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## **ARTICLE**

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## Systemic Silencing Mechanisms in Autism/Autistic Advocacy in Ontario, Canada

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#### **Abstract**

This article reveals how systemic ableism operates within grassroots organizations in Ontario, formulating a normative standard for being an autistic person. In-depth interviews were conducted with 50 participants in the years 2021 and 2022, triangulated with document analysis from 2018 and 2022. The study participants consisted of autistic adults, parents, disability advocates, organizers of grassroots organizations, social workers, policy insiders, and academics. The findings show that most autistic adults are pressured to choose sides, either to join autism advocacy that is parent-led or expert-led or to become self-advocates in autistic advocacy. This article offers an original finding that the value policy of pro/anti-ABA of two grassroots organizations in the field of autism/autistic advocacy contributes to identity politics. Ableism operates through Pierre Bourdieu's symbolic power, excluding autistic adults who do not fit into these two main categories of advocacy. Social oppression becomes multi-directional as identity politics takes the stage and diverts from the original goals of social inclusion in advocacy. The concept of a grey area is introduced in theory building, to trouble the essentialist categories of autism/autistic advocacy and invite readers to commit to disability solidarity by moving beyond the dichotomy of sameness and difference.

## **Keywords**

ableism; autism; disability politics; grassroots advocacy; identity politics

#### 1. Introduction

Ableism serves as a form of epistemological knowledge and a "way of being" that constructs a human's identity (Campbell, 2009, p. 28). At the core of ableism is the ontological division of the "able/not-able" (Campbell, 2009, p. 7) and it manifests from belief systems, practices, and structures that favor the ideal human (Campbell,



2009, p. 5). Ableism is not simply a manifestation of "fear of the unknown"; it forms distaste for disability, so much so that disability is cast away to be terminated and to constitute the "unthought" (Campbell, 2009, p. 13). Being the pioneer of modern philosophy, Locke (1982, p. 36) instills a normative divide between those who qualify as citizens and those who lack reason. Locke (1982, p. 36) proclaims that "lunatics and idiots are never set free from the government of their parents" because they are unable to reason. Ableism operates from the cradle to the grave in our lives, dictating the ways to succeed in "abled-ness," with fantasy stories on excellence and flawlessness, forcing a divide between the normal and the abnormal (Campbell, 2009, p. 197). Like Bourdieu's (1989) "common-sense thinking," ableism is systemic and deeply ingrained in our everyday lives. The logic of practice is represented in the equation: [(habitus) (capital)] + field = practice (Bourdieu, 1984, p. 137). Symbolic violence is actualized as agents conform to their "schemes of classification" without awareness that social conditioning has shaped their habitus (p. 81). Classifications produce divisions, wherein groups are separated by polarized concepts (p. 537), such as "high/low," forming the foundation of practices drawn from schemes (p. 209).

Ableism triumphs across generations by symbolic violence, segregating disabled people from society. Symbolic power lies in the legitimization as well as the delegitimization process, thereby reproducing inequality (Bourdieu, 1989). In line with the goal of normalization, applied behavioral analysis (ABA) gains legitimacy as it offers a false promise that "there *can* be life without autism" (McGuire, 2016, p. 223). Broderick (2022, p. 165) asserts that ABA gains power politically and economically by feeding into the "politics of hope, of truth, and of fear." In Ontario, ABA has been established as one of the "core clinical services" of the Ontario Autism Program (OAP) since the 2000s (Autism Ontario, 2023; Government of Ontario, 2022). Pyne (2020) posits that ABA is coined as science in Ontario through "affective and intellectual strategies," albeit insufficient evidence. Broderick (2022, p. 259) further adds that ABA discourses of "science, ethics, rights- and evidence-based" go beyond ideology because the "autism industrial complex" (AIC) materializes and preys on autistic bodies. The ABA industry constitutes a "biocapital" in which autism and capitalism are co-dependent on each other, commodifying and consuming autistic bodies (Broderick, 2022, p. 244). The AIC commodifies every aspect of life, from the media and the education system to producing bodies that satisfy normalcy standards (Broderick, 2022, p. 247).

Roscigno (2019) explains that the biopolitical power of ABA manifests itself as a "philanthropic venture" essential to the social inclusion of autistic people. As a result of framing ABA as the solution to the recovery of normalcy (Lovaas, 1987), stakeholders in the autism community, such as parents and medical professionals, see their lobbying actions as not only justified but kind (Broderick, 2022, p. 252). Indeed, McGuire (2016, p. 93) explains that Foucault's governmentality operates through the "gaze of biomedicine and the gaze of advocacy," imprisoning both the advocate and the autistic child. Advocates who do not follow the normative form of "advocacy's war on autism" (McGuire, 2016, p. 24) risk social exclusion, whereas autistic bodies, in worst-case scenarios, may face death (p. 102). Thus, a "good advocate" is quick to detect the "warning signs" of autism (p. 101), advocate for interventions for autistic people, and raise public awareness that autism is a fearful "thing" (p. 10).

Broderick and Ne'eman (2008) attest that the dominant form of autism narratives renders the "upside down perception of the self-advocate narrative as secondary," estranging groups into two. As an autistic self-advocate, Sinclair's (1993) transformative piece *Don't Mourn for Us* opposed the stigma that autism is death, and his speech was directed against mainstream parents' portrayal of autism in the 1980s and 1990s



(Pripas-Kapit, 2020). Sinclair (2005) explains that while a passive autistic individual might be accepted as a member of groups of the status quo, autistic people mobilized in groups have been seen as a threat to "the interests of parents and professionals." Sinclair (2005) outlines three main tactics used by such groups to delegitimize autistic voices, which include (a) questioning the legitimacy of membership, (b) labeling higher-functioning autistics as unique cases that do not represent the majority, and (c) asserting that autistic activists are incompetent in knowing what is best for themselves. While medical deficit framings of autism originate from non-autistic people, neurodiversity-affirming narratives arise from autistic people and their allies (Broderick & Ne'eman, 2008). Broderick (2022, p. 187) asserts that the introduction of ethics in ABA was motivated by the industry's desire to manage associated economic and legal risks and less of a commitment to bioethics. Overall, current literature presents a dichotomous autism/autistic advocacy, with autism treatment and intervention being the most contentious topic with little agreement among stakeholders of autism communities (Carey et al., 2020, p. 105). While McGuire (2016, p. 65) briefly refers to the collaboration between autism and autistic advocacy, namely the Autism Society of America (ASA) and the Autistic Self Advocacy Network (ASAN), little is known about alternative forms of advocacy.

