



Human Rights for Autistics in Ontario: Our History, Our Future A Report to the UN Special Rapporteur on Health

October 5, 2018

Introduction

In this report, we discuss current human rights abuses against autistic Canadians. We start with a history of autistic life in Canada and a discussion of issues in data collection, then move on to our areas of focus. We will focus most specifically on Ontario (where we are based), with some data from other provinces and territories.

Our areas of focus are: schools (exclusion, restraints, isolation rooms); medical settings (lack of consent, inaccessible care); employment (access, exploitation in sheltered workshops); and housing (the impact of poverty, abuses in group/residential homes).

We write this report with a keen awareness of how intersectionality (the interconnected nature of social categorizations such as race, class, gender and neurotype) deeply impacts our lives, as well as the impact of trauma and the need for trauma-informed best practices in schools, medical settings, housing and social services.

Appendix 1 contains a list of institutions you may wish to contact and visit when you are here because they have been the subject of human rights complaints or are otherwise referenced.

About us

Autistics for Autistics Ontario (A4A) is an autistic self-advocacy organization. We are autistic youth and adults from a range of professions and backgrounds, advocating for the rights of all autistics in our province.

Since our founding a year ago, we have become involved in campaigns on issues such as: sheltered workshops; schools and housing; access to medical care; abusive “treatments” on children; violence/murder by caregivers; sexuality education; autism acceptance; and the need for Canadian policymakers to consult autistic people in the decisions that affect our lives.

For more information about A4A, please read our [Annual Report](#) (attached).

A brief history of autistics in Ontario: The residential institutionalization era

In the first half of the 20th century, Canada institutionalized many IDD and autistic people. Under the [medical model](#) of intellectual disability, many families viewed institutionalization as essential and very few parents had the good sense to keep their children out of institutions.

In residential institutions, abuse was common and there were no genuine systems in place to prevent it. Indeed, it can be argued that abuse was built into the institutional model, where an unachievable level of compliance was demanded from all residents. Residents were not allowed freedom of movement, were forcibly committed/or lacked any means to live freely, were overly-medicated with extreme drug regimes, were abused physically, sexually and emotionally and were forced to do unpaid manual labour to earn profit for the institutions under the auspices of “training”.

For autistic residents, PTSD and a host of so-called “behaviours” resulted from these experiences. These behaviours, which communicated the very inhumane conditions under which residents lived, were received with further punishments from institution staff. This pattern of abuse led to a lifetime marked by fear and pain for autistic and IDD residents. As autism historian Steve Silberman [writes](#), “Behaviours caused by institutionalization under brutal conditions were then viewed as part of the ‘natural’ course of autism.”

The institution at [Huronia](#), located in rural Ontario, is an example. Huronia was opened in 1877 as a “home for the feeble minded”. In the early years, residents lived and slept in wards with as many as 50 residents; in the 1970s, the facility was divided into smaller units with 12 residents living side by side. Beatings, isolation, restraints and humiliation were a part of everyday life. Forced sterilizations were routinely performed, despite it contravening Ontario law. Patients were forced to work for no wages in farming and piecework. Due to this practice, the institution ran at a profit. Most residents did not have the freedom to leave the institution; at first due to commitment laws and later due to poverty, fear and other factors.

Except for schooling or outings, male and female residents did not interact. However, male attendants had unregulated access to both female and male residents. As the later class-action suit documented, rape [was endemic](#) at Huronia.

In the early 2000s, Huronia was the subject of a \$35 million dollar class-action lawsuit over the allegations of widespread physical and sexual abuse. The lawsuit brought new information to the surface and was a moment of reckoning for Ontario’s institutional system. The lawsuit was fully settled in 2013 and included apologies from the governmental parties under whose watch the abuses occurred.

In March 2009, the Government of Ontario officially closed the last remaining institution in the province. A period of “de-institutionalization” in Ontario followed, where the government re-introduced institutionalized persons to the community. The period included the birth of a vibrant Community Living movement, which still exists today – advocating for independent living, free of institutionalization and free of poverty.

