# Who Speaks for Autism? Unpacking media bias in the *Toronto Star's* Ontario autism policy coverage

"When the advisory panel was announced this week, some parents criticized the inclusion of adults with autism who oppose ABA therapy. ... 'I have some serious concerns because I have had personal interactions with them over social media and I know them to be anti-science and anti-ABA,' [a] Windsor father said."

-The *Toronto Star*, <u>covering</u> the story of autistic people being on an Ontario autism policy advisory committee for the first time in history

## Organization of this paper

We examined the *Toronto Star's* coverage<sup>1</sup> of the Ontario Government's autism funding decisions between January 1, 2019 and August 28, 2019 around the autism policy funding package known as the Ontario Autism Program (**OAP**). We looked closely at who the *Star* spoke with (and who they didn't speak with); what therapy they referenced (and what therapies and services they didn't reference); factual errors/myths (and how often they were repeated); and how People of Colour, non-verbal people, and autistic self-advocates generally were drastically underrepresented by the *Star*.

We chose the *Toronto Star* in part because it is Canada's <u>highest-circulation newspaper</u> on overall weekly circulation, with about 300,000 readers. It also represents the Canadian province/territory with the largest population (Ontario), which is also the seat of Canada's federal government.

We looked at 39 news articles written between January and August of 2019, as well as 2 editorials by the *Star* and 1 commentary by a pro-ABA lobbyist (for a total of 42). Based on this review, we discuss how the *Star's* representation of autism policy appears to pivot on three myths:

- 1. The myth that ABA<sup>2</sup> is the only true therapy for autism -- and that the solution to any autism policy issue is to give more funding to ABA;
- 2. The myth that white, middle class parents are *the* authoritative voice of the "autism community"; and

<sup>&</sup>lt;sup>1</sup> We focused on autism policy news articles, excluding the *Star's* other autism coverage (about scientific research at the children's hospital, for example), to stay focused on the policy discussion. We reviewed 39 news articles, 2 OpEds written by the *Star* and 1 *Toronto Star* OpEd from a lobby leader.

<sup>&</sup>lt;sup>2</sup> ABA, which stands for Applied Behaviour Analytics, is a radical behaviourist ideology that values the use of extrinsic motivators (rewards/punishments and repetition) over developing connections with autistic children. ABA has never been tested in a random control trial and does not meet the standards for the definition of "scientific," which is why the field instead uses the term "evidence-based". Its evidence is founded on anecdotal parent reports and sometimes the misconception that an autistic child can be his/her own RCT.

3. The myth that inclusion is a burden and that positives of inclusion aren't worthy of coverage. This myth that is incredibly damaging to disabled children and all disabled people and we cover it in depth.

All three myths direct to the bigger fiction the *Star* always rounded back to: that the singular "solution" to any autism policy challenge is to *give autistic people more ABA*.

<u>Basic Background: Expanded Service Choice</u> At the time we studied, the Government of Ontario was debating a move from an autism-funding system that had **exclusively** funded ABA, to one that would also fund therapies and services such as occupational therapy, speech and language therapy, and assistive communication technologies/AAC —what we call the "expanded service choice" approach.

While the move towards expanded service choice was a key aspect of policy discussions, the *Star's* reporters didn't speak to any professionals working in any of the fields being discussed other than ABA, nor did it have meaningful discussions with autistic people, the end users of expanded services. In fact, it never defined the changes nor explained them to readers. The *Star's* coverage consistently favoured the view of one industry (ABA) to the point where its coverage was, by all appearances, biased against the expanded service choice approach.

<u>Background: No Diversity of Voices</u> The *Star* also did not speak to a representative number of families of Colour, nor low-income families. Only 3 parents interviewed were of Colour, comprising just 6% of parents interviewed, even though people of Colour represent 51% of the demographic of the Greater Toronto Area.

The *Star* did not interview any non-verbal people (even though the new AAC option affects non-verbal people directly) and it only interviewed 4 autistic people, even though autistic people are the end users of the services being covered. The *Star* only once spoke to a community member who supported the expanded service choice approach and it didn't speak to a single professional in occupational therapy or speech language pathology, despite their being newly included in the expanded services approach.

<u>Background: School Inclusion</u> Further, the *Star* reinforced a segregated model of services in its coverage of inclusion and mainstreaming in schools<sup>3</sup>. While school inclusion is a key indicator for our life outcomes--and Ontario has the highest rate of segregation for disabled students in all of Canada—the *Star*'s only coverage of an increase in autistic student inclusion in 2019 was to frame it as a "untenable situation" for teachers. To this extent, the *Star* offered safe haven for educational segregationists without the balance of *even one* pro-inclusion voice. The *Star* did not quote a single school inclusion expert through this period.

<sup>&</sup>lt;sup>3</sup> This follows Ontario's ABA approach, which is rooted in segregation and stigma. From the age of 2 or 3, many autistic children are segregated from their peers and put into full-day institutions (IBI centres). When they reach school age, they and their peers don't know each other--nor now to communicate with each other--so unsurprisingly they cannot succeed and are often streamed into segregated special education classes, full or part time, managed by ABA staff. They graduate from segregated education into segregated lives, tracked into segregated institutional living situations and segregated employment/unemployment. Read this Ontario Human Rights Report to learn more about patterns of segregation for autistic Ontarians.

When readers <u>contacted</u> the *Star's* Public Editor and City Desk to raise concerns about factual errors in its autism policy reporting, neither desk ever even responded to their emails!

In our opinion, the *Star* was compromised in its ability to provide a reasonable balance in its coverage of Ontario autism policy in 2019, because it used as its sole "expert" source a lobby group that is focused on getting public funds allocated exclusively for its service product (ABA). In this sense, the *Star's* coverage is a case study in what happens when a media outlet's sole "experts" *are also selling something*. It is also an exploration of what happens when a media outlet covers an issue without representing major stakeholders--and how falling back on familiar sources can make coverage morph from news into commentary.

For these reasons, we see this as an instructional tool about bias, and what to do about it. We hope it will bring about a broader discussion, one that will lead to fairer coverage about disability.

## Section 1: Summary of Findings, Background into the Issues

We start with a summary of possible bias in the *Star* during the studied 8-month time period. Following, our charts. (For a list of the articles we reviewed, see Appendix 2).

## **ABA Dominance**

- The *Star* focused exclusively on one specific therapeutic approach to autism (ABA) and did not describe or educate readers on any non-ABA services and therapies being presented in the new funding model;
- **Non-ABA autism therapists were never interviewed** by the *Star*, whereas ABA therapists (also known as BCBAs) often were;
- When the government proposed funding for SLP, OT and AAC technologies<sup>4</sup>, the *Star* **did not interview any SLPs, OTs or AAC experts**, instead continuing to rely on BCBAs for "authority" in these areas outside their discipline; and
- **ABA was the only autism therapy or service ever discussed** by any of the opposition politicians that the *Star* chose to interview.

<sup>&</sup>lt;sup>4</sup> SLP or "speech language pathology" is a service where professionals known as SLPs treat patients with speech, language, cognitive-communication and swallowing disorders. OT, or "occupational therapy" teaches activities required in everyday life, such as getting dressed, preparing food and using a pen to write. AAC, or Augmentative and Alternative Communication is an umbrella term that encompasses the communication methods used by non-verbal people, such as assistive technologies, sign language and other methods. About 25-30% of autistic people are non-verbal or semi-verbal.

#### The "Voice of the Autism Community"

- The *Star* **privileged one voice as representing the "autism community"** that of two non-autistic, white parents (the McIntoshes).
  - The McIntoshes represent an ABA-focused lobby called the Ontario Autism Coalition, OAC.
  - o Laura McIntosh is the President of the OAC.
  - o Bruce McIntosh is its past President and an active <u>member</u> of Ontario's professional association of ABA providers, ONTABA.
  - o 2/3 of parent quotes in the *Star* were directly from either Mr. or Mrs. McIntosh.
- Of the subset of non-McIntosh parents interviewed, 2/3 of those parents were members of the ABA-focused lobby group (Ontario Autism Coalition) over which the McIntoshes have presided for years.
- Only 3 parents of Colour were interviewed in the *Star* autism policy stories, representing less than 10 per cent of parents interviewed, although people of Colour comprise 51% of the Greater Toronto area.
- Of 52 community members interviewed in *Star* coverage, **only 4 were autistic adults. Only one autistic person of Colour was interviewed**--a six year old boy--although at least 51% of our community here is non-white.
- **Zero non-verbal autistic people were interviewed**, although 25-30% of our community is non-verbal or partially non-verbal.
- Of the 4 autistic adults interviewed, **3 were members of the ABA-focused lobby** (OAC).
  - This misrepresents the strong presence in our province of autistic groups who do not lobby for ABA and a well-established concern<sup>5</sup> within the autistic community about ABA.

## Safe Haven for Segregationists

• In 2019, the *Star* **never interviewed a single school inclusion expert** in it autism policy reporting, nor did it represent any positive elements of the school inclusion plan.