This article fills the research gap of going beyond the binaries of autism/autistic advocacy and offers an original finding that the value policy of pro/anti-ABA in two grassroots autism/autistic advocacy organizations (denoted as organizations A and Z) contributes to identity politics. Although it is not the scope of this article to discuss the nature of ABA or its effectiveness, ABA is found to be the major disagreement between the organizations and is critical in the discussion of ableism. It is important to note that the value policy of pro/anti-ABA is inclusive of being pro/anti-intensive behavioral intervention (IBI). IBI is an intensive derivative based on ABA principles (Bark, 2016). First, this article seeks to answer the research question of how the voices of autistic adults are respected or disrespected in the field of autism/autistic advocacy. Then, it shows why Bourdieu's logic of practice is maintained by structural powers propagated by ableism, prioritizing some voices over others. As part of disability justice, this article is motivated to reveal the silencing mechanisms, with the hope of providing informed knowledge to enhance the decision-making power of autistic adults.

## 2. Methods

#### 2.1. Case Study Research

Case study research is conducted as the research question is explanatory and it examines a contemporary phenomenon that is not within the researcher's control (Yin, 2018, p. 3). Although case study research is a pluralistic mode of inquiry, explanatory questions are deemed most suitable because processes are tracked across time (p. 10). Most importantly, such a methodology is flexible as it caters to both realist and relativist perspectives (p. 16). This article adopts the latter approach as it examines the different perspectives held by participants. Case studies enable the researcher to utilize a diverse source of evidence, for example, documents and artifacts (p. 12), and are not restricted to a particular type of inquiry (p. 21). The multiple-case studies consist of three cases in Ontario: (a) organization A, (b) organization Z, and (c) stakeholders of the larger disability community (e.g., policymakers, educators, social workers, union leaders, leaders of disability groups, and academics). Organizations A and Z are chosen as cases because they are examples of a polar type. In searching for alternative ways of advocacy, stakeholders of the larger disability community are included as a third case. Yin's (2018, p. 57) logic of replication is applied to the



three cases. The rationale of this research design is to provide analytic generalizations from an iterative process of constant comparison of data and theoretical propositions. For example, original theoretical propositions are re-examined when unexpected findings occur, and data collection continues after a redesign (p. 57). Data collection stops when theoretical saturation is complete, in which no new knowledge is generated from further data collection.

#### 2.2. Research Process

This study begins with exploring the lived experiences of autistic adults and the meanings they prescribe to the construct of disability. The original inclusion criteria pertained to working autistic adults (verbal and non-verbal) in Ontario, Canada, between ages 18 and 64, who were in the Ontario Disability Support Program (ODSP). A social worker provided support with purposive sampling as I was a volunteer during my undergraduate studies. The preliminary findings from the in-depth interviews with 11 autistic adults suggested that autistic adults receive little support once they turn 18. For example, the OAP ends at age 18 (Government of Ontario, 2019), and 58.2% of autistic adults are on the ODSP for income support (Stoddart et al., 2013). Historically, autistic adults on welfare in Ontario are under-researched and underfunded. The dominant discourse on ODSP focuses on highlighting recipients' limited functionality, motivation, and stability to exit social assistance, with little regard for structural oppression (see Lahey et al., 2021). Similarly, the medical model posits that the abnormality lies within the individual, rendering disability a personal tragedy, marked by its deviation from the norm (Ferrante & Joly, 2016, p. 156). The rationale of recruiting autistic adults on ODSP was to counter such symbolic violence because the legitimization of research has continued to benefit the discourse enforced by the medical model, which produces an "ableist/saneist" avenue as experts enjoy the privileged distance from the subjects (Nishida, 2016, p. 152). As an AuDHD researcher, the objective of the research design lies in closing the gap between philosophical arguments and the actual reality faced by disabled people.

The sampling process is a reflective procedure that follows an iterative data analysis process. Theoretical sampling followed after earlier stages of interviews, in which later participants were selected in accordance with new, emerging research questions. As the research design is inductive, I did not expect to find silenced autistic voices. In the exploration of social in/exclusion and disability advocacy, the inclusion criteria were expanded to include parents and autistic adults in advocacy. The division between autism/autistic advocacy, with ABA being the biggest disagreement, was shared by the participants. Purposive snowball sampling was conducted; some contacts were introduced to me, while others were referred to and approached by me. I reached out to other stakeholders (e.g., personal support workers, social workers, policymakers) of the larger disability community through recommendations. Having a diverse group of participants (see Table 1) offers insights into solidarity power despite differences in transversal politics and is beneficial in understanding how agents could face oppression on multiple levels (Cutajar & Adjoe, 2016, p. 511). Consistent with disability advocacy in Ontario, most autistic people are located across the province and are connected through the internet because most disabled people do not have the privilege to commute. It has always been a concern that research fails to reach non-verbal autistics due to accessibility issues (see Williams & Park, 2023). Engagement with non-verbal autistics was possible in this study through interviews by email and Facebook text messaging, in which participants choose the communication channel that best fits their needs.