In the 1980s, disability became a protected category under the *Canadian Charter of Rights and Freedoms*. Very slowly, policy has begun to turn towards an accommodation model of disability and away from the medical model. In March 2010, Canada ratified the *UN Convention on the Rights of Persons with Disabilities (CRPD)*. The CRPD [commits](#) Canada to a series of measures and principles to improve the social and economic condition of people with disabilities while taking steps to improve their legal and political rights.

Present-day: The Institutional Mindset in Autism Services

Although our province's institutions were closed down, an institutional mindset migrated to the non-profit organizations that now work with IDD and autistic Ontarians.

For example, although Huronia's farm –where residents would labour without pay—was closed down, it was replaced by farms and factories *in the community* who collaborated with non-profits to run “sheltered workshops” where IDD and autistic workers help companies turn a profit by working [for pennies per hour](#). And the promise of true housing independence has not come to pass for many autistic and IDD Ontarians, who languish in group homes that foster the [same punitive approach](#) towards residents that institutions did.

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. As one parent told us: “the fact that we *choose* whether or not to sign a ‘do not restrain’ option at schools each fall is pretty messed up.” Where other jurisdictions are building on concepts of inclusive design to make a safe and welcoming environment for autistic students, these classrooms do not exist in Ontario, save the ad hoc efforts of a few teachers usually spending their own money.

There are nearly [four million](#) Canadians with “physical, sensory and cognitive impairments” (about 14 per cent of the Canadian population). Yet we have not been allowed to fully “integrate” following de-institutionalization. Instead, many of us lack access to employment, education, housing and adequate medical care. This segregation comes at a huge cost to our mental and physical wellness, as well as our safety.

Autistic people are [more likely](#) to be victims of hate crimes, sexual assault and other violent crime. Autistic children and adults are also some of the main victims of violence within schools and group homes. And parents [have](#) committed [filicide](#) against autistic children in Canada. This abuse is reinforced societally when we are portrayed as burdens on parents, and on society. The research focus on finding an “autism gene” – which would mean parents could discover and abort autistic fetuses – is also a human rights issue. We are deeply concerned about eugenics and its frightening impact, demonstrated currently in [Iceland](#), where parents abort nearly all fetuses screened as having Down's syndrome.

The title of a recent Government document on autism and early interventions used the phrase “[pay now or pay later](#)” to describe our life course. The phrase belies the bureaucratic idea that those autistic adults who don’t earn a living wage are merely a burden on the tax system, rather than people with thoughts, feelings, needs and ideas. It is stunning in 2018 that Canadian policymakers would use this approach – and that they would develop any disability policy [without consulting](#) the group the policy is supposed to serve.

The institutional mindset is part and parcel of the non-profit autism services model across Canada, which too often marginalizes our community from involvement and consultation, keeping us – and the information we need to share – siloed from the broader discussion. Although there has been some progress in this area, it is still too common for nonprofits to endorse statements like “I am my son’s voice,” or for reports to contain mostly the musings of CEOs and therapists but no autistic voices. For example, a recent [campaign](#) (for national ABA) claims “to speak up for the kids who can’t speak for themselves.” Autistic and disabled people of all ages **can** express what we need through a variety of communication platforms. And we are [saying](#): *don’t speak for us*.

In Ontario, many service providers’ approach to autism still follows the [medical model](#) of autism, attempting to “fix” behaviours rather than understanding behaviour as communication and then responding to the message (the social model). The medical model, based on the same ideologies that informed our residential institutions, trickles into the broader society. It translates into abuse and exclusion. It hinders good policy. It also creates a code of silence about abuse.

Issues in data collection: If there is no record of abuse, how can you stop it?

Ontario and its school districts have generated a number a lot of statements and guidelines about disability inclusion, but the Province and school boards lack meaningful tracking mechanisms for how autistic/disabled students and residents are actually being treated. 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. Ontario school boards and other agencies 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.

Because our government does not adequately track 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. Months later, he was arrested for hitting a client across the head and face with a metal water bottle. Our Province 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.