• The *Star* referred to 1,000 newly-mainstreamed autistic children into Ontario schools (which is **less than one child per school**) as an <u>"influx"</u> and an <u>"unsustainable burden,"</u>

<sup>&</sup>lt;sup>5</sup> In <u>this survey</u> of 11,000 people from one of the most widely popular autism support pages internationally, less than 10 percent of autistic people had a favourable view of ABA. Also notable that there is no autistic self-advocacy group in the world that endorses ABA. As the end-users of that system, our views about it--and our ideas for alternatives to it--matter.

creating stigma around mainstreamed children and never speaking to any experts on mainstreaming or even defining the term.

- When the government discussed de-silo'ing autism funding to address the socioeconomic realities of autistic Ontarians throughout the lifespan, the *Star* did not report on this crucial discussion and **continued to focus on ABA**.
- When an "income-tested" system of autism funding was proposed, the *Star* ignored low-income as a genuine reflection of need, never addressing equity nor speaking to even one low-income family about the impact income testing would have had on their access to services.
- When two autistic people were appointed to the government's autism stakeholder committee (a 20-member group), the *Star* called the autistic panelists *outsiders* from "an <u>anti-science</u> group" and **didn't interview the autistic panelists**.
- When people <u>notified</u> the *Star's* Public Editor and City Desk about factual errors in its representation of the autistic panel members, the **Public Editor and City Desk did not respond to the emails**.

The result of these and other editorial decisions was an overarching story that pivoted on a false dichotomy (the Tory government *vs* "parents") and a phony solution (more government funding for ABA and no funding for anything else). The *Star's* simplistic story about autism was read by hundreds of thousands of Ontarians who were left with **the false impression that the main need of autistic people in Ontario is more ABA**.

In real life, the solutions to the problems our community faces (ableism, racism, lack of access to communication technology, crushing poverty, higher rates of suicide, etc.) aren't solved by more public funding for ABA<sup>7</sup>. Indeed, they aren't solved by any commodity or specific brand of service. And the lobby for ABA *doesn't represent* – and shouldn't be – the voice of autistic Ontarians.

## Recent Background: The Politics of ABA, 2017-18

The most well-funded and organized group of autism service providers in Ontario is the Ontario Association of Behaviour Analysts (**ONTABA**). It is the professional organization and official voice of ABA therapists in Ontario (often known as BCBAs).

<sup>&</sup>lt;sup>6</sup> Income testing (or means testing) is a determination of whether a person or family is eligible for government assistance, based upon whether they possess the financial means to do without that help. Canada uses a mixture of means-testing and universal benefits (its opposite). For example, our health care is universal, but access to legal aid, student assistance, the Child Benefit Plan and social welfare (including most disability supports except ABA) is based in part on economic need. Income testing is non-partisan. While the Tories suggested it here, the Trudeau (Liberal) administration also rolled out new income-tested models on a former Tory government's mandate that had been universal when it changed the amounts of the Child Benefit. The Trudeau government is also phasing out the child disability benefit at a rate of 3.2% on adjusted family net income in excess of \$65,000, based on means testing via Revenue Canada.

<sup>&</sup>lt;sup>7</sup> To understand some of the reasons why, read Autistics for Autistics Ontario's <u>statement</u> about ABA.

Searches of the government's <u>database</u> of provincially-mandated lobbyist disclosure shows that ONTABA hired the **Pathway Group**, a Bay Street lobbying firm, to lobby<sup>8</sup> 4 Ministries about ABA. One of the Ministries lobbied was the Ministry of Children and Youth Services, which managed the Ontario Autism Program, the governmental body that made policy for and distributed funds in relation to autism services. The Pathway Group also lobbied 5 MPPs, identified by titles (e.g., "**Office for the Member for Hamilton Mountain**").

No other autism service providers hired a lobby firm around OAP, nor did any other autism interest group, according to the public record.

In the wake of ONTABA's lobbying efforts, a new **Ontario Autism Program (OAP)** was launched in 2017 by then-Minister of Children and Youth Services, Michael Coteau (a Liberal MPP) and supported by Premier Kathleen Wynne<sup>9</sup>. Under the new plan, only ABA services were to be funded, with an initial investment of \$500 million for ABA, distributed to families via the social services system. Under the plan, a child's need and degree of therapy "required" was to be determined by an ABA practitioner.

Services that were **not funded** in the 2017-18 OAP included:

- Assistive technologies for non-verbal autistics (AAC)
- Speech language pathology
- Non-ABA occupational therapy
- Physical therapy
- Any other science-based services and therapies that didn't fall under the rubric of ABA (such as DIR Floortime, RDI therapy, SCERTS training, RPM therapy, etc.)
- Services for autistic adults

This is also important: The 2017-18 plan reached just 25% of autistic children due to the high cost of the specific service (ABA), leaving 3 out of 4 without the ABA services that their parents had signed them up for—a waitlist of 23,000 children. The main reason for this was the high costs of services, at up to \$110,000 per year for one child. As well, the 25% figure only accounts for families that sought ABA, but there were also countless families who sought other services instead of, or in conjunction with, ABA (which would make the percentage of children served even lower than 25).

Although non-ABA providers, parents and autistic people in Ontario expressed opposition to the 2017-18 plan, those stakeholders did not made the news in the *Star* in 2017-18. Instead, the "ordinary parents" that the *Star* mainly focused on were a couple that ran Ontario's parent lobby

<sup>&</sup>lt;sup>8</sup> Pathway stated the purpose in its Disclosure as contracted by ONTABA for the purpose of "advocating for and educating government officials of the services they perform and how the government can include them [ONTABA] in policy." Although some in ONTABA have claimed that Pathway was hired to lobby mainly for self-regulation of the industry, Pathway's <u>disclosure forms</u> describe its subject matter as a "legislative proposal," only choosing the box for Policy. (The Form reads: "Bill or resolution: No; Regulation: No; Policy and/or program: Yes.")

<sup>&</sup>lt;sup>9</sup> To note for transparency: Premier Wynne's <u>wife was an</u> interim director for one of Ontario's largest ABA centres and consulted with ABA centres.

for ABA (the Ontario Autism Coalition, or **OAC**): Bruce and Laura **McIntosh**. Bruce McIntosh is a <u>member</u> of ONTABA, the lobby group of Ontario's ABA therapists. 2/3 of parent quotes in the articles during the time period studied were by Bruce or Laura. Combined with the fact that 100% of therapists quoted were ABA therapists, that translates into a one-sided, one-industry perspective on the complex topic of autism policy wherein the *Star* presented a falsely simplistic view to readers with an implicit bias via omission--that ABA is the only "legitimate" service for autistic people.

Although there are many therapies that work well for children, the *Star* stayed fixed on the <u>talking point</u> that "children with moderate to severe autism require \$80,000 of therapy" per year. (In fact, out of 38 news stories it ran, the *Star* referenced that talking point <u>22 times</u>.) In fact, ABA is the only therapy that charges anything close to that amount, so the \$80k figure <sup>10</sup> was a reference to it.

A reader would assume, if they trusted the *Star's* coverage, that \$80,000 ABA is the only "evidence-based" approach to autism and that, as MP Roman Baber <u>put it</u>, budget constraints mean the government "will have to ration the number of children in treatment".

The problem with that assumption—that the only good care costs \$80,000 per year, and that within a typical budget the only answer is rationing expensive treatment among a small percentage of children—is that is not true.<sup>11</sup>

To say that the *Star* gave editorial "preference" to ABA is an understatement: **no other science-based**<sup>12</sup> **autism therapies or services were ever presented in the** *Star***. The ideology that ABA was the one-true approach to autism had become firmly entrenched in their reporting. As the** *Star* **wrote earlier in an editorial about intensive ABA therapy (sometimes called IBI):** 

"IBI essentially rewires the brain to improve its functioning. Children who get IBI as toddlers may have fewer or no symptoms [of autism] by the time they are 4 or 5."

That statement, which contains several errors, should have been fact-checked and either corrected or retracted. Yet it never was-- and myths like it were printed in the *Star* throughout 2018 and 2019.

<sup>&</sup>lt;sup>10</sup> The \$80k figure is so high that it could be argued that the only way to normalize or legitimate the figure is to repeat it a lot--while *never* repeating a statement such as: "Occupational therapy, an evidence-based approach that teaches a child life skills and makes parents a partner by giving them skills to continue the teaching at home (as is the norm in the UK) costs \$150 per session, for an average cost at two sessions per week of \$15,600 the first year and \$7,800 in subsequent years". Because if ABA's costs were presented in contrast with evidence-based practices like OT, they would appear exorbitant and not at all normal.

<sup>&</sup>lt;sup>11</sup> Please see <u>this article</u> for basic discussions about science-based alternatives to ABA. For a good discussion about the claims of ABA proponents that it is the "only way"/ a miracle cure, please see <u>this article</u>.

<sup>&</sup>lt;sup>12</sup> We use the term *science-based* and *science/evidence-based* intentionally. Science-based approaches use scientific methods such as random control trials (RCTs, <u>defined here</u>). RCTs, a foundation of good science, have never been used in any ABA research. "Evidence-based" is a weaker claim that anyone can make if they have collected any kind of evidence; in the case of ABA, the evidence in the research is largely anecdotal parental reports or developmental changes that can and do happen with or without the intervention.

