenting flawed data to the government. In fact, its 2019 national “needs study” was very small and **only 2.4% of the participants in the survey were even autistic**. Based on this so-called study, CASDA crafted a “Pillars” document with many graphics but seemingly no innovation. It is filled with simplistic, traditional approaches not supported by data.

Autistic-led groups also presented detailed policy papers to the Health Ministry, but the Ministry never read our policy papers or responded. Neither did the office of the Disability Ministry when we sent them our policy paper. Our groups, including the Autistic Women & Nonbinary Network, have also reached out directly to the Public Health Agency of Canada, which does not return our emails.

Segregation starts in childhood

Many autistic and ID/D Canadians are segregated from the rest of society (as A4A outlined in our 2018 [Human Rights Report](#) to the United Nations.) In some ways, although Canada has “de-institutionalized” from the horrific world of 20th century residential care, autism service providers and policymakers still hold onto the stigmatising ideologies that keep us separate--and policymakers have not made the attitude shift that would embolden policy to ensure our rights as Canadians.⁵

As we outline in our “Social Inclusion” report, segregation begins when autistic children as young as 2 or 3 are sent to IBI/ABA centres instead of being integrated into their communities. They are then streamed into special education at school and graduate into segregated lives, in housing, employment and social life.

The federal government has not engaged in oversight to ensuring that autistic children are safe at school. While in other countries/states, restraint and seclusion are either banned or tracked for accountability, most school districts in Canada do not have universal measures for tracking the use of seclusion and restraint, which are endemic to the special education system (Please read our [Human Rights Report](#) for more information). There is also a clear lack of transparency within the special education classroom, which do not have cameras in classrooms and many of which do not even allow parents to enter the classroom space during the school day! Without transparency or government oversight, and with an approach that systematically excludes autistic students, Canadian public schools are set up for failing *all* students, with devastating impact on autistic students’ lives.

Canada is behind many other nations on school inclusion of disabled students. In fact, [according to](#) the Ontario Human Rights Commission, **the special education/streaming system here hasn’t changed meaningfully in more than 40 years.** School exclusions and special ed referrals are commonplace; there is no accessible/universal design in Canadian classrooms (not even a pilot program); and many families end up homeschooling just to give their autistic children an accessible education. When we have approached federal policymakers, they claim these human rights issues are not the Government’s mandate because the “Autism file” is silo’d in the Public Health Agency of Canada (*where it does not belong*).

Because autism policy is silo’d at PHAC and kept separate from other disability policy, the Government has been able to ignore its responsibility to include autistic people in disability

⁵ For more on this in the context of social inclusion and social policy, please see Reports 1 and 2 (“social inclusion” and “evidence-based interventions”).)

rights legislation and enact human rights policy to ensure autistic children have safe and accessible education in Canada. While a few districts in Canada have [piloted](#) positive inclusion based programs such as SCERTS, these efforts remain ad hoc and marginal because federal policymakers haven't implemented rights legislation to ensure Canada's classrooms are accessible to neurodiverse students.

Housing Segregation is still the norm in Canada

The Government of Canada and provincial/territorial governments continues to allocate [the majority](#) of IDD housing budget towards segregated facilities. **In 2013/14, more than 90 percent of federal funding in this sector went for segregated housing and just 9 percent for independent supported living.** Provincially, the numbers are similar; for example, in Ontario, 80 percent of housing funds for autistic and I/DD individuals is still allocated to segregated group homes.

These investments ignore evidence that autistic and I/DD people fare better with [independent supported living](#) (ISL) in the community, not segregated housing. This is because with ISL, the person has their own housing and supports they control to live in the community, as an integrated member of the broader society.

When we met with a representative of the Health Ministry to discuss housing, she interrupted our presentation share with us the news of a new segregated housing project being built "for men living with autism" in her district. It did not appear, from that meeting, that [independent supported living](#) was even on the Ministry's radar. The cultural disconnect is clear in the very language the government still uses, officially describing us as "people living with autism," as though autism were a dachshund or a ferret. Many of us would like to *live with* a roommate of our choosing or alone; however the current system sets people up in group homes that are neither safe nor accessible. (See our "Social Inclusion" report for more on this).

Instead of continuing to break new ground of segregated living institutions, the Government of Canada should consult with experts on independent living to empower more autistic and ID/D individuals to achieve supported autonomy, integrated in the community.

The Government can look to the best practices of Ontario organizations such as [LiveWorkPlay](#) for models of fostering housing autonomy by offering support in areas requested by individuals such as financial management; meal planning; social gatherings; and co-ordinating supports. It can also study best practices and pilot projects in other jurisdictions. (The [Money Follows the Person](#) pilot project in the US is one promising example.)