There are ways to prevent these incidents and there is no excuse for Ontario not to have appropriate systems in place.

Within our government, conversations about IDD and autism tend to dwell within “safe” territory such as inclusion and diversity statements, but avoid discussing physical abuse and other human rights violations. We need to ask: why is this? How can we change the culture to one of accountability and fairness?

In addition to a lack of core data on abuse, the needs and circumstances of autistic Ontarians have not been meaningfully studied. In fact, there isn't even a basic demographic picture of autistic people here other than “1 in 66”. Research into our economic and social realities is essential to inform any useful policy. Put simply: policymakers have to talk to us, and they haven't. This disconnect is one factor behind failed policy such as the [Ontario Autism Plan](#), a \$500 million project rolled out last year without **any** consultation from the group it is intended to serve: autistic people.

Schools: Segregation & exclusion, isolation rooms, restraint

While special education programs have made progress in many countries, in Canada there has been relatively little change in the structure, methodology and mentality of the education setting [in the past 40 years](#). Indeed, one could walk into a special education class in Canada and feel like one has stepped out of a time machine into the 1970s and 1980s. Below, we give just a few examples of human rights violations that happen daily in our province's schools: exclusions, isolation rooms and restraint.

Segregation and exclusion. Ontario special education students are routinely segregated from mainstream students at lunch, recess and many school activities. School exclusions are also common, where 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.”

These exclusions are given for a range of reasons, from “behavioural” issues to, more commonly, schools not having unionized aides available to help in the classroom that day. The union has forbidden outside workers in the classroom: so when families offer to bring in their own aide worker, the aides are kept out. As one mom put it: “In the US, my understanding is that kids can have their own support person but this private person isn’t allowed here and the board won’t provide one, so it’s a hopeless situation sometimes.”

Ontario schools do not have a uniform approach or training on AAC and other communication methods. “I want to be in school but need a facilitator,” writes a member whose aide was not allowed in the classroom in Toronto. The government also doesn’t support continued education beyond age 21. Yet this education is key for many autistics, speaking and non-speaking, in Ontario.

Under Ontario’s new \$500 million autism plan ([OAP](#), 2017), only ABA-trained support workers are allowed in schools. Some families who oppose ABA are pulling their children from Ontario public schools and paying out-of-pocket for evidence-based non-ABA services – services that are funded without issue in other jurisdictions. A father shared: “We are forced to homeschool our son because they won’t let us use a non-ABA support worker. [The PSW] is absolutely wonderful and knows him well but they wouldn’t let her into the school.” A member who has worked in schools notes: “There are professionals working in schools who don’t support ABA, but aren’t free to say so if they want to keep their jobs.”

Much like the bureaucrats in the era of residential institutions, the architects of the current provincial “autism plan” made a massive investment without consulting the people it claims to serve. When autistic individuals, ally parents and therapists brought this concern up at a March 2018 Tele-town hall with the Ministry of Children and Youth, the visibly irritated Minister cut their questions off. Our community was left wondering if anyone in government cares, and also wondering where this one-sided approach came from. We looked a bit and learned that the market dominance of ABA/IBI is rooted in [ABA/IBI investments](#) in the provincial budget in the early 2000s and picked up strength in 2017, when the Ontario Association for Behaviour Analysis hired Pathway Group to lobby eight Ministries at Queen’s Park and effectively [shut out](#) most stakeholders from the funding discussion.

Within the special education classroom, lack of access to the outdoors, free play and physical activity is a problem that is not being addressed by districts or the province. As one mom of a 6-year old autistic boy in the GTA 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.”

Oftentimes, it comes down to who is watching and whether a parent has the strength to go against a Board and try to take action. A child in the York Region School District was denied the right to use the toilet and forced to wear a diaper, as well as restrained in her wheelchair by Grade 2 teachers who didn't “have time” to take her to the washroom or ensure her safety in her wheelchair. As a result, she began to hate her wheelchair, which is essential for her mobility. Her mother switched her to a new school (a common workaround when a Board won't take action), and there the teachers made the time to offer her proper supports.