## 2019: A policy shift

A sudden policy shift around ABA funding in Ontario occurred when the Tories took power from the Liberals in the provincial election of June 2018. One of their first acts was to assess existing spending. They offered audits to cities and school boards <sup>13</sup> for example. In reviewing the OAP, the new government decided the current policy was not sustainable and needed an overhaul <sup>14</sup>. The new government began to develop a plan that would fund programs other than ABA and proposed a model based on income-testing <sup>15</sup> to bring more families into the system quickly, with less government funding allocated to wealthy families <sup>16</sup>. The new government also sought to end the silo'ing of autism services, by spreading the mandate among different ministries, rather than just Children and Youth Services, as it had been.

They soon found it impossible, however, to get ABA interest groups to support the plan, since the new government sought to fund to some non-ABA services. As Derek Rowland, spokesperson for Lisa MacLeod, then-Minister of Children and Youth Services <a href="mailto:said:">said:</a> "Despite collaborative dialogues that took place over six months of consultation, ONTABA was unwavering in their desire to self-regulate and unwilling to work with government to open up the sector to provide parents more choice in support services for children with autism."

ABA interest groups critiqued MacLeod's plan from their virtual parking spaces in the *Star's* news section. ONTABA demanded that MacLeod apologize what they viewed as "bullying". A BCBA<sup>17</sup> Louis Busch told the Star he had Tweeted the following to MacLeod: "I will accept your apology when you restore funding to all children with autism at the level they need and deserve." Laura Kirby McIntosh, the president of OAC, the pro-ABA parent lobby, told the Star: "This is real trauma she [Minister MacLeod] is causing."

While acknowledging that the former government's plan had provided services for just 25 per cent of autistic children and that the new government's program would serve more, Monique Taylor (MPP, Hamilton Mountain) described the new government's current redistribution like this to the Star: "Now you are giving 100 per cent nothing<sup>18</sup>. It doesn't make sense." (emphasis added. The Star Editorial Board echoed the BCBAs and MPP Taylor in an editorial against the income-testing and the MacLeod ministry, giving this rather enigmatic statement: "All the government has done is to distribute the current \$321-million budget for autism services among

<sup>&</sup>lt;sup>13</sup> 90% of eligible Ontario cities and 2 school boards took them up on it.

<sup>&</sup>lt;sup>14</sup> According to Premier Doug Ford: "When we came into office, we saw a bankrupt system when it comes to supporting families of children with autism. We had to run to the president of the treasury board ...to keep the system going. Then, when we looked into it even further, we saw systemic problems throughout the whole system." <sup>15</sup> For a definition of income testing (or means testing) and its use in Canada, see Footnote 6. Income-testing is used for most social services; however the former government instituted a new, universal system for autism services, with need determined by individual assessments by BCBAs. For discussion of the various equity issues around that, please see the Media Bias section at the end.

<sup>&</sup>lt;sup>16</sup> Under the former plan, families earning more than \$250k had all their ABA therapy expenses covered by the government under a universal model.

<sup>&</sup>lt;sup>17</sup> A BCBA is a person who is licensed to practice ABA.

<sup>&</sup>lt;sup>18</sup> Her statement is factually incorrect. 100% of nothing is zero and the program allocated \$309,000,000 annually, an amount which is greater than zero. The number 1 is also greater than zero and the new plan allocated an amount that was 309 million times greater than 1.

## far more people. 19",20

By contrast, in the <u>words</u> of the Minister: "This is the best option to get every, single child some level of support from the Ontario government." The potential new plan (which wasn't clearly explained in the *Star*), based on income testing<sup>21</sup> considered economic need as a factor for the first time, providing more funding for poor families and an income cut-off point (\$250k) for funding.<sup>22</sup> It offered OT and SLP funding, unlike the old plan. As well, non-verbal youth and their families could for the first time receive funding for technologies for assistive communication (AAC) in the OAP (a change that the Ontario Autism Coalition officially <u>opposed</u>).

Meanwhile, autistic stakeholders were invited to consult as stakeholders by the new government-who followed in the footsteps of Scotland, England, Ireland, Australia, New Zealand and other countries by including autistic people in policy discussions. In spring and summer of 2019, autistic individuals met with Ministers, did research and drafted reports to the new government, and talked with representatives about their lives, realities and ideas. Also, two autistic Ontarians began sitting on the government's official stakeholder panel as the government discussed reforming its model of autism services, a ground-breaking equity decision that was long overdue.<sup>23</sup>

Media such as CBC Radio and Accessible Media Inc. (AMI), reported the news. AMI did a feature about self-advocacy in the context of the panels, and CBC was thorough as well as talking about school inclusion as a policy issue. In reaching out to autistic panelists, they followed the <a href="mailto:mandate">mandate</a> of the Society of Professional Journalists to seek out unheard voices and to "boldly tell the story of the diversity and magnitude of the experience."

By contrast, the *Toronto Star* didn't report news: it editorialized with a negative spin about autistic people being invited to serve on the Ontario consultation panel. In fact, one of The *Star's* main sources for that coverage was an OAC member who regularly tweets against the neurodiversity movement: "I have some serious concerns because I have had personal interactions with them over social media and I know them to be anti-science and anti-ABA," he told the *Star* about the panelists. That was the beginning and end of the *Star's* coverage about autistic people being a part of the government consultation panel.

<sup>&</sup>lt;sup>19</sup> If you take the same sentence and substitute the word "All" with the word "What", you get a factual statement. Try it and see what the resulting conclusion is: a piece of information, instead of a rhetorical game.

<sup>&</sup>lt;sup>20</sup> The *Star* described the income-tested model as "such a ridiculous notion that the government couldn't even keep all its own people onside for a single day," referring to former OAC President Bruce McIntosh, who had quit his post in an MP's office in protest.

<sup>&</sup>lt;sup>21</sup> See note 6 for definition. The move towards income-testing fits within the broader context of austerity and follows the model for the bulk of social services in Canada, including disability supports. One form of equitable campaign would oppose income-testing for *all* disability services and programs; however ONTABA only argues for universal coverage to apply to its own services.

<sup>&</sup>lt;sup>22</sup> Under the 2018 plan, a child's "need" was determined through "needs assessment sessions" with a BCBA--a plan that ONTABA and the OAC still advocate.

<sup>&</sup>lt;sup>23</sup> It has been a quarter-century since Ontario de-institutionalized its IDD population, but de-institutionalization was unrolled during those two and a half decades without consulting autistic people.

In some ways, the *Star's* approach towards disabled voices was no surprise. As disability writer Amiee Louw <u>writes</u>, coverage related to neurodiversity too often "only featuring the perspectives of parents or family members of a disabled person about their life. This is patronizing and results in limited coverage." Wendy Porch of the Centre for Independent Living in Toronto (CILT) adds: "It is not the same thing to talk to the parents of a person with a disability as it is to talk to the person with the disability themselves."

To illustrate the scope of the problem, we will next present our data, followed by breakouts/analysis and recommendations.

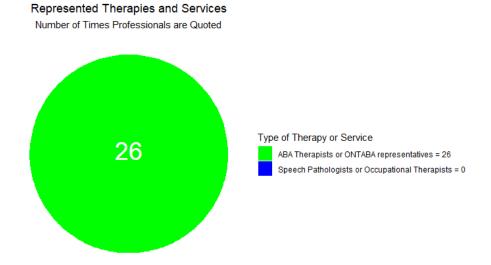
## Part 2: Data in Graphic Form

The following data is for the time period between January 1 and August 26, 2019, in *Toronto Star* news articles about changes to the public funding policy for autism-related services, the Ontario Autism Plan<sup>24</sup>. We focused on autism policy news articles, excluding the *Star's* other autism coverage (about scientific research at the children's hospital, for example), to stay focused on the policy discussion. We reviewed 39 news articles, 2 OpEds written by the *Star* and 1 *Toronto Star* OpEd from a lobby leader.

#### Dominance of ABA in Star coverage

One type of service, ABA, was presented in the *Star* as the only valid service, even as the government began to discuss funding for others, such as AAC, OT, SLP, RDI, RPM and FDM.<sup>25</sup>

Figure 1: Represented Therapies and Services



ABA represented AAC, OT, SLP, RDI, RPM and FDM represented

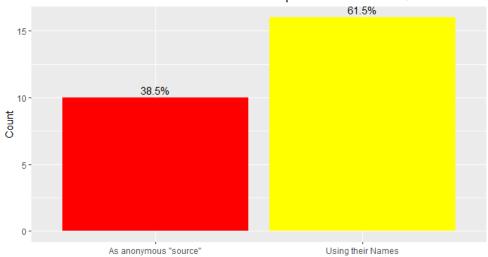
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<sup>&</sup>lt;sup>24</sup> See the bibliography for all articles accessed.

<sup>&</sup>lt;sup>25</sup> See Appendix 1 for definitions of these services and resources.

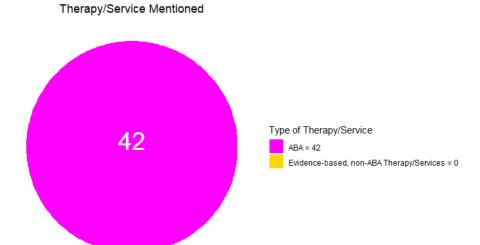
Figures 2-3: Therapists Quoted

Number of Times BCBAs and/or ONTABA Representatives Were Quoted...