Employment: Best practices ignored by policymakers

Progressive thinkers in the private sector have made groundbreaking efforts to recruit and retain autistic employees. In fact, Autistics for Autistics gives presentations before some of these employers and advises them on recruitment, hiring and retainment. They appreciate

what autistics bring to the workplace and are committed to workplace access. According to Robert P Austin and Gary Pisano, writing in the *Harvard Business Review*:

Many [autistic] people have extraordinary skills, including in pattern recognition, memory, and mathematics. Yet they often struggle to fit the profiles sought by employers... A growing number of companies have reformed their HR processes in order to access neurodiverse talent—and are seeing productivity gains, quality improvement, boosts in innovative capabilities, and increased employee engagement.⁶

Companies such as SAP, HPE, Microsoft, Willis Towers Watson, Ford, EY, Caterpillar, Dell, Deloitte, IM, JP Morgan Chase and UB have all implemented innovating hiring and retention practices. They recognize the benefit for employees, society and their companies. As Silvio Bessa, senior vice president of digital business services at SAP, put it: “Having people who see things differently helps offset our tendency, as a big company, to all look in the same direction.” Recognizing that inclusion benefits everyone, these private sector innovators have implemented: new approaches in interview/hiring processes; flexibility in workplace environments; and respect for individuals’ communication differences.

The ultimate goal? For neurodiversity to be so integrated into the workplace that eventually there won’t be a need to distinguish special programs from the rest of the hiring and retention process. For example, Microsoft is now working with the vision that the term “neurodiversity programs” may become outmoded, because hiring and work environment will have successfully integrated the elements of an inclusive process for all hires.

Unfortunately, by leaving these initiatives up to individual employers, the Government of Canada is missing out on a golden opportunity. By advising with autistic-led groups, the Government of Canada could be developing modular employer-education programs so that many more of us could work and be independent. Our members are connected with the top innovators and we’re ready to connect the Government with them.

But the Government has not reached out to us, nor to innovative employers, [instead appropriating \\$600,000 on a “mentorship” program through an “autism centre” where the mentors are not themselves autistic](#). We don’t need well-meaning social work students to be our “mentors”. We don’t want “buddy mentors” – we need people in our own fields of interest, who are also neurodivergent to build an *authentic* relationship as equals... as in, real mentorship programs, across the spectrum of careers.

It is also time for our federal government to ban sheltered workshops⁷ nationally. Under the sheltered workshop model, workers with intellectual or other disabilities are placed in factories

⁶ Neurodiversity as a Competitive Advantage: Why you should embrace it in your workforce, by Robert D Austin and Gary P. Pisano. *Harvard Business Review*, May-June 2017.

⁷ In the late 20th century, as part of de-institutionalization in both the US and Canada, many communities supported 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. Sadly, these programs still exist throughout Canada.

and other workplaces to do jobs for [pennies on the dollar](#). To add insult to injury, the low wages are often accompanied by the myth that it's "training" for future employment at a living wage. But sheltered workers aren't being trained; they're trapped. We understand that some corporations or parents may not agree with the statement that sheltered workshops are unfair to workers. But the Government of Ontario did,⁸ banning them in 2018. As then-Ministry of Community and Social Services spokesman Daniel Schultz [writes](#):

"There is simply no justification in the 21st century to segregate any group of people and pay them less than minimum wage for the work they have done."

The key to all economic inclusion policy is to root that policy in rights, not charity. Autistic-led groups are recognized as education partners by progressive corporations, and should likewise be consulted by the Government of Canada. When a disability is accepted and accommodated, the disabled population fares better in life and the entire society is lifted in the process. Autistic people deserve that chance in Canada. Canada deserves that chance.

Conclusion

Autistic people deserve better than the policies Canada has been delivering via the PHAC and Health Ministry. Just because Canada has "always done things this way" doesn't mean it has to. There are better ways and best practices elsewhere that our federal government can learn from. By finally setting inclusion as the standard, our government can begin to move Canadian autism policy into the 21st century. This will take a significant, multi-agency/Ministry effort. But it's the right thing to do and it a change that's long overdue.

About Us

[Autistics for Autistics](#) is a Canadian autistic led-and-run advocacy group. We advise on policy in Canada, the UK and with IGOs such as the United Nations. We also engage in community education and [outreach projects](#) with schools, employers and health care providers and host [events](#) for autistics, families & friends across Canada. We are an international affiliate of the Autistic Self Advocacy Network (ASAN).

⁸ In 2017, the Ontario government [decided](#) to close all sheltered workshops, following the lead of many communities in the United States. Unfortunately, with a new government, it has not followed through on that promise. We've authored a [statement](#) with Community Living about the closures, supporting the transition away from sheltered workshops towards including community participation supports and employment opportunities at and above the minimum wage. The Canadian Down Syndrome Society also [supports](#) the closure of sheltered workshops and the development of new alternatives and leveraging of existing partnerships and programs.