JAE
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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

April 2021 Volume 1 Issue 1

Gerald
Beaulieu

Ryan
Collis

Maddy
(Matthew)
Dever

Amy
Kim

Rebekah
Kintzinger

Terri
Robson

Mackenzie
Salt

Joseph
Sheppard

Cameron
Winter

Cover painting
Beautiful Nightmare
By: Ryan Smoluk

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Cover Art by Ryan Smoluk

Beautiful Nightmare 2012

Photograph by
Diana Thorneycroft

Ryan Smoluk is a powerful self-advocate and a seasoned spokesperson for autism awareness. His art has been showcased internationally.

In 2012, the United Nations selected an original painting of Ryan's named "The Path", which was reproduced on a postage stamp and is available for sale world-wide. Ryan has been an honoured guest of the United Nationals Assembly in New York and in attendance was the United Nations Secretary General, H.E. Ban Ki-Moon.

In 2017, Ryan was deeply honoured to receive an art award from the Canada Council for the arts. Ryan has accomplished his Fine Arts Degree at the University of Manitoba and has been awarded grants from the Manitoba Art Council and the Winnipeg Art Council.

Ryan's art has been featured on several television interviews, magazine articles and books. Ryan has recently accepted a featured role in a documentary film out of Miami by composer Justin Morell. Other collaborators in the project include Grammy award winning trumpet soloist John Daversa and the Henri Mancini Orchestra. The opening premier event is scheduled for the fall of 2021.

Ryan continues to exhibit his artwork in galleries. Ryan has a very unique style that is original to him. His artworks feature multi-layered detail which explores the way that Ryan sees the world. Ryan feels that autism is both a blessing and a curse.

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Foreword

Dr. Stephen Gentles

Dr. Janet McLaughlin

Canadian Journal of Autism Equity, Volume 1 Issue 1: Foreword

Stephen Gentles[1] and Janet McLaughlin[1]

The arrival, on April 6, 2021, of the first issue of the *Canadian Journal of Autism Equity*—timed to coincide with events happening globally in recognition of *World Autism Acceptance Day*—is a noteworthy event for the autism community in Canada. The Autistic-authored content of this particular issue, both in text and images, is a worthy debut for this journal with its broad scope and potential.

Moving through the pages, it becomes apparent this is a different kind of academic journal. From the intricate and haunting cover art of Ryan Smoluk, whose other artwork has been featured by the United Nations, to Gerald Beaulieu's photographed sculptures and essay on the challenges of navigating an arts and culture system that is disabling to Autistic artists and silences their narratives, to Terri Robson's poetry that invites readers to understand and empathize, and even the electric-coloured side panels throughout—the issue bears the distinctive mark and innovative artistic energy of the Autistic minds behind it. This is because the journal, with its all-Autistic editorial board, is firstly a safe space intended to give primacy to the Autistic voice in a world where it has too often been ignored or demoted.

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[1] Wilfrid Laurier University, Canada

Autistic self-advocates' firsthand experiences and sense of urgency for solving system-related concerns provides a powerful source of motivation for action (something that we as family-focused researchers have witnessed in parents too). This motivation perhaps sets self-advocates apart from non-autistic researchers, professionals, policy-makers and other formal leaders in the autism community. It not only drives their advocacy, but also leads many to assume informal leadership roles. This journal is therefore important both for providing a much-needed venue to advocate, and for taking a small step towards recognizing Autistics' position as effective leaders, and at least partially addressing the imbalance with the non-autistic researchers, professionals, policy-makers and other formal experts in the autism community who have traditionally held more positions of authority than Autistics.

Several conceptual and policy-relevant articles authored by the journal's editors embody this advocacy and leadership. Amy Kim's autobiographical graphic portrays the personal identity conflict, intersectional experience, and barriers that many Autistic adults struggle to overcome related to society's lack of awareness. Ryan Collis, meanwhile, shares his analysis of the literature to understand how policy is often driven by experts with little to no direct experience with autism. Later in the issue, Kaela Scott and co-authors discuss four solutions to equity-related barriers to ensuring access to the healthcare and resources that each Autistic individual needs to achieve their full potential. And Rebekah Kintzinger provides a useful review of disability models culminating in an appraisal of the International Classification of Functioning (ICF) framework. Matthew (Maddy) Dever's video article draws attention to the importance and power of language for changing attitudes, actions, and ultimately Autistic lives. Two novel and interesting analytic articles include Cameron Winter's case study of a negatively-perceived Autistic historical figure, which he uses to critically question the possible flaws in our tendency to use historical figures to construct our understanding of autism; and Dr. Joseph Sheppard's exploration of the ethical dynamics of a peer support writing group for neurodiverse university students he founded. Finally, Dr. Mackenzie Salt draws attention to another stage of life—the "teenage years"—when there is a need to begin to engage the Autistic youth, and not just their parents, in research, so that both of these voices can be heard.

Although the journal is and will remain led and primarily authored by Autistics, it is also inclusive—true to its commitment to equity. We personally saw this in the reason we were given for being invited to write this Foreword even though we are non-autistic researchers and parents: the intention is for this journal to become a platform for all voices within the community; and so, we were told, our voices would supplement the first issue by providing some diversity of perspective.

Anecdotally there is a lot of excitement and hope from this journal from the wider autism community in Canada. And non-autistic researchers, professionals, policy-makers, and parents/caregivers, will likely make up a significant segment of the readership. Many of these readers, like ourselves, may see themselves as partially informed, but with an interest and desire to know more to inform their work, become better allies, and know how to engage with the populations they care for and serve more respectfully and appropriately.

We were invited to share our perspective as academics whose research has been caregiver-focused (one of us is also a parent of an Autistic child). At younger (particularly pre-teenage) ages, it is primarily parents who must advocate for their child's needs, navigating and accessing care and services across sectors to address the ultimate parental concern of their child's current and future happiness. Sometimes, such as when independent communication and living is never established, this advocacy and support role can continue throughout the lifespan. Therefore, as we do more to amplify the voices of Autistic people, we believe that parents' perspectives can also be a relevant part of equity-related conversations.

It is well documented that accessibility and family-centeredness of this services landscape is a problem for parents, even those with privileged backgrounds. But what about the experiences of the full diversity of families and Autistic individuals in Canada? Barriers to service access can be much higher for structurally disadvantaged populations—including Indigenous, immigrant, refugee, racialized, Northern, rural and remote, LGBTQ2IA+, disabled, and impoverished. But research that gives a voice to these groups, or provides an understanding of how to promote equity or provide culturally appropriate care, is severely lacking. The 2020 CASDA Leadership Summit equity panel article written by Scott and co-authors speaks to these important issues from a diversity of perspectives, highlighting the role that intersectionality can play in compounding inequities and poor outcomes of underserved populations. Addressing the issues facing structurally disadvantaged families and Autistic individuals alike could generate discussions of complementary experiences, such as of colonialism, racial and gender discrimination, that would enrich and deepen understandings of autism equity presented in the journal.

As the Canadian government moves towards implementing a National Autism Strategy, conversations around equity have perhaps never been more urgent. We must ensure that any such strategy does not reproduce past inequities, and includes the voices of those who have historically been excluded. The *Canadian Journal of Autism Equity* represents an important new frontier in scholarship and artistic expression, one that promises to help non-autistic people, or any privileged group, understand how to engage appropriately and respectfully with communities and cultures that may be different from their own. By promoting the values of diversity and equity, and most importantly providing a validating voice that promotes the strengths and value of Autistic people, the journal should be of interest to everyone in the autism community, and beyond.

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Editorial

Autism, Equity, and How the Journal Came to Be

Megan Krasnodembski[1], Stephanie Côté[1], Jonathan Lai[1,2]

Over the past year a pandemic has swept across the world and, unsurprisingly, revealed gross inequalities across all aspects of life. We saw this in the constant pandemic media coverage that overlooked the experiences of the disability community and, more specifically, the autism community, at least at first. Furthermore, let us not forget in the early days of the pandemic that in countries such as Italy, people without disabilities were prioritized for life-saving machines (Andrews et al., 2020; Lund & Ayers, 2020), contributing to a culture of fear for the one in five Canadians with a disability (Morris et al., 2018) about what would happen to them here. As COVID-19 reached Canadian shores we saw this pattern of inequity quickly replicated within our society. For instance, Canadians with developmental disabilities, such as autism, living in residential settings did not receive the same level of support as those living in different kinds of residences such as retirement residences (Abel & Lai, 2020). Likewise, the initial claims that only people with 'preexisting conditions' were at risk implied that those at risk were somehow less valuable to society. Nothing has highlighted the very real problem and extent of ableism within Canadian society as a whole more than these injustices arising from the COVID-19 pandemic, and this is what planted the seed for the Canadian Journal of Autism Equity (CJAE).

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[1] Canadian Autism Spectrum Disorder Alliance
[2] University of Toronto, Canada

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As these events unfolded, our organization, the Canadian Autism Spectrum Disorder Alliance (CASDA), a national alliance advocating for the rights of Autistic Canadians within federal policy, began its conversation on equity. Employing an "equity mirror", wherein an organization reflects and evaluates its relationship with equity, CASDA opened a call to its members to look at equity issues within the alliance (Schmitz, 2015). One overarching question was: How can we become more equitable? We think that in utilizing the "equity mirror" approach and in turn recognizing both the conscious and unconscious power systems that exist within our own wall has been the first step of many in addressing how we as an organization can and do perpetuate inequality. Although we have been making efforts to have Autistic and marginalized voices represented within our organization, we still have a long way to go. For instance, at the time of writing, we currently have only one Autistic Board Member. Furthermore, Autistic people were only half of our organization's speakers at our yearly Canadian Autism Leadership Summit conference, and most of our committees and working groups have only a handful of Autistic people writing recommendations for a National Autism Strategy. Also, at the time of writing, CASDA members are mostly parent organizations and researchers from large cities, and we lack representation of people of colour and LGBTQ2S+ communities in our alliance. Although we are not close to finishing looking into the equity mirror, the alliance has taken its first of many steps towards equity and, in partnership with McMaster University, has created this Autistic-led platform with the goal of Autistic and marginalized voices being heard by the federal government and Canadian decision-makers. In addition to the journal, a series of Equity Toolkits containing pieces from future issues will be released to specific groups, such as employers, on making their spaces more equitable for Autistic Canadians.

In this first issue, we ask why Autistic people are historically ignored by systems like the media, advocacy organizations, governments, and decision-makers. To begin responding to this question, we must recognize that disability in and of itself has a ranking of tolerance and acceptance, namely the pan-disability hierarchy (Deal, 2003; Hayward, 2005). This ranking reflects society's bias towards disabilities that closely fit its ideal model of an individual (Deal, 2003), for example, people with physical disabilities tend to be generally more accepted by society than those with developmental disabilities such as autism (e.g., consider the differences in accessibility standards for these two groups) (Wilton, 2000).

In addition to this disability hierarchy, we cannot downplay the effects of intersectionality. Each person has many identities, and those identities, whether gender, sexual orientation, race, background, socioeconomic status, or any others, can be an advantage or a disadvantage at different times and in different contexts. The scope of the content in this issue does not give a complete view on equity issues impacting the autism community of Canada. Nor does it give a full view of the effects of intersectionality. Instead, it provides a short sketch and an introduction to the state of inequity in Canada as perceived by each of its Editors.

So that is CJAE – the beginning of what we hope becomes a rooted platform for first- and marginalized-voiced people to be recognized and heard by decision-makers across Canada. We invite Autistic, racialized, Indigenous, and all Canadians from parents of Autistic people to government to businesses to write, draw, film, and publish with us. A unique platform such as this can add strength and power to Autistic voices and encourage federal policymakers and decision-makers to listen and make changes for a more equitable Canada. Thus, as CJAE opens the floor to voices nationally and beyond, we present to you pieces from the Editors themselves on what equity is, and more particularly, what it represents in the context of autism and Policy. We cannot wait to read, watch, and overall listen to what equity means to you. We are excited to see the change that will be mobilized as a direct result of your contributions to this journal.

With that, let's listen.

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Supporting Autistic Culture in Defining Autistic Identity

Gerald Beaulieu[1]

Abstract

Late diagnosed Autistic adults who are also practicing artists are very likely to have clues about their identities expressed in their work. This gives them the opportunity to reevaluate their meaning through a more accurate lens and proper context. It also challenges viewers and audiences to do the same and to confront misconceptions. These biases are likely to extend across all forms of cultural production. This leaves Autistic and disabled artists with a very small and unrecognized footprint in our current cultural landscape. This needs to be rectified by rejecting outmoded stereotypes and establishing committed programs of engagement with Autistic culture by our public institutions.

Résumé

Les adultes autistes qui ont reçu un diagnostic tardif et qui sont également des artistes actifs sont très susceptibles de trouver, dans leurs œuvres, des indices de leur identité. Cela leur donne l'occasion de réévaluer la signification de leur travail à travers une optique plus précise et un contexte approprié. Cela incite également les spectateurs et le public à faire de même et à confronter leurs idées fausses. Ces préjugés sont susceptibles de s'étendre à toutes les formes de production culturelle. Les artistes autistes et handicapés n'ont donc qu'une empreinte très réduite et non reconnue dans notre paysage culturel actuel. Il est donc nécessaire de rectifier la situation en rejetant les vieux stéréotypes et en établissant dans nos institutions publiques des programmes d'engagement ciblés envers la culture autiste.