Within our school boards, IDD, autistic and/or disabled students are often lumped into a broader discussion of “diversity” when in fact their needs are unique and require distinct attention that they are not receiving. Speaking of “inclusion” and “diversity” in Ontario schools, 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.

Schools: Restraint and isolation rooms

As far as we know, there is no provincial or federal organization that tracks the degree and frequency of restraints and isolations in special education classrooms. In fact, it appears most studies of autistic youth by the government and autism non-profits avoid discussion of this issue. What we hear from our members, from caseworkers and from families (as well as media accounts) is that violence, especially restraint and isolation, is common, and increasing. Regulation is completely inadequate.

Medical and other organizations publish “guidelines” on the use of restraint and isolation, but do not have enforcement against providers who cause harm, instead putting the onus on vulnerable individuals and their families to report to professional regulators or the public advocate. Cases that do go through the rigours of reporting are sealed and only rarely leaked to media. There is no publicly-accessible data on the degree or amount of abuse, so there is no way to codify, study or solve the problem.

Isolation. Isolation abuse in special education exists across Canada. In September of this year, an autistic boy in Saskatchewan was [stripped naked and locked in an isolation room](#). As the CBC reports:

“The room had paper taped over the window and was locked from the outside. The boy's teacher later emailed the parents a photograph of the 12-year-old that showed him naked and covered in feces. When the father arrived at the school about 45 minutes after receiving the email, he found the classroom empty. When the father took the paper off the isolation-room window, he saw his son and heard him whimpering.”

Inclusion Alberta (an advocacy group) called on the province to ban or regulate the use of seclusion rooms, as no regulations existed. The Province of Alberta has now [promised](#) to enact regulation within weeks. It took an extreme situation to motivate the province to regulate. We wonder: what will it take to motivate other provinces?

In another reported [case this year](#), a six-year-old student was locked in a storage room by a teacher who walked out of the room and left him there alone. She was punishing the child for a “meltdown”.

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. The School Board calls these kinds of spaces “alternative learning environments,” or ALEs. ...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. Soon after, school administrators called his mother and told her to keep Christian at home.”

Restraint. Ontario school workers also use sedatives and restraints in place of de-escalation techniques. This year, a student in Ontario reported being [put in restraints and injected](#) with a sedative after walking out of school following a disagreement with another student. “They said when you calm down, they’ll take one (restraint) off one by one,” he said. “ I calmed down, they didn’t take one off. They put it tighter. I freaked out again and that’s when they put the needle in me.”

One of our Toronto-based members, who is now 20 years old, recalls his experience with restraint: “In Grade 3, I was physically restrained by school staff on an almost daily basis. Frightened, I would often try to escape by screaming, kicking...This of course made it only less likely that I would be released from the hold. At some point in time, it got so bad that I was temporarily expelled and homeschooled by someone sent by [the school district].

“The trauma that I endured in Grade 3 has stayed with me throughout my life and is at least partially responsible for several severe issues, such as c-PTSD, depression, Dissociative Identity Disorder and even problems in my sexual life due to the fact I had no concept of my bodily autonomy.”

Parents of autistic students in Ontario are given the option of sending a signed *Do Not Restrain* statement to the school. The fact that this kind of statement exists is a testament to the commonness of restraint in these classrooms. It gives proxy consent for restraint to the parents, begging the question: what happens to the children whose parents do not send the statement? Are they treated as a different class of child? Are schools and other settings making the best effort –or any effort --to create a trauma-informed classroom that doesn't use restraints?

Children in special education also feel trauma at the impact of seeing classmates being restrained. A mom reports to us that she witnessed a violent restraint of a student that caused her to pull her own child from school. The program wouldn't let parents visit the classroom, but one day she "snuck" past the receptionist and stepped into the classroom. In the centre of the room, a boy was being restrained and everyone was watching. She took her son home that day and began home educating him.