**Table 1.** Study participants.

Study participants	N = 50
Academics	3
Autistic adults	19
Autistic parents	3
Non-autistic parents	6
Current and former leaders, organizers, or coordinators of autism advocacy groups	6
Current and former leaders, organizers, or coordinators of autistic advocacy groups	6
Current or former union representatives	3
Disability employment specialists	2
Leaders, organizers, or coordinators of disability advocacy groups	15
Personal support workers, social workers	3
Policymakers and insiders	5
SEN Educators	3

Note: Some participants partake in multiple roles.

#### 2.3. Trustworthiness

According to Korstjens and Moser (2018), four criteria should be evaluated to assess the findings, and criteria include (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. To enhance credibility in qualitative research, I adopted the strategies of (a) continuous engagement with participants over time, (b) triangulation, and (c) member checking. Continuous engagement with participants was important to build rapport. An empathetic and safe atmosphere was established with non-judgmental and attentive listening, where all interviews were conducted one-on-one. Second, multiple sources of evidence (see Table 2) were collected to provide a contextual background for the phenomenon as it exists in the real world (Yin, 2018, p. 127). The Hansard transcripts provide rich contextual information detailing policymakers' responses to autism/autistic advocacy groups over time. The statements and news releases published by the Ministry of Children, Community and Social Services (MCCSS) are useful for cross-checking data. After changes to the OAP were announced by MCCSS on February 6, 2019, stakeholders of autism advocacy relayed their grievances to members of the provincial parliament (MPP). For example, a recurring pattern highlights that ABA/IBI was life-changing for parents, and parents could not afford the costs under the new OAP. On February 20, 2019, MPP Ms. Jill Andrew said: "I should also say that one of the parents said that this new plan from the government is a 'death sentence'...a 'death sentence for their children'" (Legislative Assembly of Ontario, 2019a). On February 21, 2019, MPP Ms. Andrew Horwath stated:

With therapy and treatment, children who seem to be in their own worlds are able to communicate. They're able to feed themselves. They're able to tell their own parents that they love them. No parent should have to choose between selling their home and denying that to their children. (Legislative Assembly of Ontario, 2019b)

Following uproar against the new OAP within autism advocacy, the Autism Advisory Panel was announced on May 30, 2019 (MCCSS, 2019b). The OAP Advisory Panel Report, published in October 2019, is a relevant document for triangulation as well. The public information available on organizations A and Z's websites was



reviewed to verify participants' stances towards ABA. Member-checking on the themes drawn from individual interviews was completed with 37 participants, and 13 participants did not participate in member-checking as they were preoccupied. Some participants appreciated member-checking as a space for clarification and reflection while some felt that it was redundant because their perspectives have not changed.

The criterion of transferability is addressed by the "thick description" drawn in this study (Korstjens & Moser, 2018). The reader can evaluate whether the findings could be applied to other white colonialist neoliberal capitalist settings. For dependability, the research process is discussed, showing how explanation building occurs (Korstjens & Moser, 2018). For example, preliminary data suggested that nondisabled people did not have the lived experiences of disabled people and thus might not commit to anti-ableism. Later findings highlight that disabled people could also experience internalized ableism. Thus, the theoretical proposition of nondisabled people as an in-group with dominant power and disabled people as an out-group was rejected. Lastly, confirmability is achieved as the findings are based on the data, coupled with the author's reflexivity and positionality (Korstjens & Moser, 2018).

**Table 2.** Data sources for triangulation.

	Data	Description	Delimitations
1	In-depth e-interviews with 50 participants	Interviews were conducted to understand the lived experiences of participants. The main topics are (a) disability advocacy, (b) disability policies, and (c) social inclusion.	11 interviews were conducted in 2021 and another 59 interviews were completed in 2022 (ranging from 1 to 4 hours, averaging 1.5 hours).
2	Hansard transcripts house debates	Contextual information on how policymakers debated autism.	The "subject of business" is restricted to topics related to autism, which include "waves of changes for autism," "autism," "autism awareness and acceptance month," "autism treatment," and "Autism Awareness Day Act, 2021." Irrelevant topics such as "land use planning" are excluded. The data include the 42nd Parliament, 1st session from July 11, 2018, to September 12, 2021, and the 42nd Parliament, 2nd session from October 4, 2021, to May 3, 2022.
3	Organizations A and Z's public websites	Public information includes press releases, public letters, petition templates, policy papers, and blog posts.	From June 2018 and June 2022.
4	The OAP Advisory Panel Report	A recommendation report was submitted by a 20-member advisory panel after 18 days of consultations (MCCSS, 2019c).	Report published in October 2019.
5	Statements and news releases by the MCCSS	Public announcements and statements.	From February 6, 2019, and February 3, 2022.

Note: The time interval of the data is delimited to coincide with Ford's government premiership from June 2018 and June 2022 (Legislative Assembly of Ontario, n.d.).



#### 2.4. Reflexivity

Due to the interpretative orientation of TA, Braun and Clarke (2023) disagree with positivist ideas of "researcher bias" because meaning is prescribed rather than rooted in the data. Since reflexive thematic analysis (TA) requires the researcher to "own one's perspective," practicing reflexivity is important (Braun & Clarke, 2023). Wa-Mbaleka (2020) posits that the researcher is essentially an instrument in qualitative research. Keeping a reflective journal was critical as I practiced open-mindedness, welcoming new findings that might stand in contrast with previous data. While there is doubt as to whether triangulation, which is of "realist/positivist quality practices," is compatible with reflexive TA (Braun & Clarke, 2023), TA's flexibility allows me to explain why triangulation is utilized. Triangulation enabled me to explore different points of view and strengthened my contextual understanding of a phenomenon (Korstjens & Moser, 2018).