Keywords

Autism, Culture, Disability, Identity

Mots clés

Autisme, Culture, Handicap, Identité

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[1] Independent Researcher, Canada

Late-diagnosed Autistic adults who are also practicing artists are very likely to have clues about their identities expressed in their work. This gives them the opportunity to reevaluate their meaning through a more accurate lens and proper context. It also challenges viewers and audiences to do the same and to confront their own misconceptions. These biases are likely to extend across all forms of cultural production. This leaves Autistic and disabled artists with a very small and unrecognized footprint in our current cultural landscape. This issue needs to be rectified by rejecting outmoded stereotypes and establishing committed programs of engagement with Autistic culture by our public institutions.

Once you make the discovery that you are Autistic after spending over half your life not knowing, it is common to review your life looking for clues and signs. When you have also made art your entire life, you look for that evidence in your work. Were there any red flags, anything obviously Autistic?

Normally, I don't do autobiographical work. I prefer broader social themes to personal narratives, so I was doubtful as to what I would find. However, in 1997 I decided to make a life-sized superhero figure, and eventually made a total of seven figures over the coming years. It was worth looking at these figures through a focused Autistic lens. What was the real story they were telling?

Now, there are lots of things to like about the superhero ethos; the action, capes, and near God-like powers. There is a reason they're popular and remain a mainstay of pop culture. My interest was different though – I was fascinated by the notion of maintaining a secret identity, of living a dual life. I wanted to strip away the disguise, render my heroes naked, and see what I would find. So that is what I did.

When you make art, at some point, you have to stop conceptualizing and start making; putting things together, working intuitively, trusting your emotions and senses to guide you. Carving my first figure, I gave him wings so he could fly. Posed him head down, arms folded, standing in quiet, patient resolve. Then, I set him on fire. If these works were to be truly autobiographical, then his state would not be of flight and soaring but of crashing and burning. Any heroism was in the resolve to keep getting up; to keep going, and to face the fate of being consumed by flames again.

Other figures were telling the same story – wrestling with the same plight, not to achieve any heroic feat, but struggling just to be. There were figures trapped in seized and rusted armour, turning themselves inside out, melting and crumbling in a state of disintegration and decay. There was no flight or fight; they were all frozen in their state of reveal. In hindsight, informed by a new awareness, what these works were revealing and exploring is the phenomena known as Autistic masking or camouflaging. This occurs when an Autistic person adapts their personality to

suppress their Autistic behaviours in an attempt to gain social acceptance (Hull et al., 2017). It is the act of creating an acceptable social persona so as to conceal one's actual personality. Because my greatest weakness wasn't Kryptonite; it was people finding out who I really was, revealing my true identity. I learned at an early age this is not what people wanted to see. I understood what stigma was and perfected my persona to avoid it. I was good at it. After all, I am an artist, and one thing I excel at is creating fictions.

In June of 2006, I finished the final works of this series at an artist residency at Gallery Connexion in Fredericton, New Brunswick. Residencies are interesting exercises, as they give you immediate audience feedback. My work was initially well received, but this success did not last long. All my attempts to show the works at other public galleries and art museums failed. At best, some curators were mildly amused. Most seemed to view the series as a misguided adventure into comic book fandom. When I made the work, I just assumed that everyone behaved the way I did – that everyone carefully observed the world around them and meticulously constructed their public persona. Carefully scripting each interaction, refining and adjusting their presence, replaying each conversation, inventing and reinventing themselves. Wasn't this how everyone moved through the world? Weren't these feelings and experiences universal? When expressed, how did they miss their mark with my curatorial peers?

Of course, these pieces failed to connect. Without context there could be no real understanding. Everything I felt and experienced was concrete, but evaporated without comprehending its source, their origins, the back story. My otherness could not be properly understood if it was not correctly defined or in tune with expectations. My experiences had no point of reference in popular culture even though I was trying to use that culture as a medium for communicating them.

This is why we need Autistic voices to define who we are, and why we need Autistic voices to be heard. It is our voices that need to articulate our experiences, to become the principal authors of our stories rather than being a footnote to someone else's narrative about who we are. Through this sharing of our experiences and our culture, we can attain a greater understanding of our place in the world and how we can contribute to shaping its future. Looking for these authentic Autistic voices in the current cultural landscape is a disappointing experience. It should first be recognized that being an artist is hard and getting more difficult; having a disability will not ease that struggle. The British neurodivergent artist Anna Berry (2017) writes:

> There is so much conversation in the art world about identity (arguably too much) – race, gender, culture, sexuality – but we're still not on an equal footing in that discussion when the identity is one of disability. It's the poor relation of identity politics. Disability is not afforded anything like the same graceful acceptance, tact, and recognition about the need for representation in that discussion […] disability is lagging way behind; roughly where other strands of identity politics were in the eighties, I'd argue. The sad reality is that it's still an identity you think twice about adopting if you want to be taken seriously in the art world (paras. 8-11).

This willingness to keep the invisible out of sight can be found lurking in institutional policies that appear to support diversity. Many arts organizations like funding agencies have user profiles to access client services. These profiles allow one to identify by gender, race, linguistic or cultural minority, with all the nuances associated with these identities. For disability, it is usually a check box with no specifics. These organizations portray disability as some unfortunate thing that happens to you. It is not something you're allowed to celebrate, but rather something you admit to having; a situation that ideally you would want to overcome if given the chance. The challenge of accommodating a population of creators with social deficits must seem too daunting to deal with in the current cultural ecosystem. It is easier to pretend the problem isn't there.

While tech companies like IBM have recruitment programs for neurodiverse talent and

Forbes magazine writes frequently about the subject, it is embarrassing to say that neurodiversity is almost never discussed in terms of cultural policy. This is where the problem becomes systemic, because the main vector in the arts for opportunity and career advancement is social networking. It is built into every network and support system – it is a ‘who you know’ business.

As an artist, you need to do two things in order to be successful. You need to make good work, and you need to get noticed. Artists that never get noticed have really lousy careers. While getting noticed is good, getting noticed by the right people is better. This is where social networking comes in to play. This is how so much opportunity happens. This is how doors are opened, and how careers are made. This is also how Autistic artists are disabled by a system they cannot comprehend, let alone navigate. This is what having social deficits looks like, and you pay a steep price for being different.

It stands to reason that if Autistic creators can’t succeed, then Autistic stories will not be told. We know the power of culture and the narratives that we construct, and we also know how important it is to see yourself reflected and participating in these narratives. We also know that succeeding in the arts is not easy to begin with. It is a tough career path with a high rate of failure. Marginalized communities often need assistance and conscious efforts at inclusion to take their stories out of the margins and into the mainstream.

The first steps are to stop making disability a dirty word. Then to recognize that neurodiversity exists, that Autistic artists are present and have something unique to say. To lift the shaming veil of invisibility and actively seek out Autistic artists. To connect these artists with audiences but on their own terms, with grace and acceptance.

It is a sad state of affairs to think that arguably the most recognized Autistic people are fictional characters created by non-autistic authors. This is our starting point in asking for equity in the twenty-first century. It is time for our cinemas, theatres, libraries and galleries to reflect who we are. It is time to embrace and recognize Autistic culture and to present the artistic endeavours of people who think differently.

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Over and Over and Over: A Continued Call for Autistic Voices

Ryan B. Collis[1]

Abstract

As an Autistic student in a master's degree, I focused on the way expertise is understood. I was specifically interested in how policy decisions in education were made without Autistic involvement. I looked at the literature that was used to make these decisions and interviewed Autistic people as to their thoughts on who should be considered experts when it comes to autism. I found that policy was driven by experts who had little to no direct experience with autism or Autistics and who had no personal connections to the approaches they recommended. I argue that Autistic people must be involved in research design, execution, implementation, dissemination, and policy decisions.

Résumé

En tant qu'étudiant autiste en train d'effectuer une maîtrise, je me suis concentré sur notre compréhension de la notion d'expertise. Je m'intéressais plus particulièrement à la manière dont les décisions politiques en matière d'éducation étaient prises sans la participation des personnes autistes. J'ai étudié les ouvrages utilisés pour prendre ces décisions et j'ai interrogé des personnes autistes pour savoir qui, selon elles, devait être considéré comme un(e) expert(e) en matière d'autisme. J'ai découvert que les politiques étaient façonnées par des experts qui avaient peu ou pas d'expérience directe avec l'autisme et les personnes autistes, et qui n'avaient pas souvent des liens personnels avec les approches qu'ils recommandaient. Je soutiens que les personnes autistes doivent être impliquées dans la conception, l'exécution, la mise en œuvre et la diffusion de la recherche, ainsi que dans les décisions politiques.

Keywords

Representation, Policy

Mots clés

Représentation, Politique

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[1] York University, Canada

I will always remember how to spell the word 'tender'. The word was one of several I would be tested on in class, somewhere around Grade 5. My mother would quiz me over and over and over before these tests, and I still remember her sounding out the word, adding a syllable to emphasize that the second letter was an '*e*' and not an '*a*'. "Tah-End-Der". Over and over and over. We would do this every week. On Fridays, all the students were given a strip of paper, the teacher read out that week's words for us to write out, and then we would pass our strip to someone else to mark as the teacher put the correct spelling on the board. Then, inundated by disappointment, I would take my strip of paper home to show my parents that I managed to fail yet another test. The education system did not train my teachers to look for the patterns I was exhibiting – I had nearly illegible handwriting, serious spelling issues, a horribly messy desk and no interventions created to assist me. This despite having the ability to read well above grade level. It was not until Grade 7 that I was diagnosed with dyslexia and dysgraphia. It was not until I was encouraged to use a computer to write my assignments that school finally became less stressful. I started to be more successful.

I had no additional problems until university when my spelling and handwriting threatened to derail me. While working on my first degree, I was fortunate that the Computer Science and Information Technology Undergraduate Program Director recognized my problems and encouraged me to go to Disability Services. It was here that a cursory examination of the poor muscle tone in my wrists and weak grip entitled me to accommodations. While access to a note taker (who was given unlimited access to the photocopier to provide me with a copy of their notes) was helpful, it was access to a computer for exams that was the most valuable. For three degrees, I was a student with learning disabilities, and I learned to cope.

After my son's autism diagnosis, I started to understand things that I had done as a child, all pointed in one direction – autism. The pulling at the heel of my socks until they tore; tearing out the tags from my shirts; throwing up when the dentist touched my tongue with the gritty polishing compound; emotional outbursts; eating the same lunch every day for decades; even the way I played with my toys or ran around watching TV after school. I was fortunate that my wife's health insurance covered the bulk of my private assessment, which I used (along with other documentation) to register with Disability Services when I went to do my fourth degree, my second Honours Bachelor of Science.

As a student in the Department of Science and Technology Studies (STS), in the Faculty of Science at York University, I became interested in the sociology of expertise, especially the work of Harry Collins. Collins (2014) questions, "who is an expert, why, and how do we know?" Besides Collins (2014), other STS authors also looked at how AIDS patients (Epstein, 1995), sheep farmers (Collins & Evans, 2002), and scallop fishermen (Callon, 1986) were experts in fields with practical experience and yet had to deal with scientists who felt that their theoretical knowledge was the only form of understanding that deserved to be considered knowledge.

It was also around this time that I joined Twitter. I attended a conference and was asked by the department to Tweet about it. As a result, I encountered disability activists and Autistic activists on Twitter for the first time: people like @AnnMemmott, @ekverstania, @drstevenkapp and @NeuroClastic. Because of what I was studying, the discussions on the exclusion of Autistic voices in decision making and policy caught my eye. I needed a topic for my fourth-year thesis and decided to investigate something I had read - that Ontario autism policies had little to no Autistic input in their design.

One of the first policy documents I looked at was the report of The Ministers' Autism Spectrum Disorders Reference Group (Ministers' Autism Spectrum Disorders Reference Group , 2007) and the biographies of the members of the group (*McGuinty Government Helping Students With Autism Reach Their Full Potential*, 2006). When I examined the list of members of this group, I found two parents of disabled people (only one of an Autistic person), two professors of "special education" (a catch-all phrase for many different types of non-traditional learners), and eight people who had worked in some way with disabled people. Three of these people had previously been on the Minister's Advisory Council on Special Education for ten, nine, and six years, respectively. While these people had lots of experience in treating Autistics and advising Ministers, none of them were Autistic. No other identity group would accept having a policy about them decided without representation. We have to ask why this is considered appropriate for autism or disability in general. I found in the report what I had heard from people on Twitter – that only one form of intervention was being recommended, that the opinions of Autistic people were not being considered and that many Autistic people were against that intervention.

Applied Behaviour Analysis (ABA) and Intensive Behavioral Intervention (IBI) were the only treatments listed in the glossary of the report (see Appendix B: Glossary of Terms (Ministers' Autism Spectrum Disorders Reference Group, 2007, pp. 62, 65). No other interventions were included. As a result of this report, the Ontario Ministry of Education issued *Policy/Program Memorandum No. 140 (PPM 140): Incorporating Methods of Applied Behaviour Analysis (ABA) Into Programs For Students With Autism Spectrum Disorders (ASD)* (Government of Ontario, 2007). This document mandated the use of ABA (where appropriate) in all schools in Ontario. It noted that "[t]his memorandum has been informed by recommendations of the Report of the Minister's Autism Spectrum Disorders Reference Group." Yet this "evidence-based" treatment was supported by only one citation in PPM 140, Perry & Condillac (2003). Both of the authors are Behaviour Analysts and teachers of ABA practitioners, but they did not declare that as a potential conflict of interest in their report on Behaviour Analysis. Bottema-Beutel et al. have found such conflicts of interest common in research on autism intervention (Bottema-Beutel et al., 2021; Dawson & Fletcher-Watson, 2021).