The fact that a parent would have to sneak in to see her child's classroom may seem shocking, but it is not unusual in Ontario. At many schools the special education classroom is segregated and even parents are not allowed to enter. There are no rules requiring teachers to open their classrooms to parents. Because the classrooms lack transparency, a teacher can abuse vulnerable children with relative impunity. When children do not have the capacity to report it and there are no witnesses, no action is taken to stop the abuse, year after year.

Medical settings: Autism pseudoscience and proxy consent

Lax notions of proxy consent are not just a problem in Ontario schools; they also have devastating consequences for autistic children whose parents invest in "biomedical treatments", otherwise known as autism pseudoscience. These businesses claim to "cure" autism or "recover" autistic children through unproven and often risky procedures and diets.

Autism pseudoscience flourishes in Ontario due to a lack of regulation of both proxy consent and complementary medicine. In our province, minors do not have consent rights in their health care; parents are legally allowed to proxy consent to any "medical" procedure on their children. Since there is almost no regulation of biomedical "cures" for autism (even those that are risky or life-threatening), this creates an especially unsafe environment for autistic children. Autistic and disabled children's rights to appropriate health care, safety and comfort are being routinely violated here with little to no legal repercussions for the clinics that promise the false cures.

As the Westminster Commission on Autism (UK) [writes](#) in its report recommending improved policy and practice on autism pseudoscience: "Healthcare fraud is big business and autism is one of its many targets." 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. 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 for the family relationship.

Examples of biomedical “treatments” offered in Canadian clinics include [chelation](#) (the removal of essential minerals and metals from the blood); injections and vitamin IV drips; off-label prescription drugs such as long-term antibiotics and antifungals (32 clinics in Canada); chemical castration; phony “stem cell” treatment ([24 clinics](#) in Ontario); herbal and vitamin supplements; hyperbaric [oxygen tanks](#); “gene therapy”; bleach enemas ([MMS](#)); severely restrictive diets; “translational therapy”; and other regimes that are sometimes called *biomedical treatment*.

Other than MMS, which Health Canada is [cracking down on](#), none of the other treatments are regulated. Anyone can practice them on a child of any age and the government will not generally take action.

This year, when a parent complained about an MD performing chelation on autistic toddlers in Ontario, her concerns were turned away by the College of Physicians and Surgeons of Ontario (CPSO), the regulating body of physicians in Ontario. Despite being given data on the risk-benefit ratio of chelation for autism, the CPSO [rejected her complaint](#) and took no action, indicating that it accepts proxy consent despite safety concerns. The parent had shared with them a case where a child had [died](#) from chelation for autism; a case that has inspired the UK to reform its regulatory system. Nevertheless, in a letter to the mom, 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.

The fact that some autistic children in Ontario are treated like guinea pigs in biomedical experiments --and that this was recently endorsed by a professional regulating body-- is extremely alarming and demonstrates the need for provincial and federal oversight into autism pseudoscience. Policymakers must reconsider our province’s overly-broad definition of proxy consent, in the interest of child health and safety.

As it stands, we wonder if there is a **two-tiered system** of risk management within children’s medical care, where it is acceptable for a provider to do things to autistic children that regulators would not allow to be done to neurotypical children. We will discuss this below as well in the context of more traditional care.

Medical Settings: Lack of Access

According to a [study](#) by the Redpath Centre and University of Toronto, in Toronto between 1998 and 2008, 14% of the autistic youth surveyed had a hospital stay (lasting longer than 12 hrs) and 20% accessed emergency services for “psychiatric or psychological problems.” When autistic Ontarians access services, their experiences are mixed.

Since the passage of Ontario [Bill 168](#) in 2010, which allows medical professionals greater leeway in refusing to treat, more autistics are being turned away from appropriate medical care once their diagnosis is revealed. “I want to share my diagnosis because it could help in my care,” says a member, “but I’m afraid to because it could affect whether I get care.”

A parent recalled: “When my son was experiencing suicidal ideation, we called a crisis hotline. Because he is autistic, they didn’t offer help; instead they referred him for ‘behavioural services’ (ABA). I know of two other teenagers who are autistic who were taken to Emergency during suicidal episodes and were discharged because the psychiatry unit in ER was not ‘equipped’ to help autistic people.”