## 2.5. Positionality

I am an AuDHD neurodivergent Asian female with the privilege of being born into a middle-class family. Traditionally, it is assumed that the researcher and the study participant have a unilateral relationship in which the researcher has power over the study participants. While I have the privilege of conducting this research, my research process coincides with Kinitz's (2022) study, as they outline the emotional burden of examining a topic intimately related to a marginalized researcher. I am both an insider and an outsider, as my identity does not automatically grant me access to disability groups. While insider researchers are often scrutinized for their attachment, detached researchers enjoy the privilege of not having to explain their objective stance (Kinitz, 2022). Besides, neurodivergent brains have long been under scrutiny by the medical gaze in the making of research, as the words of neurodivergent people are judged as the output of invalid brains (Yergeau, 2016).

## 2.6. Data Analysis

Reflexive TA using NVivo is utilized because it is flexible, compatible with the inductive, iterative research design, and it entails a reflexive process. This type of TA is "artfully interpretive" because it values the researcher's subjectivity as an asset and does not seek to achieve intercoder reliability (Braun & Clarke, 2023). Following the guidelines of the "six phases for analysis" (Braun & Clarke, n.d.), the first stage required deep reading of the data. For instance, interview transcripts and memos were read several times for familiarization. Next, I let the data guide me instead of having deductive codes generated from the literature. I coded for each source of data separately and revisited each set of data to analyze the implicit meanings. Data was coded in relation to the research question. Initial themes were drawn to deliver the latent meanings. For example, the initial themes generated from interviews were (a) infighting about ABA, (b) not enough listening to be inclusive, (c) awareness but not disability acceptance, (d) power dynamics go unrecognized, and (e) government wants a measurable outcome. Each theme consisted of multiple sub-themes, coupled with quotations in participants' words. The initial themes were re-examined closely with continued theme development so that the themes were not descriptions but "meaning-united stories" (Braun & Clarke, 2023). For example, in the within-case analysis of organization A, it was found that A repetitively criticized the OAP for being one-size-fits-all but was focused on securing one type of autism treatment, which is ABA/IBI services. Such a pattern was also confirmed in cross-case analysis, both by the cases of organization Z and the larger disability community. Then, the themes were refined and renamed to



reflect the breadth and depth of the story (Braun & Clarke, n.d.). The last stage was the consolidation of the analytical data concerning the context and literature on autism/autistic advocacy (Braun & Clarke, n.d.).

#### 2.7. Ethics

Informed consent was obtained from all participants, and ethical approval was granted by the College Human Subjects Ethics Sub-Committee of the City University of Hong Kong. In cases where participants experienced technical difficulties in giving written consent, verbal consent was recorded by voice memos. During data collection, most interviews were not recorded because some participants felt uneasy about having the interview recorded. Some suggested having the interview recorded, and they were recorded by Voice Memos. While this is a non-funded study, I felt that it was important to add a token of appreciation (25 CAD e-gift cards) to participants on ODSP. Many were happy that I was working on this topic and did not want any compensation. While I commit to protecting participants' rights to privacy, confidentiality, and anonymity, some participants expressed that they wished to be identified. As this study is written for disabled people, it is important to credit their names. As for the participants who did not express such intent, anonymity was ensured by numbering the participants and removing identifiable information from the data.

### 3. Findings

The findings are structured by a cross-case analysis, explaining the processes involved in silencing autistic voices. In Ontario, A is a grassroots organization founded in 2005 that is known for its commitment to fighting for government-funded ABA/IBI therapy for autistic children. A's decision-making power lies in the hands of parents and medical professionals, with a tokenism of two or three autistic adults on the board of directors over the years. A's advocacy approach is reflective of the medical model, and autistic individuals are often referred to as individuals with autism. Indeed, McGuire (2016, p. 4) posits that such a framing isolates autism as an external "thing" from the child, a "thing" to be feared, to be managed, and a "thing" that triggers stress. A prohibits any disagreement upon ABA within its community, in which members are silenced or removed if they voice any concerns or doubts about ABA. Such a phenomenon coincides with Broderick's (2022, p. 109) observation that any disagreements against ABA are framed as being "'emotional,' 'influenced...by ideologies, personal beliefs, and social movements,' and as 'largely the opposite of disciplined science." Consequently, some members left A for Z. Z is a grassroots organization established in 2017 and adopts the North American minority group approach in the elimination of societal barriers and the promotion of disability pride and defending that disabled people are the real experts, as echoed in "nothing about us without us" (Goodley, 2017, p. 14). Z's policy prohibits its members from meeting with organizations that promote or provide ABA. While both A and Z condemn school exclusion of autistic people and highlight the need for proper police training, their stances on ABA rendered them oppositional to one another. For example, some autistic adults in A who are supportive of ABA have been criticized for betraying the autistic community and are perceived as anti-LGBTQ because ABA has historically been put into practice on "feminine boys" (Broderick, 2022, p. 143). Hence, autistic adults who do not abide by the all-or-nothing approaches of A and Z are excluded from the conversation.

The sequence of the findings is guided by theory building. The first section introduces the binaries enforced by autism/autistic advocacy and the processes agents took to support their stance in pro/anti-ABA. The second section speaks to the benchmark of what an autistic person should look like concerning functionality and the



distaste for disability. The third section shows that advocates could gain power by adopting a nonpartisan approach. The nonpartisan approach provides insights that taking an ambivalent stance is a creative strategy to break away from dominant forms of advocacy.