While PPM 140 made ABA the standard approach in schools based on the report, that same report also found that "Individualized programs conceptualized to meet the needs of the individual student" and "[s]tructured environment – structure of the school environment and activities are organized, predictable and understandable for the student" have "been found … as important and, in some cases, may be more important to child outcomes than the use of any specific technique" (Ministers' Autism Spectrum Disorders Reference Group, 2007, p. 21). This language directly contradicts the decision to mandate a single approach mandatory. Additionally, the report goes on to say that:

> … it is not true that all children need exactly the same type of treatment. Not all children need incredibly intensive intervention that takes up between 20-40 hours a week. Some children do respond, but other children do not respond to even that level of intensity and can do just as well with

> less intensive forms of treatment that are carried out in more naturalistic settings. We do not know the relative proportion of those types of children but there is now more and more scientific evidence showing us that different forms of intervention can be adapted to different types of Autism Spectrum Disorder. (Ministers' Autism Spectrum Disorders Reference Group, 2007, p. 22)

This raised the question for me: how does a report that includes a recommendation that "different forms of intervention can be adapted" and noted that predictable and understandable environments were more important than the specific intervention used become an argument that only one form of 'treatment' should receive provincial funding and support? And how does the report not cite any research that calls into question that approach (e.g., Kohn, 2020; Kupferstein, 2018; Rodgers et al., 2020; Sandbank et al., 2020; Sandoval-Norton & Shkedy, 2019; Shea V, 2005; *The Department of Defense Comprehensive Autism Care Demonstration Annual Report*, 2019; *The Department of Defense Comprehensive Autism Care Demonstration Annual Report*, 2020; Wilkenfeld & McCarthy, 2020)? I set out examine how something under the label "evidence-based" was made policy against the wishes of Autistics (as represented by many detractors on social media) and wrote a fourth-year honours thesis called "Negotiating the Meaning of 'Evidence Based' Autistic Programming" (Collis, 2019) where I interviewed Autistic people on their thoughts around treatments and interventions, and on who was considered an expert in autism. I was not the first researcher to ask these kinds of questions. Damian Milton also uses Collins and Evans' work (Collins, 2004, 2010, 2011; Collins et al., 2006; Collins and Evans, 2007) to critique how autism studies often ignore the lived experience and expertise of Autistic people in favour of input from relatives of Autistic people (Milton, 2014; Milton et al., 2014). Others are using Community Based Participatory Research (CBPR) to work with Autistic people to ask the research questions they want answered and together they cooperate on how the research is designed, carried out, and disseminated (Nicolaidis et al., 2019). For Autistic research to be valuable to Autistic people and their supporters, the research must be guided by their priorities, designed with their input, and shared so they can use it to improve their lives (Collis, 2019; Milton et al., 2014). It is research springing from such sources that must be the basis of policy decisions. We would not accept a report on the education of girls, based on scant research with potential conflicts of interest, written by authors whose only connection with women is that they have daughters or wives or worked with women in the past. We must change the attitude that policy can be made without input from Autistic people when those decisions directly affect their lives and are better informed by their lived expertise.

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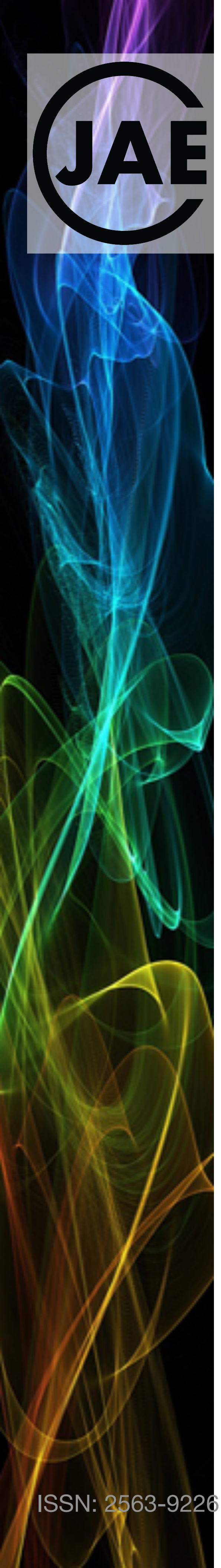

CANADIAN JOURNAL
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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

Moving From Autism Awareness to Acceptance - Language of Inclusion

Maddy (Matthew) Dever[1]

Abstract

For the last 50 years, April has been celebrated as Autism Awareness Month, and media campaigns and fundraisers have occurred alongside, trying to raise "awareness" of the difficulties and challenges associated with having a family member diagnosed with autism. The stigma that "awareness" continues to foster creates real barriers for Autistics to be seen as more than a stereotype. Many Autistics believe strongly that we need to move past a time of awareness and move to a time of autism "acceptance". Accepting who we are, and our different ways of thinking, acting, and presenting ourselves to the world. This video and associated transcript will look at how we can move from autism awareness to autism acceptance through a change in the language we use. Moving from words and thoughts that cause exclusion and segregation to words that promote inclusion and accommodation. Changing our language changes the way we think, changing the way we think, changes the way we act, and our actions can bring about change that will allow Autistics to thrive. If we change how we talk about autism in policy, in programs, in research and in media, we will change how autism is conceived of and start to see the barriers around Autistics come down.

Résumé

Depuis les 50 dernières années, le mois d'avril est célébré comme le mois de la sensibilisation à l'autisme. Parallèlement, des campagnes médiatiques et des collectes de fonds sont organisées pour tenter de conscientiser les gens aux difficultés et aux défis associés au fait d'avoir un membre de sa famille qui reçoit un diagnostic d'autisme. La stigmatisation que cette « sensibilisation » continue d'entretenir crée de véritables obstacles qui empêchent les personnes autistes d'être considérées autrement que de manière stéréotypée. De nombreuses personnes autistes croient fermement qu'il est temps de délaisser cette période de sensibilisation pour passer à une période d'« acceptation » de l'autisme. Il est temps de commencer à accepter qui nous sommes, ainsi que nos différentes façons de penser, d'agir et de nous présenter au monde. Cette vidéo et sa transcription examinent comment nous pouvons passer de la sensibilisation à l'autisme à l'acceptation de l'autisme en changeant la langue que nous utilisons, en passant de mots et de pensées qui provoquent l'exclusion et la ségrégation à des mots qui favorisent l'inclusion et l'adaptation. Le fait de changer notre langue change notre façon de penser, qui, à son tour, change notre façon d'agir. Ces nouvelles actions peuvent apporter un changement qui permettra aux personnes autistes de s'épanouir. Si nous changeons notre façon de parler de l'autisme dans les politiques, les programmes, la recherche et les médias, nous changerons la façon dont l'autisme est perçu et nous commencerons à faire tomber les barrières qui freinent les personnes autistes.

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Keywords
Awareness, Acceptance, Language, Stigma, Inclusion
Mots clés
Sensibilisation, Acceptation, *Langage, Stigmatisation, Inclusion*

Minute 1 - *History of Awareness*

It's April once again.

With that come the usual things like rain, walks outdoors, flowers, gardening, all the signs of Spring, Passover, Easter; and Autism Awareness Month.

Autism Awareness Month has been experienced in some form over the last 50 years, starting in the United States as a means to inform the public and government of the challenges of autism, and the difficulties in parenting Autistic children (Autism Society, n.d.).

Campaigns of Autism awareness began by National Autism Society in the US in 1970, and the first National Autistic Children's Week was observed in 1972 (Autism Society). This later evolved into what is now Autism Awareness Month that takes place every April in many countries throughout the world.

In 2008, after the adoption of the UN Charter of Rights for Persons with Disabilities, the UN passed a resolution (United Nations) to mark April 2nd as the day chosen to celebrate World Autism Awareness Day every year.

So after over 50 years of Awareness what has been the effect on the supports, services and quality of life of Autistic People. Has awareness been a benefit to us? Has it allowed us to thrive?

Minute 2 - *What is awareness?*

So what does awareness look like and why have autism advocates focussed on it?

In the past it was felt there was a need to let the public know what parents struggled with raising autistic children and push for increased funding for therapies and research.

The focus on awareness flows from the medical model of disability which looks at autism through its perceived deficits (Kapp, 2019). Many of the terms used to describe autism focuses on what we can't do, and emphasizes that parents need to get therapies that can intervene and fix their child (Kapp, 2019).

Some of the terms we hear in the medical model are: deficit, intervention, symptoms, red flags, risks, "special needs", as well as talk of an increasing "Autism Epidemic" (Lilienfeld et al. 2015).

In describing autism, Autistics are frequently compared negatively to their non-autistic peers in how we communicate, our social skills, and in our “behaviours” (Sasson et al. 2017).

However, evidence shows us that “awareness” doesn’t actually educate the public about autism or Autistic people (Alsehemi et al. 2017), and it doesn’t help them to understand what our needs are, or what accommodations might be needed to help us thrive in schools, in the community and in the workplace.

Awareness instead becomes another barrier and leads to continued fear and stigma, for people to be watchful and concerned.

Autism awareness has run its course.

Minute 3 - *Introducing Autism Acceptance*

So let’s talk about Acceptance.

The concepts behind Autism Acceptance come from the social model of disability, developed by disability rights activists (National Disability Arts Collection and Archive, n.d.). In it we are disabled by the barriers that exist in society, not by any internal impairment or difference. The barriers we experience can be physical but they can also be systemic attitudes of what we can or cannot do.

Autistics want to be accepted for who they are and how they think and do things.

For the last 10 years Autistics have been trying to change this message every April by instead celebrating Autism Acceptance Day and Month. Acceptance changes the focus on what we CAN do, not what we can’t do.

Now, after 10 years, other autism-focussed organizations are beginning to make the same change, including National Autism Society in the US where the original Autism Awareness started (Autism Society), and CASDA - The Canadian Autism Spectrum Disorder Alliance. (Canadian Autism Spectrum Disorder Alliance, 2021).

They are joining autistic-led organizations and adopting Autism Acceptance Month and Day - moving the conversation forward.

The message of Acceptance is that autism is not scary, it isn't something to be feared, an autism diagnosis does not mean your child is broken, and there is no “Autism Epidemic”.

So the age of Autism Acceptance is here, but how do we make acceptance a reality?

Minute 4 - *The Language of Acceptance*

Attitudes about autism are a barrier to acceptance. The way to change those attitudes is to change the words we use to describe ‘autism’ and Autistic people and not be afraid to use these words.

In fact a majority of Autistic adults prefer using Autistic as their identity. “I am Autistic” (Organization for Autism Research, 2020; Botha et al., 2020).

Instead of ‘deficit’ use “challenge”, “intervention” use “support”, “symptoms” use “characteristic”, “red flags” or “risks” use “signs”, and we don’t have “special needs” just needs (Bottema-Beutel et al., 2021).

The way we look at the “spectrum” needs to change from a linear to spherical view. We aren’t more or less Autistic, we each have strengths and weaknesses across multiple domains and this can change from day to day, over time, and in different situations. We have varying needs for supports to meet our challenges, and some of these can be quite extensive.

There is no low or high functioning, as these labels ignore the Autistic person whose strengths in some domains may mask the significant challenges in other domains and who may be held to too high an expectation. As well, the Autistic person with challenges in more areas may be harmed by low expectations, with their strengths in other areas being ignored.

What’s important is seeing our strengths, acknowledging our challenges, and supporting our needs - not our label.

Words matter.

Minute 5 - *Beyond Acceptance towards Full Inclusion*

If Acceptance is an idea, and is about changed attitudes, then what actions are needed to flow from acceptance? What is beyond Acceptance?

Inclusion. There is a fallacy that our world is an inclusive one, and that we are inclusive towards people with disabilities and Autistics. But “Inclusion”? I don't think they know what that means.

In the past many Autistics were segregated from their families/peers (Evans, 2013). Then came a push to mainstream and put Autistics together with their peers, in schools, and in the communities. Many called this “inclusion” and felt this was enough.

However, the actual term for this is “integration”. A good first step. The next step is accommodations.

Wherever we are not accommodated, it leads to more barriers, and exclusions, and a slippery slope towards segregation again. However when our needs are understood and accommodated, we are only then truly included as we are and barriers are removed.

As a society, we need to actively tear down barriers and accommodate people’s unique needs and not their labels. Let’s celebrate differences great and small.

Words can change thoughts. Thoughts change hearts. Hearts change actions. And actions can change the world.

Happy Autism Acceptance Month!

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REVUE CANADIENNE DE L'ÉQUITÉ
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Intersectionality, The Social Model of Disability, and Identity

Amy Kim[1]

Abstract

The introductory graphic represents the identity conflict that the author experiences daily. The terms represent labels assigned to the author in the past, the barriers that Autistic people must constantly overcome, and some of the social rules the author has very consciously and intentionally adopted to "fit in" with society. The accompanying experience piece outlines some of the difficulties the author has experienced that suggest that there needs to be more awareness in Canadian society regarding autism and intersectionality. Anecdotally, there appears to be a need for increased access to diagnostic and clinical services across Canada for women across the spectrum, and further investigation into how disability, race, and gender interact.