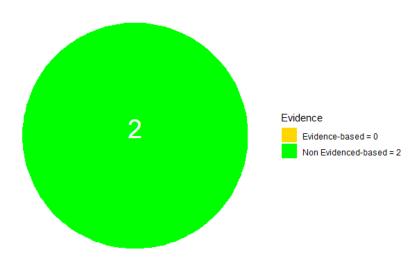
Note: These figures exclude reprinted info from ONTABA press releases

100% of therapists quoted were ABA therapists, with a high representation of anonymous quotes.



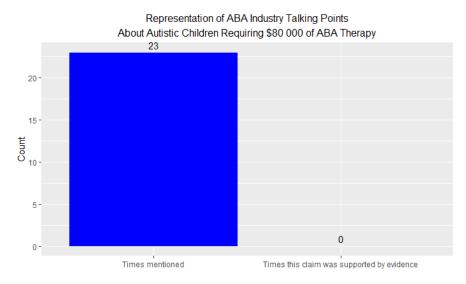
No evidence-based autism therapies were described during the time period-studied.

Figure 4
Non-ABA Therapies/Services Mentioned



Non-ABA evidence-based autism therapies or services mentioned: 0 Non-evidence based autism therapies mentioned: 2 times (dolphin therapy: 1, diet therapy: 1)

Figure 5



Times that ABA industry talking point about "autistic children requiring \$80,000 per year of ABA therapy" stated in the *Star*: 23. Times the talking point was backed by evidence: 0

## Voice of the "Autism Community"

As mentioned, Bruce and Laura McIntosh are the couple who lead the OAC (a parent group that lobbies for ABA) and Bruce is an active <u>member</u> of ONTABA, the lobby group for ABA providers. The McIntoshes were over-represented in *Star* coverage, with more than 60% of

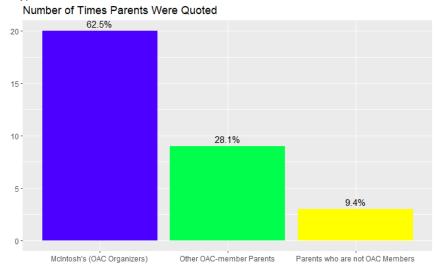
parent quotes attributed to them.

When other parents were interviewed, OAC members were still over-represented by a ratio of 2 to 1.

People of Colour, non-verbal and autistic people in general were severely under-represented.

No parent-led groups were referenced other than the OAC.

Figure 6



Times the McIntoshes (OAC organizers) were quoted: 20

Times other OAC-member parents were quoted: 9

Times parents *not* in the OAC were interviewed: 3

Figure 7



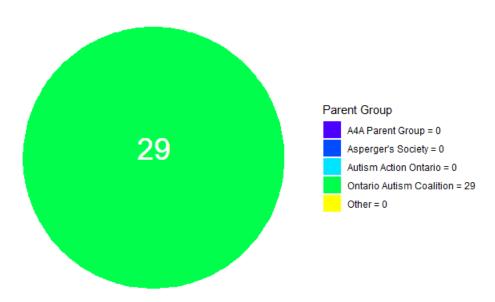
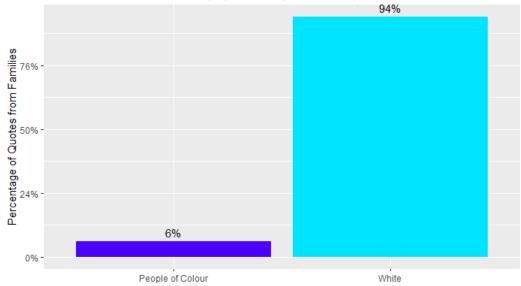


Figure 8

## Ethnic Makeup of Families Quoted

(Represented by Total Quotes)

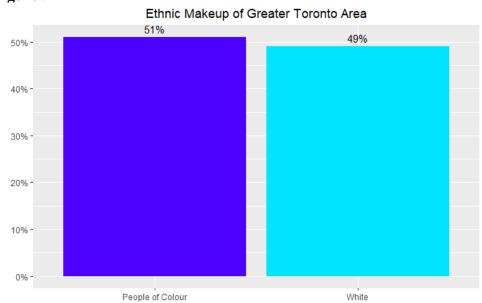


Ethnic makeup of families quoted (represented by total quotes).

White: 94%

People of Colour: 6%

Figure 9

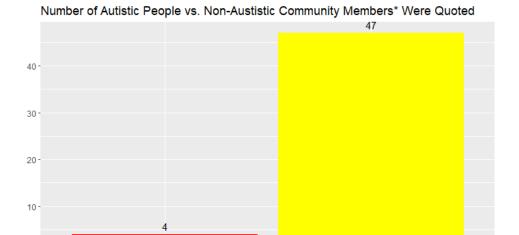


Ethnic makeup of the Greater Toronto Area

White: 49%

People of Colour: 51%

Figure 10



\*includes BCBAs, but not ONTABA spokespeople or official IBI/ABA centre representatives

Non-autistic community members\*

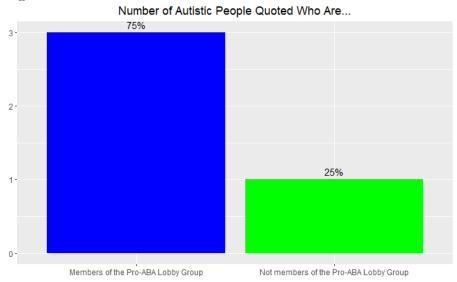
Times autistic people were quoted: 4

Times non-autistic community members were quoted\*: 47

Autistic People

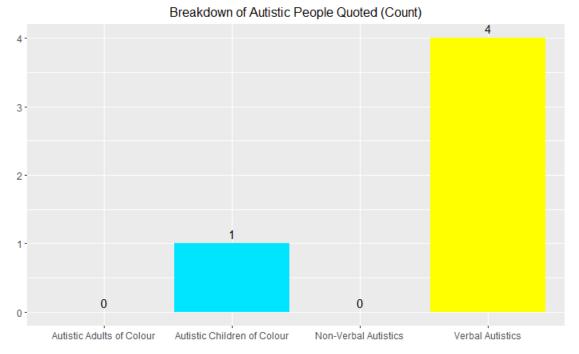
\*includes BCBAs, but not ONTABA spokespeople or official IBI/ABA centre representatives.





Number of autistics quoted who are members of the pro-ABA lobby group: 3 Number of autistics quoted who are not members of the pro-ABA lobby group: 1

**Figures 12 & 13** 

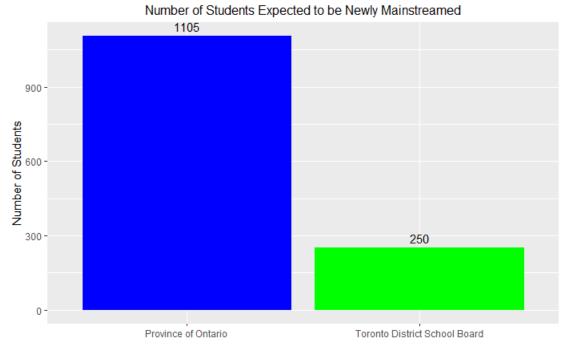


Number of times autistic adults of Colour were quoted: 0 Number of times autistic children of Colour were quoted: 1 Number of times non-verbal autistics were interviewed: 0 Number of times verbal autistics were interviewed: 4

## Safe Haven for segregationists

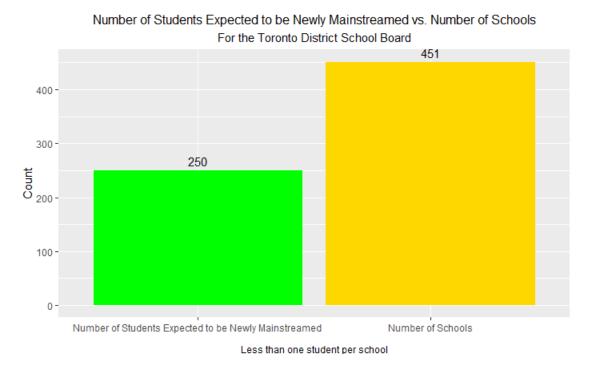
The *Star* consistently presented school inclusion as a "crisis" and never referred to inclusion and mainstreaming in positive terms. They never spoke to any inclusion experts or even anyone who was in favour of inclusion. While the number of mainstreamed autistic children was less than one per classroom, the *Star* promoted a panic about autistic inclusion by referring to it as an "influx" and a "burden" to teachers. The term *influx* was the *Star's* shorthand; used in nearly every article that discussed the inclusions.