## 3.1. You Are Either With Us or Against Us

On February 6, 2019, the news release Ontario Takes Decisive Action to Help More Families With Autism issued by the MCCSS (2019a) was met with uproar amongst A, who wants ABA for autistic children. Parents relayed their grievances to MPP, concerning how the program of providing alternative choices to ABA (such as speech-language pathologists, occupational therapy, and augmentative alternative communication [AAC]) does not address their children's needs for intensive ABA. Thus, parents criticized the new OAP for being a one-size-fits-all program that prioritizes equality over equity. Overall, the political tactics employed by A include: (a) ongoing protests; (b) earning media coverage from public protests; (c) raising public awareness with lawn signs and truck displays; (d) petitions; (e) connecting with municipal and provincial politicians; (f) calling for the minister's resignation; (g) building ties with labor unions; and (h) the use of influence amongst white, middle-class parents. Further, they stressed that the government had broken the 2018 campaign promise as MPP, Ms. Andrea Horwath, reiterated parents' disappointment on February 20, 2019:

My question is to the Premier. During last spring's campaign, I stood next to the Premier in the leaders' debate when he promised the parent of a child with autism, "We will be there to support you 1,000%....I promise you, you won't have to be protesting on the front of Queen's Park like you" have with the Liberal Premier. I want the Conservative Premier to look at families in the gallery today who have come from across Ontario to protest his policies. Does he feel he has supported them 1,000%? (Legislative Assembly of Ontario, 2019a)

In contrast to A's disappointment, Z welcomed the new announcement because the previous program, with a central focus on ABA, did not address families' needs (such as AAC). One of the former organizers of Z stated that:

[A] is centrally a pro-ABA group, and most autistic advocates oppose ABA; the irony is when most autistic youth spoke against their policies, doesn't look good on them...instead of motivating to look past ABA...use that to label us these "neurodiversity high-functioning extremists."

While A argues that the new OAP will cause a crisis in the school system, Z advocates for reversing policy/program memorandum 140 (Government of Ontario, 2021) so that ABA aides would not be allowed in classrooms. In March 2019, Z was invited to a consultation with the government on autism policy for the first time. Equally, it was the first time two autistic people were chosen to join the 20-member Autism Advisory Panel, announced on May 30, 2019 (MCCSS, 2019b). The inclusion of two autistic members in the Panel was met with backlash amongst parents, as a former board member of A stated:

The controversy comes from adults who did not participate in ABA, [who are] outside looking in, think[ing] it's negative shock reinforcement....I don't want to be told by someone who can speak, drive, and work, no idea what reality is, no idea what my child is, and he may never get a job or speak.



While a few could enjoy a privileged status of periodic involvement in policy negotiations, insiders on the peripheral tend to have minimal effect on policy development. For example, the OAP Advisory Panel Report published in October 2019 (MCCSS, 2019c) misrepresented Z, as one of the autistic panel members was not a member of Z. However, the information remained unmodified in the public document. Most critically, the report does not cover Z's stance on anti-ABA. The value policy of Z entails social exclusion, as a self-advocate claimed:

When we were contacted by a reporter of a national news outlet, they didn't use any of what we said, "autism was a tragedy and ABA the solution." Autism Ontario wants nothing to do with us because we are anti-ABA.

Such a value policy also results in the social exclusion of autistic adults in the grey, who are less visible as participants reported that they "don't want to be attacked" and "just stay out of it." The leadership of A and Z contributed to identity politics by delineating pro/anti-ABA, as former Ontario Child Advocate, Irwin Elman, confirmed:

Both groups don't realize their own power, the system makes you feel less power, people on both sides, they are not powerless, but they feel they are stuck. Instead [of] feeling powerless, you look over beside you and fight beside you.

#### 3.2. Silencing Voices in the Name of Science and Functionality

The de/legitimization of autistic voices functions by ableist mechanisms such as tokenism, infantilization, and low societal expectancies. While it is socially acceptable for parents to speak for their children, and for medical experts to speak about autistic people, autistic adults' voices are often deemed illegitimate. For example, an autistic adult in the grey recalled taking further education to counter symbolic violence:

There'd be parents [who say] "you are not that autistic," so okay, if you don't like my diagnosis, I have a fancy piece of paper.... There is a cultural appropriation, no other groups experience that, you are not +1, this is not LGBT+1, you are not parenting a transgender parent, therefore you are also a transgender extension.

The onus of responsibility is placed on autistic people, explaining how they might fit with the benchmark of what an autistic person should look like. The objectification of autistic people is reinforced by the dichotomous measurement of speaking/non-speaking. An autistic adult in the grey summarized the situation:

It is ableism, it's using your disability against you, setting the bar for autistic people...so it is parents for kids...so it is only caregivers, or specialists or, like, officials, but where are the autistic people? Where are they? The answer is, if you can speak, you are disqualified, but then if you can't speak, you can't speak.

Although it appears to be a social requirement for autistic adults to explain their legitimacy to obtain a voice, it is socially acceptable for experts to portray autism using a medical deficit framing, with a disregard for power dynamics. For example, A supports the statement by Perry (2019), in which the clinical professional stated:



Autism spectrum conditions can be likened to heart conditions....Some people may need a heart transplant, heart bypass surgery, a pacemaker, medication, or an aspirin a day....What this proposed autism program will do is akin to giving everyone an aspirin.

The overgeneralization of portraying disability as an unwanted identity feeds into ableism, while many autistic adults do not wish to be normal. This article rejects strict binaries and does not argue for the full abandonment of medical practices. Instead, this article invites the reader to reflect on how the logic of practice has structurally privileged some and suppressed others. The dichotomous societal belief cultivates stories of a pitiful poster child in need of charity and an inspiring "supercrip" who miraculously overcame the disability (Shapiro, 1994, p. 16). As autistic children are argued to be marketable, parents' voices could garner public sympathy, as MPP Ms. Teresa J. Armstrong said on February 21, 2019:

She told me, "My son cannot speak out against this. He is non-verbal. I need to be his voice. This is going to be terrible for our family and others." (Legislative Assembly of Ontario, 2019b)

While society may sometimes perceive autistic individuals as voiceless or powerless, it is important to recognize that everyone has a voice. For example, AAC aids non-verbal autistic people in conveying their feelings. Despite the good intentions to speak for or give voice to autistic people, such an action maintains a power hierarchy, sustaining the unequal relationship between the speaker and the subject. Once subjectification is complete, social order is maintained, and power inequalities are naturalized (Bourdieu, 1985).