Résumé

Le graphique d'introduction représente le conflit d'identité que l'auteure vit au quotidien. Ses termes représentent les étiquettes qui lui ont été attribuées dans le passé, les obstacles que les personnes autistes doivent constamment surmonter et certaines des règles sociales que l'auteure a très consciemment et intentionnellement adoptées pour « s'intégrer » à la société. L'article qui accompagne le graphique décrit certaines des difficultés que l'auteure a rencontrées et qui suggèrent que la société canadienne doit être davantage sensibilisée à l'autisme et à l'intersectionnalité. De façon anecdotique, il semble qu'il faille améliorer l'accès aux services diagnostiques et cliniques de part et d'autre du Canada pour les femmes sur le spectre de l'autisme, et approfondir les recherches sur l'interaction entre le handicap, la race et le sexe.

Keywords

Autism, Intersectionality, Disability, Identity, Equity

Mots clés

Autisme, Intersectionnalité, Handicap, Identité, Équité

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As an Autistic woman and as a first-generation immigrant, the barriers I have faced during my lifetime have felt at times to be insurmountable. Diagnosed relatively late at 27, the revelation that there was a reason for why my life had been so chaotic and confusing was in some way a relief. However, at a major turning point in my life, this revelation also led me to the uncomfortable realization that I lived a life devoid of authenticity, which resulted in what can only be described as an extreme conflict in identity. The regret, anger, and sadness that I felt at the realization that I had spent the last couple of decades "trying to be good" and trying to conform to the expectations of other people resonates strongly with the experience of many other Autistic women, pointing to the stark reality of gender-based inequity in current clinical practice (Bargiela et al., 2016, p. 3286). The interconnectedness between ethnicity, gender, and disability in my narrative also underscores the need for autism research concerning historically marginalized groups.

From a very young age, I always felt very different from my peers. One of my earliest and enduring memories is of a classmate who I thought was my friend giving every girl in my class a Christmas present except for me, stating to a peer that I made her feel "uncomfortable". And the idea that there was something inherently and seriously wrong with me only grew as I grew. To avoid the chronic bullying I endured during my childhood, I began to "pretend to be normal", as many Autistic women report doing at some point in their lifetimes (Bargiela et al., 2016). But despite my best and most earnest attempts, I found that being negatively labelled was unavoidable.

Even though I generally tried to avoid confrontation and stay out of the way, I found that black-and-white thinking made this nearly impossible and would only result in me being seen as stuck-up, aloof, and labelled as an "antisocial bitch". If I tried to contribute to the group, then I was an insufferable know-it-all. Despite graduating as valedictorian of my high school, after disclosure, I would be assigned to alphabetizing files. Female colleagues would make off-hand and thinly veiled comments about my eating habits, making sure to whisper the words "eating disorder" within earshot. Employers would label me as bipolar following multiple misunderstandings and meltdowns. And because I collected clothing and makeup instead of stamps, trains, or buttons, I would be reduced to being vain and superficial despite my work ethic. From being asked if I am running a massage parlour at an IT job to being told I cannot possibly recognize harassment and discrimination because I am Autistic, I can say that my interactions with others have ranged from mildly irritating and confusing to truly incredulous.

There is no instruction manual for how to conduct yourself in these kinds of situations. Current conceptualizations of autism in clinical practice ignore empirical evidence that Autistic women show a higher social motivation to "fit in" than Autistic men and that females require more severe symptoms and greater cognitive and behavioural problems in order to be diagnosed (Bargiela et al., 2016; Mandy et al., 2012). Arguably, this gender bias, which can prevent the identification of needs and appropriate interventions and services, becomes even more complicated when gendered racial stereotypes and the “model minority” myth are taken into account.

Within a pan-ethnic category of “Asian”, the expectation of passivity and submissiveness commonly associated with the model minority myth is further popularized by the pervasiveness of problematic portrayals of Asian women in popular media (Cho, 1997; Lee, 2015). Perpetually caught between the stereotypes of being the meek, subservient, and overly-sexualized “Lotus Blossom", and the untrustworthy, foreign and conniving "Dragon Lady", the complex set of power dynamics culminating from this convergence of racial and gender stereotypes results in a social landscape that is, needless to say, extremely confusing for an autistic person to traverse. With characterizations ranging from the “tragically passive” to “demonically aggressive”, I was simultaneously expected to be invisible, yet part of the group. I resigned myself to a “damned if you do, damned if you don’t” mentality, which resulted in many years of unhappiness and a profound loss of self (Cho, 1997, p.185).

My recent involvement with the Canadian Journal of Autism Equity and the Canadian Autism Spectrum Disorder Alliance, and my introduction to the Social Model of Disability, has allowed me to shift my focus from “what’s wrong with me?” to “how can we improve the quality of life of Autistic Canadians and make sure their voices are heard?” (Shakespeare, 2006). In alignment with the Canadian Autism Spectrum Disorder Alliance’s goal of implementing a National Autism Strategy in Canada, this last question is one we should all be seriously asking ourselves. A paradigm shift is long overdue. As a society, we are more than capable of moving beyond moral grandstanding and flaunting “diversity” and “multiculturalism” to ensuring equality of opportunity for all Canadians, regardless of disability, race, or gender. And as for the question of, “who am I?” I am now proudly able to say that I am no one but me. And I am Autistic.

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

Equity: What Model Should We Use When We Talk About Autism?

Rebekah Kintzinger[1]

Abstract

In the Canadian disability rights movement, with regards to autism specifically, there has been a shift towards recognizing what is called a social model of disability. Through this movement, there has been a desire to incorporate that model into practice in governments, institutions, and healthcare. This desire also stems from advocate-centric and first-voice communities, where disabilities like autism are not viewed through a deficit-based lens. This article aims to discuss the often polarizing social and medical models of disability, comparing their uses in the disability world while weighing their respective benefits. Finally, an alternative model of disability that intersects these models is discussed as an alternative. This model is called the International Classification of Functioning, which recognizes three levels that impair a disabled person: the body, the person, and the environment. It is from this focus that policy can be developed to answer the calls of the pan-disability movement; to provide equitable changes across services and domains that are rightly deserved for Autistic and disabled people.

Résumé

Dans le mouvement canadien de défense des droits des personnes handicapées, en particulier en ce qui concerne l'autisme, il y a eu une évolution vers la reconnaissance de ce qu'on appelle un « modèle social du handicap ». Ce mouvement a suscité un désir d'incorporer ce modèle dans la pratique des gouvernements, des institutions et des soins de santé. Ce désir découle également des communautés centrées sur les personnes militantes et sur la défense des droits, où les handicaps comme l'autisme ne sont pas perçus à travers l'optique du déficit. Cet article a pour but de discuter des modèles social et médical du handicap, qui sont souvent diamétralement opposés, en comparant leurs utilisations dans le monde du handicap tout en évaluant leurs avantages respectifs. Enfin, nous discutions d'un modèle alternatif du handicap qui recoupe ces modèles en tant que solution de rechange. Ce modèle, appelé la Classification internationale du fonctionnement, reconnaît trois niveaux de handicap chez une personne : le corps, la personne et l'environnement. C'est à partir de cette perspective que l'on peut élaborer une politique qui répond aux appels du mouvement panhandicap, afin d'apporter des changements équitables dans les services et les domaines que les personnes autistes et handicapées méritent à juste titre.

Keywords
Autism, Disability Rights, Advocacy
Mots clés
Autisme, Droits des Personnes Handicapées, Militance

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[1] Canadian Autism Spectrum Disorder Alliance

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In my journey as an Autistic self-advocate in Canada, I have seen my country struggle with adopting a unified approach to the Autistic community's needs. In Canada, I see service providers, institutions, and the government working from the perspective of a medical model of disability which views the Autistic person as needing to be treated, or cured, or otherwise have a plan in place for their impairments in an attempt to achieve "normality" (Shyman, 2016, p.367). The widely used medical model of disability in Canada involves a disabled person, and them specifically having an abnormality or deficiency. In a medical model of disability, disability is interpreted as negative, and often pathologized as a constellation of deficits while ignoring any inherent strengths or advantages the person might have (Kapp, 2019). It is an area of health where disease is detected, identified, and treated without looking at the person.

For example, in Ontario, one of the main supports for children funded under the Ontario Autism Program is behavioural services, which include Applied Behaviour Analysis (ABA) and its more intensive form of Intensive Behaviour Intervention, aimed at teaching new skills and reducing unwanted behaviours (see Ministry of Children, Community and Social Services, 2019). ABA therapy incorporates the medical model of disability and treats an Autistic person as having a medical problem that interferes with 'normal functioning' (Shyman, 2016). The main goal of ABA therapy in Autistic conditions is to reach an "acceptable" level of normality in social, behavioural, and intellectual functioning (Shyman, 2016).

Often, on social media, I see Autistic and disabled people calling for the acknowledgement of the role that society plays in perpetuating disability through the very act of keeping people disabled. Increasingly, there are Pan-Canadian disability strategies being developed that reflect this by placing responsibility on societal structures, for example, the Pan-Canadian Strategy for Work and Disability with the workplace (Disability, 2019). I have questions about a model of disability where disability is interpreted as a negative that needs to be fixed or cured - where autism is seen as something that can and needs to be treated. A model of disability where Autistic behaviours are seen as symptoms that can and should be eliminated or reduced does not come across as socially equitable for the disabled person. It does not reflect the whole of who I am, how society is involved with my disability, how it is that my environment impacts me, and how all of this plays a role in my health and wellbeing.

This medical model of disability is a model intended to expand or improve functionality of the disabled person, but the focus is on deficit-based treatment (Anderson-Chavarria, 2021; Shyman, 2016). It should be mentioned that there is a focus on intervention that is intended to treat the disabled person's impairments or functioning level, and that this can be considered a benefit (Shyman, 2016). In fact, many medical interventions in the disabled community have been lifesaving (Anderson-Chavarria, 2021). Whatever the intention, when you focus on deficit-based treatment, the emotional wellbeing of the disabled person can suffer. For example, when I am being seen by medical professionals, my autism and the comorbidities that come with it are all that are being focused on, as if it is something to be fixed, that it is something I have to fix. I feel completely overwhelmed and depressed. Oftentimes the traits of being Autistic are viewed negatively as well, and this leads to further mental health issues that impact and interrupt my ability to be healthy and productive in my life.

The way that the medical model of disability is structured, there exist some key flaws. It lacks an element of society, and the impact that society and the environment have on someone's disability. The medical model of disability does not recognize society as a key player in the wellbeing of disabled people and how they function in society. As Berghs and colleagues (2016) wrote in Implications for public health research of models and theories of disability: a scoping study and evidence synthesis, "The medical model could be seen as especially weak in conceptualizing comorbidities or multimorbidities, which is at odds with the idea that many people will possibly experience various forms of impairment during their lifetime"(p. 53).

I notice there are also a lot of extra costs associated with a medical model of disability such as investments into technologies and research to treat impairments that the autism community experiences based on the function of the medical model. When I am being treated for my deficits, rather than an adaptation of my environment, which could be more physically attainable and cost effective for myself, I feel pathologized. I am paying for medication, communication training, physical therapy and personal training, counselling, and equipment. I feel as if the medical model of disability is used to justify large investments in areas such as pharmacology, research, and technology - when it could be better for society as a whole, if like I said, adaptations were made in the environment of the Autistic person. Another way in which the medical model falls short, is in the lack of focus on reaching a level of equality between the disabled person and the rest of society. Reaching an equal level of social inclusion does not seem to be a goal in the medical model of disability when the focus remains on treating a disabled person's deficits. It seems to be a rather unfortunate and deterministic model in deciding that the deficits a disabled person has prevent them from becoming equal in society. Furthermore, the frame of reference for the medical model of disability is that of an able-bodied person, rather than that of the disabled person's frame of reference. Thus, with this model, social balance becomes something unlikely to occur and begs the question, how can disabled people and the barriers they face be seen within the context of equity if it is not being seen from their perspectives?

Which brings me to an alternative model of disability whereby a person's disability is seen as a difference and neutral in society, rather than being deficit-based, or seen as negative (Kapp, 2019): a social model of disability. In a social model of disability, the core tenet is that it is through the manner in which society succeeds and or fails to accommodate disabled people that people are disabled and barriers are erected (Berghs et al., 2016). In this model of disability the way to success and equality is to change the relationship between society and the Autistic or disabled person, rather than forcing them to change themselves. To be more clear, this problem is not localized to only the Autistic person or the individual with disability, instead it requires society to enact the changes that need to take place to create an inclusive environment.

The social model of disability has been around for many decades, and begun as a movement in the 1970s (Shakespeare, 2006). There were many international disabled movements focused on overturning the medical model of disability (Commonwealth Disabled People's Forum, n.d.), and in 1979 the only multi-disability organization in Canada formed (Canadian Council of Disability [CCD], n.d.). It was called the Coalition of Provincial Organizations of the Handicapped (COPOH), and a headquarters was established in Winnipeg, Manitoba (CCD, n.d.). Society is moving in a more inclusive direction in a lot of areas. There has been a stronger push from the disability rights movements for governments, institutions and organizations to incorporate a social model of disability further into policy. Having said that, this "push" towards inclusivity has been occurring for decades and policy is slow to adapt change.