Autistic people in Ontario can also face a lower quality of care due to medical professionals’ lack of understanding about AAC and other communication methods in appointments. Some have also had difficulty getting timely care due not having communication access to the phone. This is slowly improving with increased availability of online appointment-making. Lack of accommodation for processing time is also an issue in care and after-care instructions. As one member wrote: “Before I know it I’m being pushed out the door. I have no time to process information, ask follow-up questions or even the questions I planned to before coming in.” Many autistics prefer written to verbal communication and can get better care if they email the MD prior to the appointment and receive written, not just verbal, instructions.

Other autistic patients face barriers due to [interoceptive](#) differences or the way they communicate their symptoms to medical professionals who may not understand. One of our members writes: “When I’m in pain or distress, I speak louder, quicker...and it’s read as aggression, anxiety, or (in the case of an incident with the paramedics last year) meth overdose.”

Some autistics do not access dental care due to its prohibitive cost (it is not covered under provincial health care and many autistics do not work full time/have supplemental insurance). In addition, for autistic adults who may have experienced drugging or straightjacketing earlier in life, PTSD is a barrier to dental care. Luckily, some dentists have the knowledge to provide sensitive care, but they learn these skills outside of dental school, where it is not required.

Unfortunately, there are also dental clinics that state they “specialize” in treating autistic children but who really specialize in giving expensive general anesthetic procedures for a range of dental needs, including regular cleanings. One mom reports: “We visited one ‘autism expert’ dentist who said our daughter had 4 cavities and would need to come back and go under a general [anaesthetic]. They were very aggressive about it, but we said no. We took her to a regular dentist who was relaxed and eased her into cleanings. She didn’t need to be knocked out and she also didn’t have four cavities!”

This points back to the two-tiered system of risk management within medical care in Ontario. General anaesthetic on toddlers and preschoolers carries significant risk. Why is a dentist promoting an expensive, last-resort option as the only way to treat autistic kids? Is there a

watchdog who inspects the clinics for questionable practices, or is the onus solely on individual families to go through a formal complaint process that may lead nowhere?

Clinics make a lot of money offering “easy” solutions to worried parents in place of healthier, cheaper, feasible options. They are part of what’s known as the autism industry, where adding a puzzle piece to one’s company logo allows a company leeway in costing and in the quality of the services provided... because “autism”. These providers view the parent as the client and the needs of the autistic person – *who is the patient!*– are brushed over for the sake of convenience and profit.

Employment: Marginalization and exploitation

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](#).

The Ontario government’s [autism plan](#) doesn’t fund any services for job-seekers, nor for continuing education. In fact, **employment, higher education and housing are not mentioned once in the plan**. While some non-profits run annual job fairs and the private sector does some recruiting there, it is not enough to address the magnitude of the problem. There is no province-wide data about the number of IDD and autistics who are seeking employment, nor about the specific needs, qualifications and barriers to employment. Without this data or any funding, autistic job-seekers remain marginalized in our province.

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.

For this reason, many communities in the United States discontinued sheltered workshops and replaced them with positive alternatives. Following this lead, the former Government of Ontario under the Liberal Party [decided](#) to close all “sheltered workshops, [effective January 2019](#).

Unfortunately, with a new (Progressive Conservative) majority recently elected to Ontario Parliament, this legislation is now under attack by regressive forces in our province and it is unclear if the sheltered workshops will close in January.

The Torchlight sheltered workshop, which has been scheduled to close in 2019, [states](#) its purpose as: “to establish and operate workshops and sheltered workshops for the purposes of providing treatment, education and vocational training for handicapped persons.” But a Toronto Star [investigation](#) showed that in sheltered workshops, the workers were doing the following: “building wooden crates for 50 cents an hour; packaging student exam care packages for a few pennies each; and assembling windshield wiper tubes for roughly a nickel a piece.”

As *Globe and Mail* columnist Andre Picard [has written](#): “What these workers – who by all accounts do their jobs well – need is not pity, but respect. They need to be afforded the same rights as other Canadians, including the protection of the country's labour laws.”