#### 3.3. Strategic Move to be Nonpartisan to be Heard

Both A and Z were criticized by autistic adults in the grey and some disability stakeholders for maintaining a political minefield in which social oppression becomes multi-directional as identity politics take the stage and manifest as distractions from advocacy. A's former leadership has been criticized for being partisan coupled with a conflict of interest, from being members of the Ontario Association for Behavior Analysis and having worked under the Progressive Conservative Party of Ontario in the past. A former member recollected: "[A] was so vocal, it was just a way to shut [A] up and it backfired. It was a disaster." An autistic adult in the grey reiterated: "[A] agitating to get the Liberal Party out of power, really pushed the parents to vote them out." A parent of an autistic child who disagreed with the approaches of A and Z said:

[A] misinform and they don't let people express their actual experiences if they go against the leadership, but the protests...the lack of fact-checking....Their tactics have done a lot more harm to themselves and their families than they realize because they play politics...it's all about screaming and yelling and getting attention and not about solving.

When asked about the importance of adopting a nonpartisan orientation in disability advocacy, former minister Tracy MacCharles stated:

Nonpartisan is always ideal as governments from various parties come and go over election cycles and accessibility should be a universal issue. However, the value systems of parties vary. For example, some governments may be more committed to sustainable change and support for people with



disabilities versus "window dressing" type initiatives that do not really move the yardsticks in the right direction.

Parent advocates shared the significance of maintaining respectful ties with politicians because, in times of crisis, politicians may be able to help them. Sherry Caldwell of the Ontario Disability Coalition explained:

Whoever is elected, we will work with them, we work with the opposition too, we use all the tricks that we can find...we are a smaller movement than the autism, there are a lot of MPPs out there, call the people with the most influence.

## 4. Discussion

As part of disability justice, this article aligns with the key principle of "first, do no harm" (Badesch & Ne'eman, 2014). The logic of practice in the field of autism/autistic grassroots advocacy in Ontario maintains a binary value policy that is harmful not only to A and Z but is equally harmful to autistic adults and families in the grey. This policy value diverts from disability solidarity, resulting in the social exclusion of autistic adults in the grey who do not share such black-and-white perspectives. The infighting between A and Z could be exploited by the hegemony as identity politics undermine the broader movement. For example, silencing autistic adults for voicing against ABA undermines their lived experiences. Equally, blaming parents for their decisions to choose ABA for their children will ignore how society is structured to uphold normalization in colonial, neoliberal capitalism. By enforcing strict binaries of pro/anti-ABA, A and Z strengthen the ableist hierarchical structure and undermine disability solidarity. In the name of science and functionality, social exclusion mechanisms operate by policing how an autistic adult should be, using speaking/nonspeaking as a benchmark for de/legitimization. The ability to speak deters the legitimacy of autistic voices, as autistic adults must satisfy the ableist benchmark of being autistic enough to speak, much like the subaltern is only allowed to speak after they have attained such pain that they finally receive the recognition as human (Tuck & Yang, 2014). Instead of fostering a political minefield, agents could break free by creative means, such as practicing nonpartisan advocacy.

In the process of theory building, Bourdieu's logic of practice offers little room to explain autistic adults in the grey. Critics assert that the conceptualization of habitus is deterministic as Burawoy (2022, p. 127) argues that it fails to account for the progression of how an agent comes to realize that they could resist conformity. The concept of a grey area is introduced to trouble the essentialist categories of autism/autistic advocacy. The grey area is a fluid, boundless space that embraces the countless possibilities of being an autistic adult. Garland-Thomson (2011) shows that the experiences of disabled people differ drastically by gender, race, and location. Vernon (1999) asserts that the bigger problem than representativeness lies in how intersectional issues experienced by disabled people are not addressed. Garland-Thomson's (2011) misfit reminds us of how our lived identities and experiences are ever-changing and relational to time and space. To be a good fit in society is to satisfy the "dominant subject positions such as male, white, or heterosexual," as agents enjoy the comfort of not recognizing how their world is designed for their needs (Garland-Thomson, 2011). With misfitting, however, we come into conflict with the world as we reveal the political and relational powers of the "fragility of fitting" (Garland-Thomson, 2011). Notably, I have left the demographics of autistic adults in the grey open for a reason. Contrary to "mak[ing] identities more visible" (Alcoff, 2006, p. 8), I argue that autistic adults in the grey area pertain to all the unheard autistic voices beyond the categories of autism/autistic



advocacy. Autistic adults in the grey area are misfits who do not engage with the world as constructed by the two categories of advocacy. By misfitting, these autistic adults are less visible, and simultaneously, misfitting provides them with the agency to organize disability solidarity.