It's not surprising that groups and individuals would want more inclusive practices in policy and society. I have seen many Autistic movements and organizations on social media for these very things. What is surprising is that the medical model of disability is still used today when people have been advocating for change for many decades. Autistics and people with disabilities prefer the social model of disability over the medical model of disability because it recognizes the systemic and institutional barriers that disabled people face (Botha et al., 2021; Bury et al., 2020; Zolyomi et al., 2019). In terms of autism, the medical model is limited when dealing with the various symptoms, severities, and many treatment options available when accessing services (Singh, 2016). The social model of disability identifies derogatory attitudes and social exclusion in the environment of Autistic and disabled communities in order to shape that environment to be more inclusive. For example, for myself and many Autistic Canadians, the use of person-first language to identify Autistic people instead of identity-first language is especially harmful (Botha et al., 2021; Bury et al., 2020; Zolyomi et al., 2019). Person-first language follows the deficit-based medical model of disability (Anderson-Chavarria, 2021), and ends up dissociating the person from their autism by saying "Person with autism." Person-first language attaches a negative value to disability by separating it from the person (Botha et al., 2021). Society does not use person-first language when traits are highly valued, for example, we don't say "person with intelligence", rather we say "intelligent person." This is an aspect where a social model of disability recognizes derogatory attitudes in society and adjusts to be more inclusive in comparison to the medical model.

Even the social model of disability has its drawbacks, however. Its main component is that disability remains a social construct, and the question becomes, if nothing else is considered in the model, is this model too narrow of a concept (Samaha, 2007)? As much as a social model of disability identifies systemic barriers and derogatory attitudes towards Autistic people, the model does little to address the physical aspects of an Autistic person's impairment (Lawson & Beckett, 2021). I feel like the extensive list of comorbidities that come with many autism spectrum diagnoses is poorly attended to in a social model of disability. For these pain and impairment issues, the social model of disability is not equipped to plan intervention and treatment options that many health issues require. Another downside is that the social model of disability is that it is not widely applicable within the context of intersectionality of race, gender, and sexuality. In fact, it has been criticized for positioning disabled people unified into one group (Oliver, 2013). While the social model of disability is meant to address social exclusion of the disabled community from society, it struggles beyond that scope (Samaha, 2007).

So if the medical model of disability does not address society and the environment's role in a person's disability, and the social model of disability does not reflect the impacts of intersectional identities and impairment needs of the disabled person, then the question becomes, is there something more encompassing that can be used in their places? Fortunately, the answer is yes and in many countries this alternative model is already being used.

The World Health Organization published a new model of human functioning and disability in 2001 called the International Classification of Functioning (ICF) to update its previous 1980 International Classification of Disabilities Impairments and Handicaps (ICDIH) (Stewart & Rosenbaum, 2003). The updated model of human functioning and disability resolved some problematic and negative language around handicap and disability, as well as the somewhat narrow and limiting approach to consistent and chronic disabilities (Stewart & Rosenbaum, 2003). The ICF is a multipurpose classification system that was designed to be universal and use neutral language surrounding disability and health while existing in the social, cultural, environmental and physical contexts of persons with disabilities (Üstün, n.d.). For example, no distinction is made between a mental or a physical health condition and all conditions are considered equally (Üstün, n.d.).

Not only is the ICF a multipurpose classification system that is universal and neutral in its language, it "is a framework for describing and organizing information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability" (Üstün, n.d., p. 1). That means when it is used universally, it can be used for people who are disabled as equally as those who are able-bodied with no distinction between. The ICF is being used in many countries who have ratified the Convention of Persons with Disabilities, countries such as Germany, Switzerland, South Africa, Chile, Brazil, the Netherlands, and Mexico (de Camargo & Snyman, 2019; Gesley, 2017; Hollenweger, 2011; Yañez, 2019). While some parts of the ICF are being looked at in some universities and rehabilitation centres in Canada, it has not been accepted as a model of human functioning and disability for the country as of yet (de Camargo & Snyman, 2019).

Criticisms of the ICF include that it still takes from the medical model of disability, perhaps too much so - and applications of the ICF model in health research is limited (Berghs et al., 2016). Another drawback is that the ICF has been criticized for not theorizing some of its components thoroughly enough, and overlooks the impacts of poverty and inequity on disability impairments (Berghs et al., 2016). Despite these criticisms, one of the reasons that I see the ICF as a complimentary model of functioning for use in Canada is grounded in the fact that it resolves a lot of the problems that both the medical and social model of disability have had over the past decades. Its universal and neutral language addresses disability and functioning in a way that does not focus on the negative or abnormal aspects of a person's ability, which the medical model is criticized for (Üstün, n.d.). In addition to addressing the criticism of the medical model of disability, the ICF addresses some of what is lacking in a social model of disability, especially as it pertains to impairment and functioning. For example, the ICF has a domain that recognizes the role that body functions play in health and disability, whereas the social model is not structured this way. In addition, the ICF commits focus on the personal and environmental aspects that play a role in the functioning of the person. For instance, the ICF is built to universally recognize body functions, body structures, activities, participation and environmental factors (Üstün, n.d.). Body function and body structure are how each component of the body is capable of functioning and what those components are respectively. The ICF also considers activities and participation that cover things such as communication, mobility, self care, interpersonal relationships and interaction, community, social and civic life and more. Environmental factors include services, systems, and policies, attitudes, natural and man-made changes to environment, products and technology, and support and relationships (Üstün, n.d.). The last type of factor is personal factors, and has to do with what the disabled or Autistic person wants or needs to feel meaning in their life.

With the ICF, there is the health condition as well as all of the factors surrounding the health condition including the person themselves built into the model. If one factor is improved upon, it can and is likely to benefit another area. For example, if changes to the environment are made in relation to the health condition, then an area such as activity or participation will also be impacted. Or, if systemic changes were made in the way that language was used in society to reflect the autistic community's desire to use Identity-first language, a positive change might occur not only in the Environmental factors (policies, attitudes), but also in Participation factors (interaction, civic life, community) and Personal factors.

So the ICF is a more universal model of functioning and disability health that has many additional components than the previous medical or social model of disability. The language that the ICF uses is neutral in its description of health, functioning and disability, and it is intended to be used internationally. Because it involves more aspects and factors of human health and disability, it is well-suited to not only be a classification tool but also to be used in policy and research as well (Stewart & Rosenbaum, 2003). There can be much benefit to Autistic people and persons with disabilities, in policy makers considering an approach that involves neither of the polarizing models of disability discussed above, and the ICF works in tandem with the UN Convention on the Rights of Persons with Disabilities on disability data and social policy modelling. As stated in the ICF Overview, "[The ICF] provides a valuable information framework for monitoring mechanisms in order for countries to report to the UN on progress against the Convention's targets" (Üstün, n.d., p. 7).

Currently, in environments like hospitals, public service buildings, and spaces the government runs, it can be difficult or stressful to fully access the services for Autistic people or people with disabilities. It is essential to have the government engage, and have a deeper understanding of issues like this, and accommodate the needs of the autism community and bring us closer to equity in services and realize our rights more fully. Education and training are necessary in reducing stereotypes perpetuated about autism and to increase understanding of the complex needs of Autistic people in order to accommodate them in public spaces where proper accommodations are currently not in place.

Inclusive social policies happen when we address how Autistic people or people with disabilities are being denied full participation, exposed to prejudicial attitudes, and subject to inaccessible social activities. These are real issues which create the current barriers that disable

Autistic people. Through a healthy implementation of a full ICF model in Canada that aligns with the UN's Convention on the Rights of Persons with Disabilities of which Canada has ratified, we are much more likely to make these universal and inclusive policies happen, and be that much closer to an equitable future for the autism community and those advocating for them.

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CANADIAN JOURNAL
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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

Are We Equal

Terri Robson[1]

Abstract

The poems are the musings of an Aspie (not ableist, just how I refer to myself) mind, wondering where, how and if I fit in. I would suspect many on the spectrum ask these questions, or others similar in nature, themselves. I often wonder if I shouldn't just create my own niche and have you meet me there. In many ways I already have.

Résumé

Ces poèmes sont des réflexions tirées de l'esprit d'une personne Asperger (pas par capacitisme ; c'est seulement la façon dont je me désigne), qui se demande où, comment et si elle est à sa place. Je soupçonne que beaucoup de personnes sur le spectre se posent ces mêmes questions, ou du moins des questions de nature similaire. Je me demande souvent si je ne devrais pas simplement créer mon propre créneau et inviter les autres à m'y rejoindre. À bien des égards, c'est déjà le cas.

Keywords

Equity, Unique, Adrift, Trapezoid, Square Peg Round Hole

Mots clés

Équité, Unique, à la dérive, trapèze, cheville carrée dans un trou rond

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[1] Awkward Spirit: Looking Beyond the Mask, Canada

Who Are We?

What moment are we in?

Strong, resilient

Melting down, resentful

What day is this?

Good with minor moments of fear and angst

Can I push through?

I have some tools in my toolbox

Are they right for this situation?

Is it time for hard learning, a search for different tools?

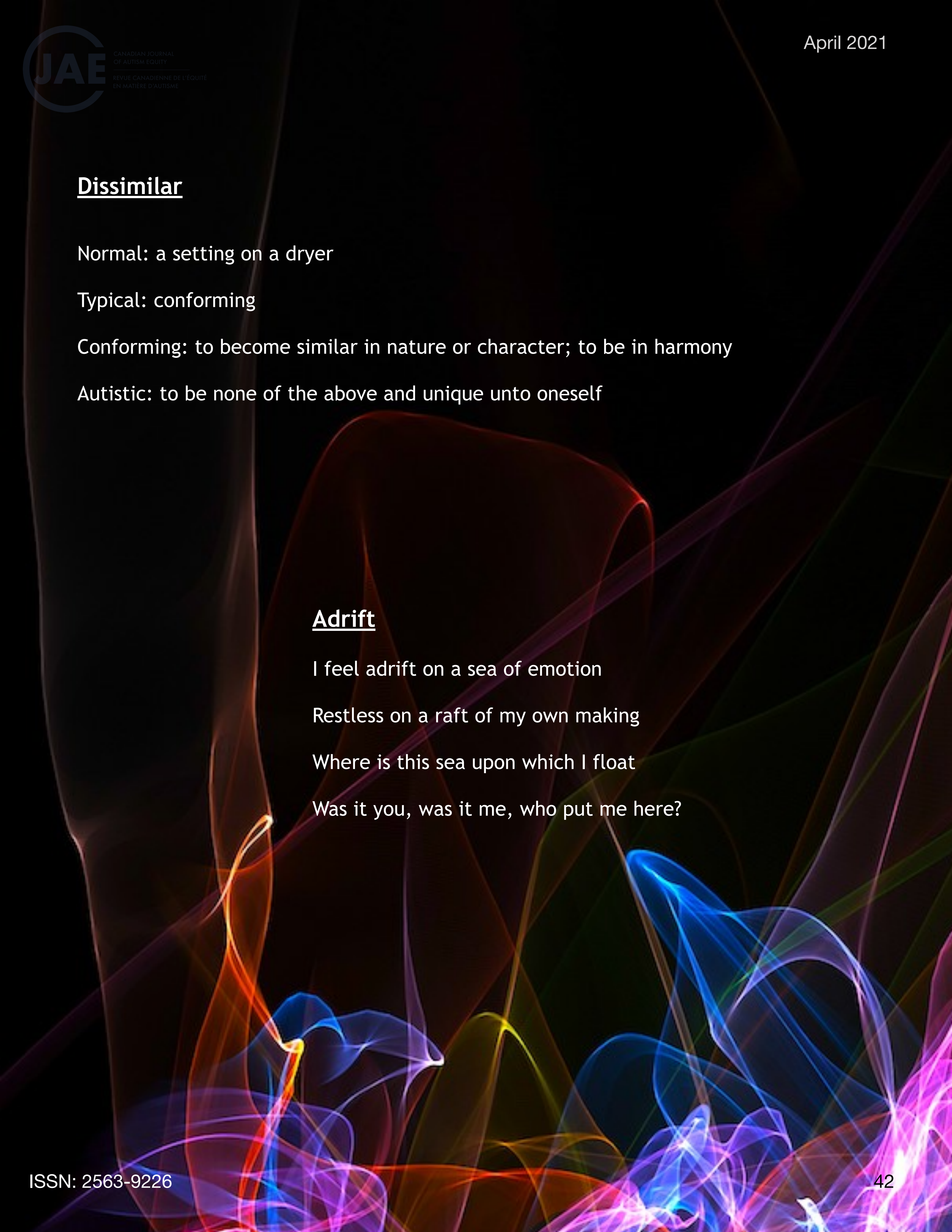
Not necessarily better, just new

Struggling with old patterns

Behaviours

They don’t work with the evolving individual

For worse or better for the ever-changing group



Dissimilar

Normal: a setting on a dryer

Typical: conforming

Conforming: to become similar in nature or character; to be in harmony

Autistic: to be none of the above and unique unto oneself

Adrift

I feel adrift on a sea of emotion

Restless on a raft of my own making

Where is this sea upon which I float

Was it you, was it me, who put me here?

Walking

Walking
Around twilight
in the dark,
bumping into things at your own peril

My life in a day as an Aspie
Crashing into awkward social situations,
Questions I don't know how to answer
Conversations I don't know how to participate in

You slide seamlessly into it all
A round peg made perfectly to fit into life's whole
I feel like a square peg, 4 corners to fit in a triangle
Do I fit anywhere? Maybe I'm a trapezoid.

You look at me; I don't look square
Yet I don't react and respond like you
I am different, but I am the same
Thoughts, emotions, questions, opinions
Just different from yours

Each one of you I meet has differing thoughts and emotions
Do you question most things so you know how you fit in
I must. I need to know how to fit into this strange world
Will I? See me as those similar to me do and give us a chance.