Figure 14



Number of students expected to be newly mainstreamed in the province: 1,105 Number of students to be newly mainstreamed in the Toronto District School Board: 250

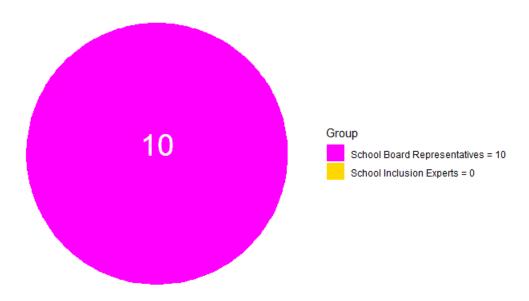
Figure 15



Number of students to be newly mainstreamed in the Toronto District School Board: 250 Number of elementary schools in Ontario: 451

Figure 16

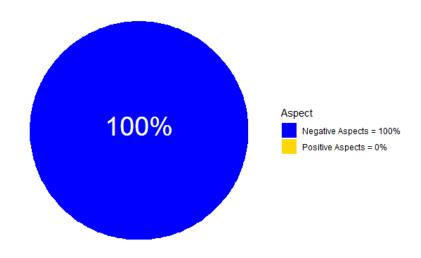
Number of Quotes about School Inclsion by...



Times school inclusion experts quoted on inclusion: 0 Times school board representatives were quoted on inclusion: 10

Figure 17

Articles Mentioning School Inclusion that Discuss...



Note: 10% of Total Articles on Autism Policy Mentioned School Inclusion

Percent of articles where positive aspects of school inclusion discussed: 0% Percent where alleged negative impact, e.g, "autistic influx" discussed: 100%

Note: School inclusion was mentioned in 10 per cent of articles on autism policy.

## Figure 18

## Terms the Star used to describe including less than one autistic child per school in Ontario this year

"the imminent influx of students with autism"

"downloading kids' behavioural therapy needs onto Ontario schools"

"an unsustainable burden on schools"

"educators are predicting chaos in the classroom as children with autism enter the school system"

## Figure 19

Terms the Star didn't use to describe including less that one new autistic child per school in Ontario
"equitable"
"inclusion"
"mainstreaming"

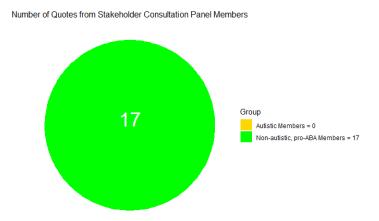
## Figure 20

Terms the <i>Star</i> used to describe autistic representatives who were being included for the first time in stakeholder consultation panels	Terms the <i>Star</i> did not use to describe autistic representatives who were being included for the first time in stakeholder consultation panels
"a group with an anti-science agenda"	"equitable"
"an anti-science group"	"inclusion"

[continued on next page]

Figure 21

## Chart 21



Number of times the *Star* quoted autistic members of the stakeholder consultation panel: 0 Number of times the *Star* quoted non-autistic, pro-ABA members of the stakeholder consultation panel: 17

Figure 22

Areas of policy that affect autistic Ontarians and number of times the *Star* referenced them in its news about Ontario autism policy

Communication Access: 0

Housing: 0 Employment: 0

Access to Health Care: 0

#### Discussion of data

#### **ABA Dominance**

Let's start with the zeros. *The Toronto Star's* coverage of autism policy centred on ABA as a therapy in 100% of articles on autism policy news. *The Star* mentioned the specifics of non-ABA evidence-based therapies or approaches zero times.

While the *Star* did reference the terms "OT" and "SLP<sup>26</sup>" 4 times, it was merely to state that these therapies would now be covered under the Tory government's new plan. **The newly-covered therapies were never defined or explained.** 

The number of OTs and SLPs interviewed by the *Toronto Star* about that change was zero. The number of other autism therapists interviewed by the *Star* that do not practice ABA was also zero. And although there are thousands of families in Ontario who use services other than ABA, the number of families the *Star* interviewed who sought funding for non-ABA approaches – including OT and SLP—was zero.

In the 42 *Star* articles, 100% of therapists interviewed were ABA therapists. BCBAs and ONTABA reps were interviewed 29 times.

The OAC, a pro-ABA lobby, was interviewed and quoted 20 times and its members another 9 times, meaning that ABA proponents were quoted 58 times. Non-ABA parent groups, as noted, were quoted zero times.

One individual opposing ABA was interviewed, 1 time, in <u>an article</u> that also featured 3 ABA proponents and did not discuss science/evidence-based approaches other than ABA --but rather referred to "special diets" and "dolphin therapy" as the alternatives to ABA<sup>27</sup>, an editorial approach that arguably verged into the territory of propaganda.

**Resulting Bias:** This erasure of non-ABA providers and misrepresentation of ABA alternatives in the *Star* is significant for two reasons: first, because through omissions it suggests that ABA is the only (or "only evidence-based") approach to autism—not an accurate reflection of the science or the diversity of science/evidence-based services that families in Ontario access. Second, it erases the fact that many families who accessed ABA using government funds were also left to pay out-of-pocket for other services, such as speech language pathology, occupational therapy and AAC<sup>28</sup>. The economic impact of these out-of-pocket costs was invisible in the story that the *Star* told about autism and funding, even as its reporter <u>linked</u> to a GoFundMe page for a waitlisted parent seeking donations for ABA.

<sup>&</sup>lt;sup>26</sup> These therapies can be done in tandem with ABA, as part of ABA or as a stand-alone.

<sup>&</sup>lt;sup>27</sup> Reporter Laurie Monsebraaten <u>wrote</u>: "Over the years, a wide range of questionable therapies and treatments have been promoted — including special diets and even swimming with dolphins — to help autistic kids learn communication and social skills and avoid self-harming behaviour and isolating fixations [sic]." No other services or therapies other than ABA were referenced in the article, creating a false dichotomy of "ABA *vs* quackery".

<sup>&</sup>lt;sup>28</sup> AAC, or Augmentative and Alternative Communication is an umbrella term that encompasses the communication methods used by non-verbal people, such as assistive technologies, sign language and other methods. 25-30% of autistic people are non-verbal.

The editorial choice to ignore science -based alternatives to ABA is also glaring *because* therapies other than ABA were a major point of discussion within the government and by interest groups (other than the OAC) in that time period. Autistic self-advocates and other advocates from the non-verbal community, for example, had advocated for AAC supports and were glad to see them funded under the new Program. On that fact, the *Star* remained silent.

**Role of Social Media:** Some ABA proponents that the *Star* featured had active social media accounts where they took on an angry tone towards autistic self-advocates and families who advocated for changes to the ABA-dominant model. For example, former OAC President and ONTABA member Bruce McIntosh took to Twitter to decry a self-advocacy group (A4A Ontario) as a "menace" 29.

Mike Moffat, who the *Star* quoted on the policy issue, commented on a blog platform that in funding AAC technologies, the government was "giving families a useless second iPad"-reflecting the paper's general class bias that erased low-income families with non-verbal children as stakeholders in autism policy changes. Moffat's wife, Hannah, took issue on Twitter with another parent who sells hand-knit stuffies for neurodiverse kids, tweeting "She's profiting off autism...typical craft fair rubbish". <sup>30</sup>

Craig Rigden, whom the *Star* quoted speaking *about* the autistic panelists (with autistic panelists *not* quoted in the article) tweets frequently against autistic self-advocacy groups. On his blog, he takes issue with the slogan of the disability rights movement, "Nothing about us without us".

Rigden <u>writes</u>: "The idea of 'Nothing about us without us' is an extremely Elitist and Supremacist Autistic attitude to say the least [sic]." Given this, it is quite shocking that the *Star* would choose Rigden to be their "expert" about the inclusion of disabled people on a government consultation panel.

Despite their ... distinctive social media presence, McIntosh, Rigden and Moffat remained some of the *Star's* key voices for the "autism community." Even as A4A submitted policy papers to the provincial government, spoke to other media and began to consult as part of a national consortium, the *Star* never reached out to A4A's leadership for information or even comment<sup>31</sup>.

\$80k and "Kidney Dialysis": The Presence of ABA Marketing Language in Coverage
The Star presented ABA services using a rhetoric that normalized it--as though it were *the only* therapy or approach to autism. While there was no mention of the uses or effectiveness of AAC, SLP or OT in the *Star* (nor, for that matter, any definition of those services), the talking point that "therapy costs \$80k per year" was repeated 22 times in the *Star* ("children diagnosed with moderate to severe autism may require between 20 and 40 hours a week of ABA therapy, which can cost between \$50,000 and \$80,000 a year," and "a child with severe needs could require about \$80,000 a year in behavioural therapies alone"). The statements aren't based in science but

<sup>&</sup>lt;sup>29</sup> Tweeted May 13, 2019 from @brucemcintosh

<sup>&</sup>lt;sup>30</sup> Tweeted Sept. 10, 2019 from @standinghannah

<sup>&</sup>lt;sup>31</sup> Conversation with A4A leadership, September 30, 2019

is rather an industry speculation<sup>32</sup>. They were never fact checked, or they would not have been printed.

The Star also presented ABA as though it was a life-saving medicine, which it is not. For example, OAC President Laura Kirby McIntosh, speaking to the *Star*, compared ABA to kidney dialysis in her interview for the *Star's* "in-depth" <u>feature on ABA</u>. In response to autistic concerns about abuses in ABA, Ms. McIntosh stated: "There are lots of evidenced-based interventions for different conditions that are unpleasant. My dad is going through kidney dialysis right now. It's not pleasant. There are times when it may be traumatic. But it's keeping him alive. And it's effective," she told the *Star*.