We 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, noting that they have been phased out successfully in many parts of the US. As it stands, all of our organizations are bracing for a fight to keep them closed in 2019.

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 liberty of movement and 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 living.

One potential path to housing independence is social assistance. The Ontario Disability Support Program (ODSP) was created in 1997, as was the welfare-to-work program known as Ontario Works (OW). However, the amount of support the program allow guarantees that many recipients remain in a cycle of poverty. The 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. In fact, the current ODSP rates [do not cover](#) average basic needs. A recent [report](#) by the Daily Bread Food Bank indicated that people with disabilities on ODSP represent a growing proportion of those who require emergency food supports from food banks.

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. Currently an ODSP recipient can earn only \$200 in any month without penalty. Anything over \$200 gets “clawed-back” at a rate of 50 per cent. While the maximum allowable earnings were scheduled to be doubled, this change was “paused” by the former government and the new government shows no sign of enacting that change.

Poverty is a reality for many autistic, IDD and/or disabled Canadians. It is a health and human rights issue impacting every aspect of life. As psychology professor 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.

Overall, our adult population is invisible in government and policy. The portfolio for “autism services” is held by the *Ministry of Children and Youth Services*. The image of “autistic” in our province’s autism-related documents are young children, the “pay nows”. Have autistic youth and adults been dismissed as “pay lateres” and thus rendered invisible in programs and services? What is the larger impact of this on our communities?

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. We have also heard from case workers about human trafficking in Toronto homes, where vulnerable youth are targeted. Sexual and other physical abuse by staff is not effectively prevented nor dealt with uniformly, as there is almost no regulation or accountability. 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.* Given the rich diversity of service providers, the applicability of universal indicators across sectors may be limited, although the Panel believes that some foundational indicators can be articulated.”* (emphasis added.)

In 2015, when 17 year old Justin Sanguiliano [died after being restrained](#) in a group home, Child Protection authorities concluded that neither criminal charges nor an inquest were warranted. “It is stunning to me how these children... are rendered invisible while they are alive and invisible in their death,” said Irwin Elman, Ontario’s independent advocate for children and youth. Elman was unaware of Justin’s death until informed by the *Star*.

Elman authored an excellent [report](#) by the Provincial Advocate for Children and Youth’s office on youth in residential care. It covered many issues, including the arbitrary and unregulated use

of restraint. The report noted: “Punishment seemed to be applied without explanation or any attempt to understand the reasons for the young person’s behaviour. We were told that in many cases staff never asked ‘why’ and just administered punishment.”

According to the Report: “The issue of the use of restraints and what the system calls ‘serious occurrences’ says more about the culture of a residential setting and the level of skill of staff than it does about the young people themselves.”

One former group home resident who [went public](#) shared his story about a staffer who “would try to pick fights. He knew that if these kids punched him, he would have the right to restrain them and he would use excessive force. He would bang their head up against the floor and they would be bleeding.” Bullying and restraint by staff was common in 3 of the 4 homes he was sent to in a year. “It was very scary,” he said. An autistic girl who also [spoke to](#) the *Toronto Star* told of being neglected and locked out of her group home. She is now struggling with PTSD.

As the Panel report suggested, solving the problems in our residential care system starts with clearer standards and regulations. Safer and more user-friendly reporting mechanisms would be incredibly beneficial as well. As one youth stated in the Provincial Advocate’s Report: “Who do you report to when you don’t know who to report to?” Children told the Advocate’s office that they were not made aware of their rights and did not have the information to self-advocate. “They were not just unaware of the Office of the Provincial Advocate for Children and Youth, but unaware of any individual who would be interested in speaking up for them or acting on their behalf.”

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 punitive approach to autistic “behaviours” has remained a reality long after Ontario’s residential institutions closed. The needs of autistics in residential care has not been studied in any depth, nor have autistic group home residents been surveyed as a demographic to understand whether their communication and sensory needs are being met.

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.

The future: Institutional retrenchment or autism acceptance?