You'll see. We can walk together.

I Am Ready

I am ready,

Are you?

I am willing,

Are you?

I am able,

Are you?

I am all these things and more
Capable, honest, trustworthy,
Hard-working, loyal,
Willing to learn, to grow, to flourish

Teach me, work with me
Learn with me and grow with me
Together we'll make a difference

Opportunities

What don’t you see in me
Is it the magic, the wonder I see every day
Why don’t you see my talents, my gifts,
My everyday quirks
I too can do what you do,
But it may be done differently
Different doesn’t mean wrong
It means not the same

Your talents and gifts are different than mine
They are what make you unique
Yet the world welcomes many of you
With open arms, open doors,
Open opportunities
Why then are those openings closed to others like me
I do not want to change, I only want to be me
Please give me the same opportunities
You’ll see who I can be

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

A Call for Expanding the Diversity of Voices in Autism Research Engagement

Mackenzie Salt[1]

Abstract

Recently, there has been a push to increase research engagement within the autism community. Historically, research engagement has largely focused on childhood disability research and participatory autism research remains rare (den Houting et al., 2021). This gap in the literature can often result in the substitution of parents' voices for those of their Autistic children within the framework of family-centred services. This article argues that research engagement should be conducted in a way that can represent the wider autism community and cautions against allowing voices of one element of the autism community to speak for the whole.

Résumé

Récemment, la communauté de l'autisme a exercé des pressions pour accroître sa participation à la recherche. Historiquement, l'engagement de la recherche s'est largement concentré sur le handicap infantile, et la recherche participative sur l'autisme reste rare (den Houting et al., 2021). Cette lacune dans la littérature scientifique peut souvent entraîner la substitution des voix des parents à celles de leurs enfants autistes dans le cadre des services centrés sur la famille. Cet article soutient que l'engagement dans la recherche devrait être mené de manière à représenter la communauté de l'autisme dans son ensemble. Il met également en garde contre le fait de permettre aux voix d'un élément de la communauté de l'autisme de parler au nom de tous ses membres.

Keywords

Autism, Participatory Research, Research Ethics, Equity, Diversity

Mots clés

Autisme, Recherche Participative, Éthique de la Recherche, Équité, Diversité

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Over the last decade, there has been an increase in the practice of involving participants from a research population in aspects of research beyond just participation. This practice has been called, among other names, family engagement in research, family-centred research, co-design, co-research, patient-oriented research, participatory action research, and participatory research (Canadian Institutes of Health Research, 2014; den Houting et al., 2021; Moll et al., 2020; Rosenbaum, 2011; Shen et al., 2017). One of the areas that has embraced this type of research the most has been childhood disability research. This is largely because this type of research came out of family-centred service, wherein families "are seen as experts on their children, and professionals are encouraged to work with them in partnership to address the family's issues" (Rosenbaum, 2011, p. 99). Family-centred service was originally proposed in the 1940s, but it was not until the 1960s when the concept was adopted and expanded by organizations, such as the Association for the Care of Children's Health (Rosenbaum et al., 1998, p. 3). More recently, the Canadian Institutes of Health Research (2014) has adopted a framework for conducting patient-oriented research within a broader scope providing resources to allow patients to be active partners in health research. However, the practice is still largely confined to research in paediatric disabilities and neurodevelopmental conditions. Despite these areas of focus, this practice continues to be rare in autism research (den Houting et al., 2021, p. 2). While this type of research is well-intended, it is not always conducted in ideal circumstances. Especially as it relates to autism, family engagement is often in actuality only parental engagement.

It is important to note that working with parents is not necessarily a bad thing, and it can be extremely helpful to engage parents with certain topics of study. However, to properly account for the patient's perspective, it is important to engage the patient as well, not just the parent. As stated by Fletcher-Watson et al. (2019) in their paper on the importance of participatory autism research:

> Historically, parents of autistic children have been listened to somewhat, and autistic people less so. Parents, like practitioners and third-sector workers, can advocate on behalf of their children and may often be stakeholders in research themselves …. Nevertheless, consultation with parents of children on the autism spectrum should not happen to the exclusion of autistic people themselves. (p. 950)

The true issue arises when one substitutes the viewpoints and priorities of parents of children on the autism spectrum for those of Autistic people. For example, in the research study conducted by Clark and Adams (2020), while the autism community is identified as being made up of parents, Autistic people, allied health professionals and educators, their study identifies priority areas for autism research only by engaging the parents of Autistic school-aged children (pp. 1, 5–6). The average ages of the children in primary and secondary school of parents in this study were 9 and 14 respectively (p. 7). In terms of what their goal is in conducting their study, the authors note that "the research priorities of parents of school-aged children are largely understudied and consequently, the understanding of what the research priorities should be for school-aged children on the autism spectrum is currently limited" (p. 3). When discussing the implications of the results of their study, the authors note that "[t]he current findings have important implications for the future of autism research and the delivery of services offered to individuals living with autism and their families" (p. 16). While the researchers acknowledge that "it was not possible to capture children's research priorities in the current study, presenting an important area for future research" (p. 14) with no further details, the larger issue is that the researchers prioritized parental perspectives in determining future autism research agendas for school-aged Autistic children. I am confident that at least some of the children of the parents involved in this study would have been capable of responding to a survey about what priorities they would like to see in autism research if given the chance or choice, potentially yielding far different results.

The idea of taking a parent's judgement over that of their child in a research context has a long history in research ethics. Since 1977, to conduct research involving children in the United States, it has been a requirement that children over the age of 7 assent to participate in the research (Carroll & Gutmann, 2011, p. 84). However, prior to this point, parental consent was all that was required for a child to be subjected to research and experimentation (Carroll & Gutmann, 2011, p. 92). While I do not believe that current issues with research engagement in the autism community are equivalent to issues of consent or assent in research, it is important that parental voices do not replace the voices of their Autistic children or other Autistic self-advocates in research engagement. Autism is a heterogeneous condition; proper engagement requires a diversity of voices and perspectives to truly represent the autism spectrum and the greater autism community.

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

What is it About our Story: Does Ergodicity help us Understand Equity from a Neurodiverse Perspective?

Joseph Sheppard[1]

Abstract

This article explores the dynamics of equity and ergodicity in a psychological lab context including navigating consent (commitments) and transparency (debriefs). The article explores how evolutionary determinants are translated into competitive gameplay in human social interactions and how cooperative gameplay based on cultural stories counteracts harms associated with competition. Other themes that are explored is a love of learning at the center of cooperative storytelling. An Indigenous form of perspective-taking called etuaptmumk or "two-eyed seeing," developed by First Nations Mi'kmaw Elder Albert Marshall, is used as an example of ergodic intervention as a balance to cognitive biases. How are concepts of dignity and respect, as support for equity in needs, and a recognition of community member competencies and contributions, work to nurture a neurodiverse writing community where individuals can openly navigate consent, transparency, consensus, and inclusion? What are both the theoretical and practical implications of using multimodal expression such as writing on a neurodiverse community?

Résumé

Cet article explore la dynamique de l'équité et de l'ergodicité dans un milieu de laboratoire en psychologie, y compris la navigation du consentement (engagements) et de la transparence (suivis/comptes rendus). L'article explore comment les déterminants de l'évolution se traduisent par un jeu compétitif dans les interactions sociales humaines et comment un jeu coopératif basé sur des histoires culturelles contrecarre les préjudices associés à la compétition. D'autres thèmes sont explorés, comme l'amour de l'apprentissage au centre de la narration coopérative. Une forme indigène de prise de perspective appelée etuaptmumk ou "vision à deux yeux", développée par Albert Marshall, un aîné mi'kmaq des Premières nations, est utilisée comme exemple d'intervention ergodique pour équilibrer les biais cognitifs. Comment les concepts de dignité et de respect, en tant que soutien à l'équité des besoins et à la reconnaissance des compétences et des contributions des membres de la communauté, permettent-ils d'alimenter une communauté d'écriture neurodiversifiée où les individus peuvent naviguer ouvertement dans le consentement, la transparence, le consensus et l'inclusion ? Quelles sont les implications à la fois théoriques et pratiques de l'utilisation d'une expression multimodale telle que l'écriture sur une communauté neurodiverse ?

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Keywords
Equity, Ergodicity, Learning, Ethics, Writing
Mots clés
Équité, Ergodicité, Apprentissage, Éthique, Écriture

My name is Joseph Sheppard. I am diagnosed with autism, and I share psychology concepts to communicate stories about social repair. This story shares my perspective about "equity" in the context of consent, transparency, inclusivity, and the reward of sharing narrative experiences.

Themes associated with "equity" are often encountered in a psychology lab context. Sometimes I work as a lab instructor in a psychology methods course at the University of Victoria. In a lab setting, we learn the foundational and functional competencies required for doing psychological experiments. Foundational competencies are capacities to regulate behavior according to mutual commitments towards ethics and social protocols; functional competencies are capacities to complete necessary tasks for conducting experiments. In the lab, foundational and functional competencies work together to safeguard each participant's dignity according to their diverse needs. Consent is acquired to preserve dignity at each step of a series of carefully planned inclusive activities. And we science detectives must be transparent about how we intend participants to be impacted by each procedure in our activities.

In the lab, we use American Psychology Association (APA) ethics as a basis for our foundational competency, including its five principles of benevolence, personal integrity in science, responsibility to others, justice as inclusivity, and safeguarding each's diverse needs for dignity. These APA principles are shown to be valid and reliable constructs that optimize psychological safety for everyone participating in an experiment. Thus, maintaining the dignity of all participants is a baseline from where each contributes to tasks and associated responsibilities utilizing their respective competencies.

We have many practices in the lab, including not gossiping about others and respecting privacy and confidentiality, and giving space for debriefing participants so they may process their experiences and can ask any relevant questions. We safeguard each other's stories and names along with their bodies, spaces, and identities. We do not use APA ethics as a replacement for our cultural stories and moralities. Instead, APA ethics are used to share scientific knowledge in a way that is inclusive of humanity's many diverse cultural narratives.

In other words, when we practice safeguarding baseline dignity, we learn together to behave and interact responsibly to maintain each other's core needs. Maintaining this baseline of dignity as a social ensemble is indicative of developing social equity. Equity pertains to maintaining each's needs across their lifetime, inclusive of needs specific to their diversity. Each person's needs are different, so equality of needs does not equate to equality of resources. Should scientists ask if a needs-based approach to equity broadly equates to adjusting human societies from non-ergodic to synthetically ergodic ensemble systems? I am curious because I do not know. Scientists ponder what we do not understand in dialogue with other scientists. Ergodicity may refer to circumstances whereby an individual system (or agent) changes over its entire temporal lifespan in equal measure to the change experienced by the ensemble population as measured in a single instance.

I am not an expert in ergodicity. Therefore, I am more curious to find questions than share answers. As a psychology lab instructor, I sometimes build hypotheses from my curiosity to predict the cognitive unknown and question unexplained psychological processes. Does our conversation and actions in support of equity, conditioned to needs and responsibilities, balance our conversation and actions in support of competitive gameplay, conditioned to winning external rewards?

Ergodicity also refers to each agent's tendency to visit all the microstates within its system. When we think of physical needs, we may consider a host of goods and services needed by each person to function and retain connection without undue suffering or risk to safety. Therefore, human life may be described as a trajectory of experiences that visit all the microstates in their environment, inclusive of needs, indicative of experiencing a recognizably human life. Each agent is diverse, with a unique trajectory, so this family resemblance between human lives may be indicative of how humans can recognize a common sense of humanity in others across cultural narratives as social ergodicity.

When I think of being in a state of "need," I first consider psychological distress. When my needs are met, I am typically removed from psychological distress. My rationale for studying psychology was to help learn and discover optimal means of reducing psychological distress with the use of valid and reliable mechanistic processes. Part of the equity conversation is about inclusive access to the goods and services required for human bodies to have their needs met. To have Voice often requires being above a threshold of the noise of psychological distress.

There are physical needs met by diverse individuals in different measures, the withholding of which, below a threshold, becomes punishment conditioning rather than negative reward conditioning. Negative reward conditioning is withholding reward rather than evoking harm. Does equity serve as a measure of human needs that are irremovable without loss of dignity? In other words, at what point of needs scarcity does withholding reward become a punishment? Psychological distress may also cause marginalization of Voice and vice versa. This marginalization of Voice may result in personal absences from roles in cultural stories connecting families and generations. Human beings have language faculties, so we have signature Voices. We are super unique--all of us. Could ergodicity also pertain to a lifetime of stories being equal to a moment of interwoven stories connecting the population?

We have physical needs for resources and services required to live in dignity and safeguard Voice, but once having Voice, do we also have needs for sharing stories as a context for Voice? Could a human with a language faculty, a Voice, visit all the microstates within a human life story, not necessarily as a linear trajectory, but as a constellation of scene elements connected by story meaning?

A participant's experience in a lab experiment should be indicative of participation in any given experiment that sets its initial conditions to be consistent with APA ethics. Ergodicity is highly vulnerable to initial conditions where individual histories can significantly diverge from expected probabilities of population behaviour. Non-ergodic influences include evolutionary determinants like natural selection and human influences from conditioned cognitive biases and Ethics are used in the lab to control these initial and operational conditions so that each participant expects a safe experience, much like any other participant. Ethics are like game rules that set initial and boundary conditions for probable benevolent outcomes. However, evolutionary game theory conceptualizes human interactions along dimensions of dominant high-risk versus compliant low-risk orientations in competitive contexts that produce labeled "winners" and "losers."