A representative of ONTABA similarly <u>compared</u> receiving ABA to receiving chemotherapy for cancer. These comparisons can lead viewers or readers to think that ABA is a medicine, a cure, like chemotherapy, when it is not. There is no cure for autism and in fact, medicine does not recognize autism as a disease at all--but rather as a condition or disability. Anyone with common sense should also be alarmed to see a lobbyist arguing that a behaviourist therapy is similar in any way to chemotherapy; such a claim is akin to miracle cure claims for other autism pseudoscience.

To understand why and how these claims are being made, we can look briefly at ABA marketing, an example being this 2019 <u>Marketing Guide</u> by an ABA industry marketer, entitled "How to Enroll More ABA Clients by Overcoming Parent Objections". Tips include "Don't Sell: Prescribe" and "Using the Doctor Frame" (speaking like a doctor), and getting parents not to worry about high co-pays (US). The author, Reece Epstein, gives a script for what BCBAs should tell parents who worry about price:

"I totally understand how you feel. The truth is that a lot of our clients felt the same way. But what we found is that saving money is exactly the reason why our clients choose us. That's because by getting your child the services he/she needs right now, you will actually save many tens or even hundreds of thousands of dollars on therapy, support services, and financial support you may have to provide to your child when he or she is an adult.

"That's because if you don't get your child the help he needs now, he will need a lot more help later. And he may not be able to get a good job.<sup>33</sup>"

There may be a reason that BCBAs repeat these talking points (and why they request that media repeat them). It may be because the idea that thousands of children in Ontario need \$80k per year of intensive therapy **isn't plausible** unless coupled with a repeated narrative that causes readers

<sup>&</sup>lt;sup>32</sup> Writing against the proposed income-tested system, the *Star's* Editorial Board <u>wrote</u>: "Even families who qualify for the maximum \$140,000, will blow through all that with just two years of therapy." This language normalizes the high fees of intensive "behaviour" services and denies the existence of the other options that many families access. Please also see footnote 11 for discussion about the erasure of data on balanced costs of other therapies.

<sup>&</sup>lt;sup>33</sup> Reece's <u>website</u> also contains testimonials from satisfied BCBAs, with claims such as: "We were approach by an applied behavioral analysis clinic for a marketing project in 2016. The client serves children with autism and wanted to increase the size of its business. Over the course of six months, we helped the clinic go from approximately \$250,000 in revenue per year to over \$936,000 per year." There is a similar testimonial on the site about a Functional Medicine Centre client.

to suspend disbelief about costs altogether. When the rhetorical hammer comes down ("the child will have no future without ABA," "it will save their life"), it seals the deal. Readers start to believe that ABA *is all* that any family has to help their children, which is not true.

We can see shadows of this strategy during the time that the amount of funding for ABA was being debated, when MPP Monique Taylor (Hamilton Mountain) <u>said</u> to the *Star*: "What we are seeing is an erosion of the entire system that serves children with autism" <u>and</u> "children [are having] week after week of critical developmental potential stolen away from them."

This idea—that catastrophe would result if the program funded services other than ABA, and that the solution to everything autism was to allocate *more* to ABA was echoed by both McIntoshes to the *Star*. Bruce McIntosh <u>commented</u> to the *Star* that Minister Lisa MacLeod's office "wants to have an excuse to ruin the ABA program that has taken 20 years to build in this province." In a January 25 *Star* Op Ed, Laura Kirby McIntosh wrote: "The reality is that we don't have enough ABA therapists," advocating <u>that</u> the government should "provide ABA training and supervision to all EAs [to] help them support **all students**— **not just the ones with autism."** 

Comparing ABA to kidney dialysis, as McIntosh <u>suggested</u> (or to chemotherapy, as ONTABA told media<sup>34</sup>) is a rhetoric intended to make *any* criticism of it "off-limits". Once that shark has been jumped, the next step is to suggest that ABA is good for everyone, in much the same way that other pseudosciences claim they are a cure-all<sup>35</sup>.

But if we take a step away from the myths equating ABA with life-saving medicine, we can see that ABA is actually just a service, one among many, and that children who don't receive ABA do indeed progress well in life<sup>36</sup>.

We can understand why ONTABA, as a professional service organization of ABA providers, might use manipulative language such as equating ABA with life-saving medicine. But why did the OAC? And why did journalist Laurie Monsebraaten, in her pro-ABA <u>feature</u>, write of an autistic man: "ABA therapy saved his life"?

### A Mythic "Voice of the Autism Community"

it is not really debatable that the Star lacked balance in its representations of families and

<sup>&</sup>lt;sup>34</sup> An ONTABA representative made the chemotherapy claim on TVO in February 2019.

<sup>&</sup>lt;sup>35</sup> For a good discussion of this and other red flags of autism pseudoscience, see the Westminster Commission on Autism's report, *A Spectrum of Harmful Interventions*, which identifies "One Cure for All" as a red flag. "A product/therapy claims to treat/cure a large range of different conditions."

As the ABA industry expands, its salespeople are marketing it as a general <u>classroom tool</u>. Here is <u>a list</u> of some more situations that ABA journals have identified as "benefiting" from ABA: "rehabilitation of brain injury, criminal behavior, HIV prevention, conservation of natural resources, education, gerontology, health and exercise, industrial safety, language acquisition, littering, medical procedures, parenting, psychotherapy, seatbelt use, sports, substance abuse, phobias, pediatric feeding disorders, and zoo management and care of animals."

<sup>&</sup>lt;sup>36</sup> For example, ABA is rarely funded in Scotland, England and Ireland, but autistic children effectively learn life skills without it. It's also important to talk about ABA regret; as some parents watch their children become tweens and have regret about aspects of the ABA process, as do some <u>providers</u> who have quit the industry.

individuals affected by autism policy changes<sup>37</sup>.

**Measuring ethnic representation and overall diversity of parents quoted:** As we saw above, the McIntoshes were the only parents quoted in 62% of *Star* articles in the studied time period. Within the subset of non-McIntoshes interviewed, parent members of the McIntosh's pro-ABA lobby (OAC) were represented in another 28% of parent quotes. This leaves just 10% of quotes by parents who were non-OAC members.

While People of Colour represent 51% of the population of the Greater Toronto Area, families of Colour represented just 6% of quotes from parents of autistic kids in the *Toronto Star*.

This is significant for two reasons. First, it is not even remotely demographically representative. Second, families of Colour have traditionally been marginalized in autism services and autistic People of Colour face dual discrimination as well as under-diagnosis, and lack of representation contributes to those problems. Racism in autism services and in the broader culture are massive problems affecting millions of Ontarians, yet the *Star*'s coverage of autism policy was dominated by white parents and indeed never addressed issues of racial and ethnic inequality at all.

**Autistic Ontarians: Invisible in** *Star* **coverage.** Autistic People of Colour and their families have been vastly under-represented in the *Toronto Star's* autism policy coverage (6%), to the point where autism may appear wrongly to be a "white" identity or over-represented among whites to readers.

In the period we studied, non-verbal autistics were never interviewed by the *Star*, even though they represent 25-30% of the autistic population. This erasure to makes it appear that non-verbal people are not a part of the autism policy discussion-- when in fact non-verbal autistics co-were active on the issues in Ontario, co-authoring reports, attending meetings and making presentations, including to the United Nations Health Rapporteur, not-for-profit service organizations and governmental policymakers.

In only 4% of *Toronto Star* autism policy stories were *any* autistic people interviewed about the policies. In the 42 articles studied, a total of 4 autistic adults were interviewed and, bizarrely, 3 were members of the pro-ABA interest group, OAC. Such an imbalance in representation could falsely lead readers to think that 3 out of 4 autistic people support ABA--when ABA is overwhelmingly <u>opposed</u> by autistic people and universally condemned by *every major autistic self-advocacy organization in the world*. In the sole <u>article</u> where one ABA opponent was interviewed, their words were juxtaposed with 3 OAC members.

Of the 4 autistic adults quoted, all were white. Just one autistic Person of Colour was interviewed, an eight-year-old boy (with his mom). This means that 0% of autistic adults interviewed were non-white, even though 51% of autistics in the Greater Toronto Area are People of Colour.

As mentioned, non-verbal autistics were never interviewed on autism policy by the *Star*. This is significant because an estimated 25-30% of autistics are non-verbal and because funding for

<sup>&</sup>lt;sup>37</sup> Well of course you could debate it, but... you'd lose.

AAC (including assisted speech technologies) was a key element being debated in the reform.

The near-invisibility of autistic people's opinions and ideas in *Toronto Star* coverage of autism policy is even more glaring *because autistic self-advocates were seated at the government's table with other stakeholders*, through presentations, meetings and official appointments to the Ontario Community Advisory Panel, convened by the government in summer 2019.

**Bias in Stakeholder Panel Coverage.** In its first coverage of autistic peoples' presence on the panel, the *Star* did not interview the autistic panelists at all, but rather <u>spoke to</u> former OAC President Bruce McIntosh, who echoed <u>the words of MPP Taylor</u>, stating: "*The anti-ABA voices on that committee ... are on the committee to tell the minister what she wants to hear... She wants to have an excuse to ruin the ABA program.*"

His statement stood in strong contrast to the actual panel itself which, according to the autistic members, was welcoming of the autistic members, who joined a collaborative force that found ways to work together for positive changes, despite any differences of opinion.