This week, Ontario Premier Doug Ford introduced the possibility of re-opening sheltered workshops. Somehow, we knew this was coming. The long-due closure of sheltered workshops was a key element in the 2015 *Fair Workplaces, Better Jobs Act* (Bill 148) passed by the former government. The sheltered workshop closure was phased, set to complete in January 2019. It remains to be seen what the new rollbacks in labour laws will look like and how it will impact our lives.

The new government's dismissal of Bill 148, like so much other legislation, points to the trend of retrenchment, favouring business interests over the needs of residents while saying that the changes are being made "for the people," (a popular talking point of Ford Nation). Sheltered workshops (like the farms at Huronia) make a profit for the business at the expense of the employees. Yet as with the fields of Huronia, workshop owners portray an opportunity for development and "training", a favour being done *for the employees*.

In 2018, this patronizing rhetoric feels as gaslighty as it likely did to our forebears in residential institutions. Workers in sheltered workshops do not have the same freedom of movement and economic choice as other workers. The jobs don't advance them. Their rights are not being honoured. Sheltered workshops should have been closed here years ago. When will they be?

What is going on in our province right now? How do we, as rights advocates, steer this boat?

We've started by collaborating and communicating with agencies that are open to change, that will listen. At the same time, we are also making our presence known in spaces where most [don't want to see or hear us](#). We are building capacity within our own communities and dialoguing to understand our diversities and intersectionalities. We are working to give a broader legitimacy to autistic voices throughout Canada – in [media](#), in the non-profit world and in policymaking. We're getting the facts out there and having hard conversations, [joining](#) on common issues wherever we can, and glad to see other groups joining us.

Despite the negative political climate in Ontario, the conversation about neurodiversity is opening up in the broader culture. Globally, autistic self-advocates and researchers are disrupting the autism industry, claiming space as agents for the ideas--and the data--that will move us in a positive direction. Increasingly, [autistic self-advocacy groups](#) and autistic researchers are [advising](#) not-for-profits and policymakers as part of best practices. Autistic researchers are also [gathering information](#) on the many topics that matter to us but haven't been studied. Self-advocates and researchers have also had success in building project partnerships that fall completely outside of the industry. A recent research example here is the AIDS Committee of Toronto partnering on one of the first-ever [studies](#) of autistic sexual health, developed by an autistic researcher with input from the community.

We disagree with Coker Capital group, which [describes](#) the autism industry as "poised for consolidation". As it stands, the autism industry [generates billions](#) for companies worldwide, but attempts at consolidation (as is [happening in Ontario](#) with ABA dominance) have led to disastrous breakdowns in useful supportive services. **Just two per cent** of autistic people support the use of ABA, making it a true standout as a therapy being forced on a disabled population that doesn't want it.

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. Services for autistics need to be flexible and diffuse.

In contrast to the medical model, consider the flexible approach that reflects [autism acceptance](#) and the [social model](#). It includes innovations such as inclusive design in classrooms, sensory-friendly spaces, improved workspaces for retention, as well as meaningful study of our demographic group, human rights regulation and enforcement, de-escalation alternatives & trauma-informed care, autistic inclusion in social assistance and jobs legislation, and education for teachers, providers and policymakers that is informed by autistic people. These are all being implemented by governments and non-profits outside of Ontario.

But Ontario remains mired in the idea that services for autistics should be delivered in a consolidated, top-down package. That idea isn't working. And the stakes are high for our community. Many of us are poor, in pain, and not receiving the services we need. Still others are victims of horrific abuse, patterns that trace back to the era of residential institutions.

The government of Ontario needs to tap into the energy and creativity of the [neurodiversity](#) movement. Our policymakers must engage *less* with the autism industry and *more* with the actual stakeholders. The Province needs to document, understand and take action to prevent human rights abuses through regulation and enforcement, while making it easier to report abuse and encouraging transparency. Finally, the Government needs to engage autistic Ontarians in meaningful consultation as it develops the policies that deeply affect our lives.

Appendix 1

Contact information for institutions that are accused of human rights violations, in the Greater Toronto Area

[this section redacted for public version]