Ethical principles not only contend with evolutionary game theory dynamics, but they also contend with each other. For example, "consent" typically enables everyone to opt-out of active participation, and "inclusivity" typically enables everyone to opt-in to active participation. Consent may strengthen personal boundaries, and inclusivity may act to reduce another's exclusion based on preconceived prejudicial personal boundaries. When boundaries are broken, psychological distress may increase. Thus, careful consideration of negative interactions between prescribed ethics may be required. May a measure of ergodicity be used to decide which ethics principle better decreases non-ergodicity?

APA founder and psychologist John Dewey described humans as a product of their urges, conditioning, and love of learning. Renninger, Sansone, and Smith (2004) describe the love of learning as a predisposition to keep re-engaging in a well-developed interest that causes positive feelings. Moreover, the love of learning is considered something regulated by the teacher-student relationship until they learn to self-regulate a self-generated motivation to continue learning and growing as students and sharing as teachers. For John Dewey, nurturing a healthy teacher-student relationship that promotes the independence and curiosity necessary for a self-regulated love of learning was central to the role of education in society. This dyadic relationship dedicated to co-learning is at the centre of the policies that govern a psychology lab. In a lab, a healthy cooperative teacher-student relationship replaces competitor dyadic relationships between dominant and compliant agents. Each person learns and can use Voice conditioned to self-advocating and taking responsibility for regulating an equity of needs versus instinctually aggressing others and intentionally conditioning others for control.

Thus, a love of learning offers hope to increase ergodicity in human society so that each person may expect a currency of needs equity that balances with a currency of external rewards. In this conceptualization, "wants" can be viewed as a subset of "needs" and not as a replacement or competitor to "needs."

I claim that equity is a specifically human form of ergodicity that emerges when empathy counterbalances non-ergodic external reward optimizing cognitive bias algorithms. For example, confirmation biases may generate preconceived notions of others that may pass costs to other individuals to reduce the variability in outcomes for a marginalized in-group. Ableism, in the context of neurodiversity, is the preference for people conforming to the average behaviours of the population, that is, neurotypical expressions, over a preference for neurodiverse folks.

Confirmation bias can also be unconscious such as in the case of latent biases involved in malevolent stereotyping. Human confirmation biases often generalize individuals according to learned categories and projected negative connotations falsely associated with their intersecting identities or in-groups.

When we use story-guided cooperative game theory, we diverge from evolutionary gameplay that is optimized for competition; and even human cognitive biases that are further optimized by evolution for competition. Human history describes how systemic use of punishment and stereotyping have marginalized preconceived categories of people. Non-ergodicity increases when an out-group is marginalized based on preconceived categories; so that they carry the bulk of ensemble risk, and little responsibility or ensemble risk is carried by a preconceived privileged in-group. Loss of ergodicity causes stalls in mixing, including social mixing and interconnection of stories. Does this reduction in mixing cause people to stop visiting the full range of human experiences indicative of a person's unique story?

I use Martin Buber's distinction between human-to-human relationships that are either "I and Thou" as accepted interpersonal Voices or "I and It" as accepted foundationally and functionally competent relationships. I add another category of "I and Marginalized" as broken relationships with those socially constructed as Voiceless or as functionally dismissed. These three caste-like interpersonal relationships may be viewed as a by-product of non-ergodic evolutionary human behavioural tendencies. Thus, non-ergodic societies may differentiate between persons as accepted persons with Voices, persons as useful machines, and persons as estranged outsiders.

Como et al.'s (2020) research show that an autistic person may encounter ableism through other people's preconceived notions or stereotypes, marginalization or silencing, and microaggressions or behavioural punishments. These characteristics of ableism translate roughly to forms of ostracism indicative of outsourcing social costs based on preconceived biases towards neurodiversity identities. The lens of ableism often dismisses the value of neurodiverse Voices as either only technically useful or not being of use, but rarely worthy of being considered a "thou" as a meaningful role in another's story.

An evolutionary theorist may expect to sample organisms found in nature and see two entities in relative symbiosis, predator and prey, and a third class, those pushed from their environment due to the consequences of natural selection. However, an equity model based on ergodicity is wholistic and does not produce dualistic "winners" and "losers" and, therefore, is synthetic to how evolution typically operates.

Humans process the world of facts as meaningful in differing ways according to their stories, and we are all diverse by multiple variables. Ethics, as initial conditions, likewise do not always cohere together. However, could ergodicity be a measure of how some bridges work better to connect stories or how ethics find balance with each other? May some stories or ethics be more ergodic than others? Is the love of human learning more ergodic than automatic learning associated with urges and conditioning? How does nurturing a sense of responsibility to care for needs and a capacity for self-advocacy to recognize needs differ from reinforcing behaviours optimized for competition? How are we conditioned to debate cultural narratives in a manner that adds to systemic biases and further competitions between debate winners and losers rather than a goal of holistically seeking bridges in narrative perspectives leading to meaningful and transparent consensuses? How do we, those with language faculties embedded in a story, become enthusiastically consenting co-authors in our chosen, but "thou" inclusive, ergodic stories of tomorrow interlinked with contextual, cultural stories? I seek questions because I am a scientist in search of verifiable hypotheses, and questions are what spark the love of learning and the recognition of our narrative ground. Could our love of learning and storytelling become responsible for an ergodic turn to preserve our odd species with language faculties, well into time and well out to the stars? Could the idea of equity as ergodicity be better understood as Etuaptmumk? Etuaptmumk is an Indigenous Way of Knowing focusing on cooperative perspective-taking using diverse stories from Elder Albert Marshall of the Mi’kmaw Nation. I do not identify as an Indigenous Voice from Turtle Island, so I encourage readers to learn more about Etuaptmumk from Indigenous Voices and Knowledge-Keepers. Humans are never disembodied from stories, needs, or lands. I wrote this article from the University of Victoria on Vancouver Island, Canada. I am thankful for my time here. I acknowledge and respect the lək̓ʷəŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

Watch the full video here. https://youtu.be/7CSjjsIX58w

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REVUE CANADIENNE DE L'ÉQUITÉ
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Nothing to Bragg About: Examining the Search for Autistic Representation in History

By Cameron Winter

Abstract

Using the career of infamous Confederate General Braxton Bragg as a case study, this article poses questions about how we search for and discuss possible examples of Autistic people in history. The article contends that we need to reconsider what we hope to accomplish when posthumously diagnosing historical figures and the way in which those discussions are structured, cautioning against both the hunt for role models and the tendency towards defining people by their disability.

Résumé

En utilisant la carrière du tristement célèbre général confédéré Braxton Bragg comme étude de cas, cet article s'interroge sur la façon dont nous recherchons et discutons des exemples possibles de personnes autistes dans l'histoire. L'article soutient que nous devons reconsidérer ce que nous espérons accomplir lorsque nous diagnostiquons des figures historiques à titre posthume, ainsi que la façon dont ces discussions sont structurées, en évitant le piège de chercher à trouver des modèles d'identification et la tendance à définir les gens par leur handicap.

Keywords

Autism, history of neurodiversity, Braxton Bragg, American Civil War

Mots clés

Autisme, histoire de la neurodiversité, Braxton Bragg, guerre civile américaine

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Early in 1863, following his repulse at the Battle of Stones River, Confederate General Braxton Bragg, in a move that has baffled historians to this day, circulated a letter to his subordinates. In it, Bragg inquired as to whether his generals agreed with his recent decision to retreat, ending with an offhanded remark about how he was prepared to resign if they did not. The response he received was unanimous and, to Bragg, infuriating: his sub-commanders thought Bragg had been entirely correct to retreat and that he should resign anyway because none of them had any confidence in him. Viewing this as an attack on his person, Bragg stayed on to spite his critics, creating a toxic atmosphere at headquarters that, in the view of many historians, thoroughly poisoned the ability of the Army of Tennessee to function in future battles (Hess, 2016, p. 136-137).

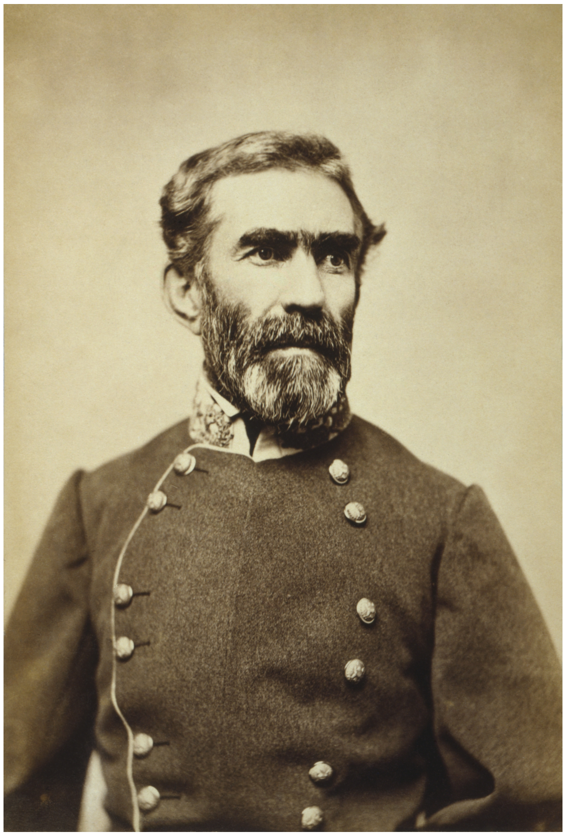

Figure 1. *Gen. Braxton Bragg*
Note. By Unknown author, restoration by Adam Cuerden, Wikipedia https://upload.wikimedia.org/wikipedia/commons/6/6e/Braxton_Bragg.jpg

The root of the discord between Bragg and his officers lay in the wording of his letter. Bragg believed he had asked them a single question, regarding whether the retreat had been a mistake, with his resignation being offered if they believed that it was. Bragg's letter, however, phrased this not as a question and an offered solution, but rather as two separate questions. They answered both, and in doing so, permanently ruined their relationship with Bragg; the rigid-minded General's good opinion, once lost, being impossible to regain. Bragg's future campaigns against Chickamauga and Chattanooga, unsurprisingly, foundered on this undercurrent of ill-will between him and his subordinates, an ill-will that historians have spent the better part of a century and a half trying to untangle (Hess, 2016, p. 136-137). Perhaps they have been searching for answers in the wrong places: given Bragg's many eccentricities and personal quirks, the explanation for what happened after Stones River may lie not in Bragg's external relationships, but within the General's own mind.

This certainly was not the first or last time the socially inept Bragg landed himself in hot water. Described by contemporaries and historians as austere, aloof, dyspeptic, and a martinet, Bragg was infamous for his inability to get along with any of the men he served with and left a trail of bruised feelings and bitter recriminations wherever he went.[2] Moody, sarcastic, and apparently oblivious to the feelings of others, Bragg caused a minor scandal when he referred to one of his

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[2] Hess' preface (pages xii through xx) offers a thorough look at what historians have traditionally said about Bragg, and the primary sources they have drawn on to do so.

divisional commanders as a "useless old woman," in front of his staff, and offended junior officers serving under him by refusing to speak to them in person, communicating only through his staff officers (Hess, 2016, p. xiii). Not every personality conflict was Bragg's fault—few generals managed to get along with blustering Leonidas Polk and psychopathic Nathan Bedford Forrest, who were among his most vociferous critics—but Bragg's lack of social tact and inability to gauge the impact of his words also destroyed his relationships with men who had once been his friends.[3] Corps commander Thomas Hindman, once a strong supporter of Bragg, turned against him after Bragg dressed him down in front of his men (Cozzens, 1994, p. 86). Bragg's fulminations against the treacherous nature of Kentuckians after a failed campaign in that state persuaded Kentucky officer John Breckinridge, whom Bragg had specifically requested for his army, that the General was plotting to have him, and all the other Kentuckians in the army, killed (Cozzens, 1991, p. 52). Bragg, for his part, was mystified by Hindman and Breckinridge's sudden dislike for him, apparently unable to connect the dots between the things he had said and their changed attitudes.

Bragg's obsessive rule-following and literal mindedness did not make his life any easier. Going back to his days as a junior officer, Bragg regularly fell out with his superiors when he questioned their decisions or objected to their refusal to enforce discipline to the standards set out in the army guidelines. On one occasion, when a reporter made a joke about Bragg's native North Carolina not being a real state, Bragg challenged him to a duel, not because of the insult to his state, but because he took the joke literally and truly thought the man was denying its existence; when the reporter altered his statement to say that North Carolina existed but was terrible, Bragg backed down (Hess, 2016, p. 3). During the Civil War, Bragg earned the hatred of his men when he executed a soldier for murdering a Black civilian, something few other officers in the Confederate Army (who were, after all, fighting to keep African-Americans in bondage) would have done. To Bragg, however, the decision was clear: the man had violated the rules of war, and had to be shot, impact on morale and Bragg's own reputation be damned (Hess, 2016, 44-45).[4]

Union General-in-Chief, Ulysses S. Grant, who opposed Bragg at the Battles of Chickamauga and Chattanooga, recalled in his memoirs a story he had heard that well-encapsulated how the socially awkward Bragg was viewed by his peers. Doing double duty as a fort's quartermaster and the captain of one of the companies defending it, Bragg, as company commander, put in a request for supplies, and as quartermaster, denied it. As company commander Bragg then appealed the denial, and as quartermaster he fought the appeal. Unable to work out this conflict of interest on his own, but also unwilling to ask for help through normal channels, Bragg referred the matter to the fort commander, who on becoming aware of the situation exclaimed: "My God, Mr. Bragg, you

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[3] David A. Powell's (2016) *Failure in the Saddle* argues, fairly convincingly, that Bragg was signally ill-served by his cavalry commanders, specifically the malcontented Forrest and the incompetent Joseph Wheeler, whose dislike of one another damaged the Army of Tennessee almost as much as Forrest's distaste for Bragg.