This statement is especially puzzling when one looks at <u>the numbers</u>: with 20 members on the panel, autistic people comprise just 10% of it. The other panelists include OAC President Laurie McIntosh, several OAC members and two BCBAs.

Autistic people, as the end-users of the services being debated, belonged at that table, just as we belong in the public conversation, *vis a vis* the media. Yet in its second (and final) reporting on the panels, the *Star* described autistic panelists as "an anti-science group," and quoted BCBA and ONTABA member Louis Busch, <u>who stated</u>: "I am disappointed by the apparent stacking of individuals with clear anti-treatment agendas."

Advocating for a plurality of services doesn't make an interest group "anti-science" or "anti-treatment." It is plain and simple bias for the *Star's* reporters to say that it is.

#### Autistic children as an "influx"

Ontario schools are not inclusive of autistic/intellectually & developmentally disabled students—a fact that the *Toronto Star* did not address in any of its coverage of the mainstreaming of 1,000 autistic students into the system in the fall of 2019.

- A Report by the Ontario Human Rights Commission in 2019 found that special education in our province has not meaningfully changed in 40 years<sup>38</sup>.
- A Report by Arch Disability Law found that "25% of parents [of disabled students] surveyed reported that they had simply been told not to bring their child to school. Of these, 76% reported that informal exclusions were communicated to parents verbally,

<sup>&</sup>lt;sup>38</sup> From page 38 of the Report: "Ontario's current approach to 'special education' is premised on exclusion. It labels students with disabilities as 'exceptions' before meeting their needs. ... Ontario's special education system is nearly 40 years old and its core premise around "exceptionalities" stands in direct contrast to progressive shifts in society and law that embrace inclusion and universal design. It's time we rethink how we can truly support and include all children."

- rather than in writing, and 41% reported that the rationale for the exclusion was not clearly stated."
- Ontario's Ministry of Education also <u>reported</u> high levels of suspensions for students who have a disability generally, with approximately 47% of all suspensions and 48% of all expulsions involved a student who has a disability in in 2015-2016.
- People for Education <u>found</u> in 2017 that over the previous 10 years there has been an increase in the number of students tracked into special education, at a time when other provinces are decreasing or <u>eliminating</u> segregated classrooms altogether<sup>39</sup>.

None of these reports from major organizations were cited by the *Toronto Star* during the time period studied. The *Star* did not reach out to these organizations, nor to any other school inclusion experts in its coverage of autism policy during January-August 2019.

This is especially notable because a key piece of the government's autism policy revision pivots on inclusion. Under the new OAP, the government expressed a commitment to inclusion (a first in an Ontario provincial government) and about 1,000 JK and SK students who had been segregated in behaviour facilities were set to enter public school beginning in the fall of 2019.

Here, the numbers are <u>very</u> important. The number of autistic students expected to be newly mainstreamed in the province in the fall of 2019 was <u>1,105</u> and the number of students to be newly mainstreamed in the Toronto District School Board (TDSB) was 250.

Toronto has 451 elementary schools, making the average number of new autistic students per classroom less than one student per classroom or approximately 5/8 of a Kindergartener<sup>40</sup>.

Yet the Star presented the inclusion this way:

- "School boards are expecting an influx of about 1,000 students with autism into schools".
- A TDSB Chair, speaking to the *Star*, <u>described it</u> as: "This strategy [sic] puts strain on our schools and staff."
- An ONTABA <u>statement</u> described inclusion as "downloading specialized interventions onto teachers and EAs".
- Various school board representatives interviewed by the *Star* used the following terms to describe including less than one autistic child per school in Ontario this year:
  - o "the imminent influx of students with autism"
  - o "downloading kids' behavioural therapy needs onto Ontario schools"
  - o "an untenable situation"
  - o "the consequences of kids in therapy coming into classrooms"
  - o "an unsustainable burden on schools"
- *Star* journalist Laurie Monsebraaten wrote: "Educators are predicting <u>chaos in the</u> classroom as children with autism enter the school system"

<sup>&</sup>lt;sup>39</sup> See Sec 6.2.2 of New Brunswick's <u>Policy 322</u>, signed into law in 2013. (Department of Education & Early Childhood Development.)

<sup>&</sup>lt;sup>40</sup> Rounding up so we aren't accused of "exaggerating" the number. The actual number is 4.4345898/8. Rounding down would be 4/8, or half.

Terms the *Star* **didn't** use to describe including less that one new autistic child per school in Ontario include:

- "equitable"
- "inclusion"
- "mainstreaming"
- desegregation
- "access"
- "equality"
- "welcoming"

## Broader policy shifts ignored in favour of a simple "story"

The *Star* also excluded a number of autism policy discussions happening that affect autistic adults. Although AAC funding was newly appropriated in the new budget, the number of AAC users or experts in AAC and communication access quoted in the *Star* was zero. Although diversifying autism across portfolios was on the table, the number of housing and employment experts quoted by the *Star* was also zero; and in fact neither issue was ever discussed in the news articles.

This points to the simplistic story the Star *always* rounded back to: **that autism is a problem** and that the solution to the problem of autism is to give autistic people more ABA.

Nowhere is this more evident than in the *Star's* assumptions around the idea of "needs-based" services. "Need," under the previous administration of Kathleen Wynne, was based on a child's assessment by an ABA professional (BCBA)--a rejection of income-testing (which is used for most social services in the province). Notably, the ABA industry's definition of "need" failed to consider poverty anywhere in its assessment of need for funding. As well, the BCBA evaluations didn't refer for government funded SLP, OT *or any services other than ABA*. So under the former plan, just 25% of children were receiving services, with a waitlist in the tens of thousands (see section 1 of this report).

The former system--"needs" assessed by BCBAs who only recommended ABA-based services-wasn't equitable across disabilities<sup>41</sup> (other disability services were still funded using income-based models); it wasn't equitably by range of services provided (only one service was ever offered); and given the exorbitant cost of ABA services,<sup>42</sup> funding for families couldn't possibly be spread equitably within the budget framework. Under the former plan, fewer families got *any* access to services. The new government's initial approach to fixing that was to apply income testing<sup>43</sup> to autism services much as with other services (although in the end they backed down

<sup>&</sup>lt;sup>41</sup> As the Ontario Disability Coalition has pointed out, for the universal model to be equitable, it would need to be applied equally to all disabilities and it is not.

<sup>&</sup>lt;sup>42</sup> As the *Star* reminded us 22 times in the period studied, BCBAs advise many families to get \$80,000 per year in ABA services.

<sup>&</sup>lt;sup>43</sup> Income testing (or means testing) is a determination of whether a person or family is eligible for government assistance, based upon whether they possess the financial means to do without that help. Canada uses a mixture of means-testing and universal benefits (its opposite). For example, our health care is universal, but access to legal aid, student assistance, the Child Benefit Plan and social welfare (including most disability supports) is based on economic need. Autism services is the only disability in Ontario with a universal service model, which raises issues of equity in funding schemes across disabilities.

from this proposal). And although MPP Taylor (Hamilton Mountain) <u>described</u> the incometested proposal as "100 percent nothing," it likely didn't seem like nothing to the low-income families who would have received funded services for the first time.

The issues of service equity across disabilities, and barriers to low-income access to services are both worthy of serious consideration, especially since alternatives to the ONTABA model were being actively debated publicly and in policy circles.

Yet no basic definition or discussion of the issues, nor the voices of low-income Ontarians, made the pages of the *Star*.

Instead, the *Star* Editorial Board wrote: "It turns out Kathleen Wynne's Liberals got it right in 2017 when they moved to a system that relied on trained behavioural therapists to recommend treatment based on need," writing during the final weeks before the cabinet shuffle that saw MPP MacLeod transferred to another Ministry. And although that commentary was an editorial column--not news--the line between the two in the *Star* had become difficult to discern. We are now left to speculate about how this impacted public perceptions about autism policy (and the potential to grow or change policy). In our view, the *Star*, Ontario's major print media, had approached proposed changes with a nostalgia for a former (broken) system and continued to treat new voices and ideas as a threat to be neutralized.

Who benefitted--and who was harmed--by this bias?

A <u>statement</u> from the beleaguered then-Minister's office, shortly before she left her post in a cabinet shuffle, read: "Our critics are focused on the industry insiders. We're focused on helping the kids." That comment was worth exploring in some depth—it was, after all, made by a major cabinet minister—but the *Star* merely printed it and left it alone, in pursuit of a different story.

### **Section 3**

## Media Bias -- and what we can do about it

Media bias is the bias<sup>44</sup> or perceived bias of journalists or producers in the selection of stories that are reported and how they are covered. The term implies a pervasive or widespread bias contravening journalistic standards, which include: independent fact-checking; corrections issued when errors are identified; and respecting privacy. The Society of Professional Journalists calls upon reporters to "take special effort not to misrepresent or over-simplify" and asks reporters to "boldly tell the story of the diversity and magnitude of the experience." It also <u>states</u>: "Analysis and commentary should be labeled and not misrepresent fact or content."