#### 5. Conclusion and Recommendations

The study demonstrates analytic generalization, in which the findings converge with Sinclair's (2005) summary of the strategies used against autistic adults in the United States. While the findings appear to apply to other white colonialist neoliberal capitalist settings, the limitation of this study is that most of the participants in leadership roles are white Canadians, except for the diversified leadership of autistic advocacy. Some participants stated that being a white Canadian proficient in English has given them an advantage in advocacy. Such a pattern coincides with the literature on how a parent's identity could have an impact on service availability to their children (see Douglas, 2013; Gibson, 2019). Future research could explore how whiteness may have an impact on securing a seat at the table in advocacy. Most importantly, the article offers an original finding that essentialist categories of autism/autistic advocacy contribute to the normalization of what an autistic adult should be, to be a good fit. To combat the ableist hierarchical structure that favors normalization, agents should commit to disability solidarity. First, Broderick and Roscigno (2021) remind us that the "cultural logic of intervention" preys on autistic children; hence, the abolishment of behaviorism in neoliberal capitalism will not stop the AIC from manufacturing interventions for consumption. Second, ABA has evolved to become a much broader practice, as a variety of non-aversive methods could now be labeled as ABA (Carey et al., 2020, p. 94). New changes to the Psychology and Applied Behavior Analysis Act 2021 will become effective from July 1, 2024, pursuant to which behavior analysts will be subjected to comply with additional regulatory requirements (Autism Ontario, 2023). Hence, it is a critical moment for A and Z to commit to disability solidarity, to demand transparency and effective safeguards on ABA reform so that autistic children would not suffer from aversive interventions that have long-lasting impacts on their quality of life. Being misfits would require autistic adults to disengage with the binaries of pro/anti-ABA and commit to joining disability solidarity. For example, organization Z can adopt a more flexible policy, like the collaboration between ASA and ASAN (Badesch & Ne'eman, 2014). After all, organizations A and Z have a mutual interest in advocating for a better future for autistic children. Nevertheless, disability solidarity could not be achieved if autistic voices were silenced in the process for not being like their children. It is critical for agents to rethink power dynamics and the importance of interdependence. The autism file has been treated as a standalone disability in Ontario, for example, a siloed subject debated at the Legislative Assembly of Ontario. The implication of isolating autism from other disabilities could have short-term gains in that voices are louder; it has detrimental consequences of amplifying the medical deficit narrative. Ultimately, the concept of a grey area is introduced as a boundless space of being an autistic adult, to embrace disability solidarity as misfits.

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#### **Conflict of Interests**

The author declares no conflict of interest.

### **Supplementary Material**

Supplementary material for this article is available online in the format provided by the author (unedited).

#### References

- Alcoff, L. M. (2006). Visible identities: Race, gender, and the self. Oxford University Press.
- Autism Ontario. (2023, September 21). Regulatory changes in Ontario for behavior analysts: Almost there but still work to be done [Press Release]. https://www.autismontario.com/news/regulatory-changes-ontario-behaviour-analysts-almost-there-still-work-be-done
- Badesch, S., & Ne'eman, A. (2014). *Joint statement of ASA and ASAN on DSM-5 and Autism*. Autism Society of Texas. https://www.texasautismsociety.org/joint-statement-of-asa-and-asan-on-dsm-5-and-autism
- Bark, S. (2016). *Making sense of ABA vs. IBI*. Kinark Child and Family Services. https://www.kinark.on.ca/making-sense-of-aba-vs-ibi/#:~:text=IBI%20stands%20for%20Intensive%20Behavioural,is%20not%20effective%20for%20everyone
- Bourdieu, P. (1984). Distinction: A social critique of the judgement of taste. Routledge.
- Bourdieu, P. (1985). The social space and the genesis of groups. *Theory and Society*, 14(6), 723–744. http://www.jstor.org/stable/657373
- Bourdieu, P. (1989). Social space and symbolic power. *Sociological Theory*, 7(1), 14–25. https://doi.org/10.2307/202060
- Braun, V., & Clarke, V. (n.d.). *Doing reflexive TA*. University of Auckland. https://www.thematicanalysis.net/doing-reflexive-ta
- Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *International Journal of Transgender Health*, 24(1), 1–6. https://doi.org/10.1080/26895269.2022.2129597
- Broderick, A. A. (2022). The autism industrial complex: How branding, marketing, and capital investment turned autism into big business. Myers Education Press.
- Broderick, A. A., & Ne'eman, A. (2008). Autism as metaphor: Narrative and counter-narrative. *International Journal of Inclusive Education*, 12(5/6), 459–476. https://doi.org/10.1080/13603110802377490
- Broderick, A. A., & Roscigno, R. (2021). Autism, inc.: The autism industrial complex. *Journal of Disability Studies in Education*, 2(1), 77–101. https://doi.org/10.1163/25888803-bja10008
- Burawoy, M. (2022). The poverty of philosophy: Marx meets Bourdieu. In G. Paolucci (Ed.), *Bourdieu and Marx: Practices of critique* (pp. 103–129). Springer. https://doi.org/10.1007/978-3-031-06289-6\_5
- Campbell, F. K. (2009). Contours of ableism: The production of disability and abledness. Palgrave Macmillan.
- Carey, A. C., Block, P., & Scotch, R. (2020). Allies and obstacles: Disability activism and parents of children with disabilities. Temple University Press.
- Cutajar, J., & Adjoe, C. (2016). Whose knowledge, whose voice? Power, agency and resistance in disability studies for the global south. In S. Grech & K. Soldatic (Eds.), *Disability in the global south: The critical handbook* (pp. 503–516). Springer. https://doi.org/10.1007/978-3-319-42488-0\_32
- Douglas, P. N. (2013). As if you have a choice: Autism mothers and the remaking of the human. *Health*, *Culture and Society*, 5(1), 167–181. https://doi.org/10.5195/HCS.2013.137
- Ferrante, C., & Joly, E. (2016). Begging and disability: A paradigmatic way to earn one's living. In S. Grech & K. Soldatic (Eds.), *Disability in the global south: The critical handbook* (pp. 151–166). Springer. https://doi.org/10.1007/978-3-319-42488-0\_10



- Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, *26*(3), 591–609. https://doi.org/10.1111/j.1527-2001.2011.01206.x
- Gibson, M. F. (2019). "Parent advocacy" as an ideological code: LGBTQ parents engage with disability services. Journal of Progressive Human Services, 30(1), 46–68. https://doi.org/10.1080/10428232.2018.1543996 Goodley, D. (2017). Disability studies: An interdisciplinary introduction (2nd ed.). SAGE.
- Government of Ontario. (2019). *Ontario Autism Program*. https://www.ontario.ca/page/ontario-autism-program
- Government of Ontario. (2021). *Policy/program memorandum* 140. https://www.ontario.ca/document/education-ontario-policy-and-program-direction/policyprogram-memorandum-140
- Government of Ontario. (2022). Ontario Autism Program: Core clinical services. https://www.ontario.ca/page/ontario-autism-program-core-clinical-services
- Kinitz, D. J. (2022). The emotional and psychological labor of insider qualitative research among systemically marginalized groups: Revisiting the uses of reflexivity. *Qualitative Health Research*, *32*(11), 1635–1647. https://doi.org/10.1177/10497323221112620
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, 24(1), 120–124. https://doi.org/10.1080/13814788. 2017.1375092
- Lahey, P., Kirsh, B., Tompa, E., MacDermid, J., & Gewurtz, R. E. (2021). The Ontario Disability Support Program work exit process: Parallels to a hostage negotiation. *Journal of Disability Policy Studies*, 32(3), 182–192. https://doi.org/10.1177/1044207320944609
- Legislative Assembly of Ontario. (n.d.). *Timeline*. https://www.ola.org/en/visit-learn/about-parliament/history-heritage/timeline/2000-
- Legislative Assembly of Ontario. (2019a). Official report of debates (Hansard) No. 67: 1st session, 42nd Parliament (Wednesday 20 February 2019).
- Legislative Assembly of Ontario. (2019b). Official report of debates (Hansard) No. 68: 1st session, 42nd Parliament (Thursday 21 February 2019).
- Locke, J. (1982). Second treatise of government: An essay concerning the true original, extent and end of civil government. Wiley.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, *55*(1), 3–9. https://doi.org/10.1037//0022-006x.55. 1.3
- McGuire, A. (2016). War on autism: On the cultural logic of normative violence. University of Michigan Press.
- Ministry of Children, Community and Social Services. (2019a, February 6). Ontario takes decisive action to help more families with autism [Press Release]. https://news.ontario.ca/en/release/51178/ontario-takes-decisive-action-to-help-more-families-with-autism
- Ministry of Children, Community and Social Services. (2019b, May 30). *Ontario announces autism advisory panel* [Press Release]. https://news.ontario.ca/en/release/52402/ontario-announces-autism-advisory-panel
- Ministry of Children, Community and Social Services. (2019c). The Ontario Autism Program advisory panel report:

  Recommendations for a new needs-based Ontario Autism Program. https://www.publications.gov.on.ca/
  CL29780
- Nishida, A. (2016). Neoliberal academia and a critique from disability studies. In P. Block, D. Kasnitz, A. Nishida, & N. Pollard (Eds.), *Occupying disability: Critical approaches to community, justice, and decolonizing disability* (pp. 145–157). Springer. https://doi.org/10.1007/978-94-017-9984-3\_10
- Perry, A. (2019). Ford's deceptively cruel autism plan must be stopped. Ontario Autism Coalition. https://



ontario autism coalition. com/wp-content/uploads/2019/03/Perry-Consolidated-OAP-Statement-Mar-11-2019.pdf

Pripas-Kapit, S. (2020). Historicizing Jim Sinclair's "don't mourn for us": A cultural and intellectual history of neurodiversity's first manifesto. In S. K. Kapp (Ed.), *Autistic community and the neurodiversity movement: Stories from the frontline* (pp. 23–39). Palgrave Macmillan. https://doi.org/10.1007/978-981-13-8437-0\_2

Pyne, J. (2020). "Building a person": Legal and clinical personhood for autistic and trans children in Ontario. Canadian Journal of Law and Society/La Revue Canadienne Droit et Société, 35(2), 341–365. https://doi.org/10.1017/cls.2020.8

Roscigno, R. (2019). Neuroqueerness as fugitive practice: Reading against the grain of applied behavioral analysis sholarship. *Educational Studies*, 55(4), 405–419. https://doi.org/10.1080/00131946.2019. 1629929

Shapiro, J. P. (1994). No pity: People with disabilities forging a new civil rights movement. Times Books.

Sinclair, J. (1993). Don't mourn for us. Autreat. https://www.autreat.com/dont\_mourn.html

Sinclair, J. (2005). Autism Network International: The development of a community and its culture. Autreat. https://www.autreat.com/History\_of\_ANI.html

Stoddart, K. P., Burke, L., Muskat, B., Manett, J., Duhaime, S., Accardi, C., Riosa, P. B., & Bradley, E. (2013). Diversity in Ontario's youth and adults with spectrum disorders: Complex needs in unprepared systems. The Redpath Centre. https://doi.org/10.13140/2.1.3994.0165

Tuck, E., & Yang, K. W. (2014). R-words: Refusing research. In D. Paris & M. T. Winn (Eds.), *Humanizing research: Decolonizing qualitative inquiry with youth and communities* (pp. 223–247). SAGE.

Vernon, A. (1999). The dialectics of multiple identities and the disabled people's movement. *Disability & Society*, 14(3), 385–398. https://doi.org/10.1080/09687599926217

Wa-Mbaleka, S. (2020). The researcher as an instrument. In A. Costa, L. Reis, & A. Moreira (Eds.), *Computer supported qualitative research*: New trends on qualitative research (WCQR 2019) (Vol. 1068, pp. 33–41). Springer. https://doi-org.ezproxy.cityu.edu.hk/10.1007/978-3-030-31787-4\_3

Williams, R. M., & Park, C. (2023). Cyborg assemblages: How autistic adults construct sociotechnical networks to support cognitive function. In A. Schmidt, K. Väänänen, T. Goyal, P. Ola Kristensson, A. Peters, S. Mueller, J. R. Williamson, & M. L. Wilson (Eds.), *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems* (Article 62). Association for Computing Machinery. https://doi.org/10.1145/3544548. 3581556

Yergeau, M. (2016). Occupying autism: Rhetoric, involuntarity, and the meaning of autistic lives. In P. Block, D. Kasnitz, A. Nishida, & N. Pollard (Eds.), *Occupying disability: Critical approaches to community, justice, and decolonizing disability* (pp. 83–95). Springer. https://doi.org/10.1007/978-94-017-9984-3\_6

Yin, R. K. (2018). Case study research and applications: Design and methods (6th ed.). SAGE.

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