Likewise, the Canadian Association of Journalists Statement of Principles and Ethics Guidelines states that ethical journalism <u>must</u>: "clearly identify news and opinion so readers, viewers and listeners know which is which." The International Council for Press and Broadcasting media ethics code likewise tells journalists to "prejudge no one at all costs" and "divorce comment

<sup>&</sup>lt;sup>44</sup> The definition of *bias* is "prejudice in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair." (Google Dictionary).

from news and label it as such."

On seeking diverse sources and views, the *Star* failed even by the standards of social advocacy journalism (and a reminder: it is a daily newspaper, not the *Nation*). In fact, it was so selective in its interviewees that entire elements of the news story were erased. As well, it relied on science by press conference (or science by press release) when repeating industry talking points about ABA being the only "evidence-based treatment" for autism. Throughout the news coverage, commentary was presented as news and major sources and information relevant to the story were left out.

#### Why? Trying to Understand the Bias

When trying to understand why a media outlet may choose not to feature diverse voices or examine the broad landscape of a story, we can look at 3 areas that often contribute to bias: personal relationships; institutional bias; and being too busy for rigour.

Our questions around that:

- 1. Can a reporter be friends with a lobbyist and still be a main reporter on news around the specific issue on which their friend lobbies? Is that possible if the editorial system is checking for bias? (We can't find any precedent.) And if bias is checked by editors, how should a paper manage the optics and public perception of bias (*e.g.*, reassigning stories, etc.)?
- 2. Where do broader biases about intellectually disabled people and the neurodiversity movement come from? What is the historic background into how we have been covered in media? Why do these historic biases manifest more in some publications that others? Is a media outlets bias reflective of, or actively shaping, cultural bias?
- 3. With labour cutbacks at so many papers, are some journalists taking shortcuts or using formulas to the point that stories lack balance and substance? If journalists under deadline develop a pattern of using the same sources, what gets lost in terms of diversity and objectivity? Does being busy preclude striving for balance--and if so, when?

And a bigger question – and this one is perhaps the most important of all:

## 4. What happens when a media outlet's "experts" are, well... selling something?

The "experts" that the *Star* turned to—exclusively—were practitioners of one form of autism therapy, ABA.

The "community voices" the *Star* used were also largely members of a lobby group that advocates for increasing ABA funding and, in fact, has stated <u>its opposition</u> to funding other supports such as AAC.

The former plan had given all the funding to ABA: the new plan was going to cut some ABA jobs and offer a broader range of support. Put that against the reality that our city has thousands of other providers, practicing different science/evidence-based therapies, as well as major

hospitals and research institutions. These were **never** cited in the *Star* coverage; only ABA centres/practitioners were.

That's a problem. It is compounded by the fact that the industry of ABA actively works to delegitimize and de-fund non ABA autism therapies and services. For example, their "scientific association" runs a database which claims to provide "scientific information about autism treatments" but instead presents flat-out lies like the claim that AAC is "not evidence-based" and "needs more research" and that "ABA methods to teach AAC" are the only "appropriate intervention" for nonverbal children. In Ontario, ONTABA has lobbied against our government funding Speech Language Pathology, Occupational Therapy and even AAC technologies. In their platform, only ABA should be funded.

The rhetoric of ABA-as-medicine, which ONTABA employs, is a red flag for exploitation of the public system for industry gain. When the OAC likened ABA to kidney dialysis or chemotherapy (see footnote 35), they were repeating an industry scare-tactic, conflating ABA with a life-saving prescription. As we see from the industry's phony "science" website, the industry even wants to lay claim to authority over services it didn't create: "AAC may improve communication skills ...when ABA teaching methods are used to teach AAC. However, benefits appear to be limited." And ONTABA's only vision is for all public funds to go to their industry.

Is that in the public interest ...or is it a business strategy? That is a question that any good journalist should be asking at this point.

When an industry has been received \$300 million per year from the former government and now is having a piece of that funding reappropriated to allow families a choice of other services, how far will the industry go to reclaim their market dominance? What are the policy implications when a powerful lobby refuses to be flexible to change?

We return to the observation of then-Minister MacLeod, who <u>said</u>: "Despite collaborative dialogues that took place over six months of consultation, **ONTABA was ...unwilling to work with government to open up the sector to provide parents more choice in support services for children with autism."** 

For 20 years, there has been one loud autism lobby here in Ontario: the ABA lobby. But just because a lobby has more money, more press conferences or greater access privilege does not make it ethical for policymakers--nor news reporters--to ignore all the other stakeholders. "The squeaky wheel gets the grease" is the wrong way to do policy or journalism--especially with an issue as complex as autism policy, which affects hundreds of thousands of Ontarians.

## The Impact of ABA bias on public perceptions

One can see how the level of bias at the *Star* could have a negative impact on public perceptions of disabled people, understanding of the problems we face and even on voting patterns that may perpetuate "solutions" that don't serve the community.

<u>Perception of disabled people</u> The average Ontario voter who mainly gets their news about autism from the *Star* is not getting a balanced picture of disability and inclusion, and thus will

absorb biases about autistic and other disabled people's rights, identities, needs, perspectives and humanity.

In the *Star*, newly-mainstreamed autistic kids were described as "an unsustainable burden" that would bring "chaos in the classroom". What perceptions did readers take away about who we are as people, and about where autistic children belong in this society?

<u>Perception of the problems</u> The real concerns of our community (which include a crisis of poverty, underhousing and unemployment; crushing exclusions at school; and major barriers to health care) were never addressed in any of the *Star's* articles about autism policy, despite the fact that they were being debated at a high level by lawmakers and within the broader community.

If our problems aren't even being named publicly (let alone measured), then policy is being made without data, programs will continue to be predictably wasteful and policymakers won't be meeting community needs or developing sustainable projects.

<u>Perception of solutions</u> In reading *Star* coverage of autism news in 2019, readers could wrongly conclude that the "answer to autism" is ABA. This can impact how they vote if they get their policy information mostly from media, and could continue to drive policy towards the ABA model.

ABA is a brand. Inclusion isn't. Inclusion is free; one only has to embrace the concept, learn and apply it. But how can inclusion compete with a brand whose marketing is so entrenched in policy, media and the public consciousness?

#### The changing role of print media in Ontario

There is also sometimes a strange sensation when reading the *Star*'s coverage about autism, kind of like walking into an old-timey donut shop where you feel like you've stepped into the land that time (and the wrecking ball) forgot. It has that enigmatic odor, a sweet staleness that makes you want to turn and bolt, yet you see there are people still sitting there, frozen in a Canucker's version of Pompeii. At the same time, you're aware that there is a whole big world, alive and spinning outside of that donut shop and that you have only to reach for the door to escape to it. And you wonder as you hit the sidewalk, if you whirled around and looked back, would that the old donut shop even be there anymore? And because you kind of don't want to know, you don't end up looking back at all.

Ideas are moving fast in our community and our sector. Faster than the speed of policy...but policy is shifting too, towards a new ethos of inclusion, a commitment to accessibility that encompasses all disabled people, including autistics<sup>45</sup>. In some sense, media like the *Star* simply haven't caught up with that yet, so when we read their coverage it feels out of synch. It is still true that a big lobby group can pull out a table and hold a press conference and the *Star* reports

<sup>&</sup>lt;sup>45</sup> It's encouraging to see that two major parties in the 2019 federal election have officially committed to a National Disability Policy, which could potentially integrate the access needs of autistics directly into all new policy rather than current models which silo "autism policy" into one portfolio (Ministry of Children and Youth, in Ontario and Ministry of Health, federally).

it, but what remains to be seen is how much longer this will be seen as a way to make news. What will happen to print media who rely so heavily on pressers and monolithic voices, in a world that is ever-increasingly grassroots and which values a plurality of voices through multiple platforms, including social media? At some point when we turn around, is it possible the old donut shop just won't be there anymore?

#### **Conclusion**

Autism policy decisions deeply impact our lives: whether we can find work; whether we can find safe, independent supported living; whether we will face barriers in access to health care; whether we will suffer trauma due to abusive therapies and segregated education; and more.

As autistic people, we have been through the systems and we know what is broken. Segregation in Ontario schools has gotten *worse* in the 18 years since the ABA mandate was introduced, and in 2018 when ABA was deemed the sole funded service, nothing improved. Put simply, an ABA-dominated system does not work for autistic children or adults in Ontario<sup>46</sup> Saying that doesn't make us "anti-science." It means we see the necessity of change and we're naming it.

Some concluding recommendations for combating media bias:

- Read the reports and policy recommendations of disability self-advocacy groups advocating for service choice and new ways of doing policy.
- When you read media coverage of autism policy, ask yourself "who is speaking? Whose voices and perspectives are missing?"
- Contact your local media when you see bias in their reporting. Make petitions, write about it and raise awareness.
- Support disability-led media and media who are meaningfully engaged with our community.
- Boycott: Do not support biased media with clicks or shares.

Thank you for reading and sharing this report!

<sup>&</sup>lt;sup>46</sup> Please read our 2018 <u>Human Rights Report to the United Nations</u>.

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