[4] Hess' own neo-Confederate sympathies shine through here when he describes the killing of a Black civilian as a "trivial reason" to execute a soldier, and tries to prove, unconvincingly, that the execution was for killing a pig, with Bragg relenting at the last moment and letting the man go.

have quarrelled with every officer in the army, and now you are quarrelling with yourself!" Grant admitted he did not know if the story was true, but he definitely thought it sounded like Bragg, and that was damning in and of itself (Grant, 2017, p. 450).[5]

The tragedy of all this, at least from the Confederate view, was that Bragg was not an unintelligent officer. He came up with excellent plans: yet again and again, his inability to get along with his subordinates, or to communicate his intentions to them, sabotaged his schemes. At Stones River, Bragg executed a brilliant turning maneuver that wrecked Union Major-General William Rosecrans' vanguard, but also thoroughly disrupted his own chain of command until orders became impossible to relay and the offensive broke down (see Cozzens, 1991, for the best existing analysis of what went wrong at Stones River). The same problems bedevilled him at Chickamauga and Chattanooga, with Bragg insisting his officers were disobeying his instructions, while they swore Bragg never made his intentions clear (see Cozzens, 1996, 1994, respectively). Bragg himself was at least dimly aware of his issues on this front, and in his letters to his wife bemoaned the fact that she was the only one who had ever truly understood him and expressed a wish that he could talk to other people as easily as he did her. Said Lieutenant-Colonel Archer Anderson, who served under Bragg for much of the war, "General Bragg seemed to know always what ought to be done, to possess the decision and the will to order it to be done, but, by some strange lack of gift, where so many gifts abounded, he could not do it himself and he could not make others do it" (Cozzens, 1994, p. 17). Depending on which historians one asks, Bragg's failures to manage his officers lost the Confederacy the Civil War in the West and helped bring about the end of the secessionist project, and with it, slavery in the United States.

Clearly, Braxton Bragg's communication difficulties were of considerable import to the history of the United States. Yet the source of those difficulties has tended to go unexamined beyond general commentary on Bragg's acerbic personality. That Bragg was, in some fashion, socially handicapped, is not really in question: his problems talking to subordinates and superiors are a matter of public record while his mercurial emotions and episodes of depression were commented on by all who knew him. Yet no one, at least to this author's knowledge, seems to have asked the following question: was Bragg's handicap *literal* as opposed to figurative? Was the Confederate high command failing to accommodate a neurodivergent general at a time when terms like "neurodivergent" had yet to be invented? Put more bluntly, was Braxton Bragg Autistic?

It is an impossible question to answer with certainty, but the evidence does seem to be there, especially when contrasted with other historical characters who are assumed to be on the spectrum. Figures like Sir Isaac Newton and Albert Einstein have been diagnosed, in the popular consciousness at least, on the basis of the details of their personal lives and little more. Bragg, however, as the leader of an army, left behind a vast body of primary sources in the form of orders, courts-martial transcripts, minutes of meetings, his own correspondence, and the

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[5] Hess contends the anecdote is entirely untrue; other historians take it at face value. This article offers no opinion on its accuracy but believes the story does demonstrate how Bragg was seen in the eyes of others.

correspondence, official and unofficial, of the subordinates, superiors, political masters, and even enemies, who had to deal with him. Anyone interested in tracking the rise and fall of an Autistic general could easily comb through those sources for evidence, yet no one has. The Autistic community, eager to claim men like Newton and Einstein, has not sought to claim Braxton Bragg, despite the ease with which it might be done. The question then needs to be asked: why is that?

Obviously, Bragg is not a household name in the way that Newton and Einstein (or Civil War contemporaries like Grant and Robert E. Lee) are. For those wishing to communicate with as wide an audience as possible, the urge—and perhaps the need—to draw on examples that their audience is already familiar with will always be there. Yet at the same time, Bragg is hardly an obscure figure, either. Anyone who reads about the American Civil War—a perennially popular topic not only within the United States, but without it—will quickly come across Bragg, and, soon after, the myriad interpersonal dramas in which he embroiled himself. Until just recently, a US military base, Fort Bragg, bore his name, and many landmarks below the Mason-Dixon line still do. Moreover, the case for Bragg being on the spectrum is easy enough to make that one might expect it would more than compensate for his comparative lack of fame. What else, then, is at work here?

The fact that Braxton Bragg makes a poor role model may be one of the factors telling against him. A traitor to the United States and a devoted proponent of slavery, Bragg was a bad officer and a worse man, and can hardly be held up as an Autistic success story the way that a Newton or an Einstein, who, whatever their personal failings, are generally well-regarded by the public, can. Even those who are morally dubious enough to offer apologetics for the Confederacy, are unlikely to sympathize with Bragg. A recent biography was entitled *The Most Hated Man of the Confederacy*, and it did not exaggerate; Bragg's reputation as a thoroughly unpleasant human being defines his legacy and his portrayal in most historical works (Hess, 2016). That reputation is a turnoff even for most dedicated historians of the Civil War, and it is not hard at all to imagine circumstances in which historians of autism, searching the history books for examples, came to the entry on "Bragg, Braxton," and after a brief perusal, quickly turned away.

An argument could even be made that, if Bragg was Autistic, we have an obligation not to talk about it for fear of poisoning the public against people on the spectrum. A reading of Bragg's papers does, after all, make it apparent that his support for slavery stemmed from the institution enabling him to run his planation without having to negotiate with, or even communicate with, his workers, something the socially anxious North Carolinian found a tremendous relief (Hess, 2016, p. 10-12). A sufficiently bad faith actor might use that to contend that Bragg was a slaver, and subsequently, a traitor, *because* he was Autistic, and using that information, paint all Autistic persons with as broad and black a brush as can be imagined. Bragg's demonstrated incompetence in high command would only add to that case, presenting a very unflattering portrait indeed of those of us on the spectrum.

Yet such a portrayal of Bragg would, unfortunately, be the logical inversion of the hunt for role models. While there is nothing inherently wrong with saying "Isaac Newton was probably

Autistic" in an effort to reduce the stigma against the disorder, it can, and often does, go wrong when diagnosis is treated as destiny. While our society has made significant strides in how we discuss *physically* disabled historical figures (few people would, for instance, define Franklin Roosevelt by his inability to walk), the same cannot be said for those we suspect to have been psychologically different. Too often, the author has encountered people who not only assume that Newton, Einstein, or pick-your-scientific-genius was on the spectrum, but that their genius stemmed *from* their being on the spectrum, a form of positive stereotyping that nevertheless reduces these men (and they are almost always men) to being the sum of a diagnosis that they may or may not have had. This kind of thinking, however well-intentioned, is lazy and ableist when applied to an Isaac Newton, and becomes ugly to the point of repulsion when applied to a Braxton Bragg, as demonstrated in the paragraph above. This in turn condemns figures like Bragg to remain undiscussed when talking about neurodiversity in history, in the hopes that we can avoid giving ideas to those with malignant intentions.

This is a shame, because our goal in talking about autism in history should be about more than just the quest for role models. It should be about the lived experience of having an invisible disability at different periods in history, and Braxton Bragg, and others like him, could be an invaluable part of that conversation. It should also be about reminding the public that autism and other forms of neurodivergency are not new, and are not the product of modern society, or vaccines, or whatever other pseudoscientific ideas the Internet seeks to push on us. Braxton Bragg may have been an inveterate jackass, but he did not get that way because of a measles vaccination, and when it comes to pushing back against conspiracy theories, he serves as effective an example as any. He might even be a better example than some of the role models mentioned above, for while the behaviour of a Newton or Einstein might be possible to write off as the eccentricity of a successful man, Bragg's career-damaging *faux pas* are much more difficult to ignore—and are attested to in official government documentation.

Moving beyond questions of incorporating these historical figures into the modern quest for social justice, every potential example we can uncover also allows us to ask questions about the society they hailed from. Assuming that Isaac Newton was on the spectrum, what was it about the scientific community in his day and age that enabled him to be as successful as he was? In what ways did his neurodivergence help him? In what ways did it hinder him? The same questions can just as easily be asked about Bragg. What was it about the Confederate hierarchy that enabled Bragg to rise as high as he did and to maintain his position for so long as he did, yet prevented him from achieving success while he was there? Why did Confederate President Jefferson Davis, the ultimate arbiter when it came to military commissions, keep Bragg on even as the personal scuffles between him and his subordinates mounted, and was Davis' judgement as poor as has often been assumed? It would only be justice to Bragg to, at this juncture, note that Davis did eventually find a post that suited the cantankerous general better than field command. This was as Davis' personal military advisor, and *de facto* chief-of-staff and inspector-general of the Confederate Army. Put in a position involving hard numbers and that limited the number of individuals he had to deal with, Braxton Bragg made real contributions to the last year of the Confederate war effort, imposing order on a supply system that had been heading for disintegration (Hess, 2016, p. 241). What was it that allowed Bragg to do that, and was it linked to the same mindset that made riding herd on his underlings so impossible for him? Were there other figures in the Confederate—and for that matter, the Union—ranks like him, and if so, how similar were their experiences, and what do those experiences say about their respective armies?

This article is not meant to conclusively argue that Braxton Bragg was on the autism spectrum, one hundred percent guaranteed. Such an undertaking would be impossible. Rather, it aims to question the ways in which we discuss the history of autism, and, more broadly, neurodivergence and disability. Some historians believe that psychoanalyzing the past is a waste of time. The author does not share that opinion. We should, however, consider at all times our own motivations in doing so, and ask what, precisely, we are hoping to prove. Neurodiversity deserves a place in the historical conversation, but determinists and those who only play with history in hopes of finding "good role models" need not apply.

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Toward Health Equity in a National Autism Strategy: A Lens on Disparities, Barriers, and Solutions

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Abstract

Health equity allows people to reach their full health potential and access and receive care that is fair and suitable to them and their needs regardless of where they live, what they have, or who they are. To achieve health equity, equity in healthcare focuses on the role of the health system to provide timely and appropriate care. When viewed in the context of a National Autism Strategy, this extends to ensuring access to the resources that each Autistic person requires to meet their health needs, such as an autism diagnosis, services, and supports. Based on the equity panel discussion held at the Canadian Autism Leadership Summit 2020, this article reflects on the current disparities and barriers to achieving health equity in a National Autism Strategy, and outlines ways to address them. Disparities to equitable care within the autism community extend from the level of support needs of an individual to how those intersect with several key determinants of health including: geography, culture, gender, and socioeconomic status. Notably, barriers arise due to a "lack of" theme, including lack of awareness, knowledge, access, and voice. Four reoccurring ideas were identified for how to address inequities in health care for Autistic people. First, allocate resources for regional or in-community endeavours; second, improve Autistic representation and connection; third, establish a community of allies to advocate and collaborate; and fourth, establish leadership within the community and government to make disability a priority for Canada. To achieve equity in health care in a National Autism Strategy, we need to look at the intersectionality of autism with the key determinants of health. Moreover, to effectively engage with the government, health professionals, and the public, the autism community should strive to find a unified and diverse voice. And finally, conversation must turn to action.

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Résumé

L'équité en santé permet aux gens d'atteindre leur plein potentiel de santé et d'accéder et de recevoir des soins qui sont justes et adaptés à leurs besoins, peu importe où ils vivent, ce qu'ils ont ou qui ils sont. Pour atteindre l'équité en santé, il faut se concentrer sur le rôle du système de santé dans la prestation de soins appropriés et en temps opportun. Dans le contexte d'une Stratégie nationale sur l'autisme, il s'agit d'assurer l'accès aux ressources dont chaque personne autiste a besoin pour répondre à ses besoins en matière de santé, tel que le diagnostic, des services et des mesures de soutien. Basé sur la discussion du groupe d'experts sur l'équité qui s'est tenue lors du Forum canadien sur l'autisme de 2020, cet article se penche sur les disparités et les obstacles actuels à la réalisation de l'équité en santé dans le cadre d'une Stratégie nationale sur l'autisme, et présente des moyens de les éliminer. Les disparités en matière de soins équitables au sein de la communauté de l'autisme sont vastes ; elles s'étendent des besoins de soutien d'une personne à la façon dont ceux-ci sont liés à plusieurs déterminants clés de la santé, notamment la géographie, la culture, le sexe et le statut socioéconomique. Les obstacles naissent notamment du thème commun des « lacunes », y compris le manque de sensibilisation, de connaissances, d'accès et d'influence. Nous avons déterminé quatre idées récurrentes pour remédier aux inégalités en matière de soins de santé pour les personnes autistes : 1) allouer des ressources à des projets régionaux ou communautaires ; 2) améliorer la représentation des personnes autistes et la communication entre elles ; 3) établir une communauté d'alliés pour défendre les intérêts des personnes autistes et collaborer avec eux ; et 4) établir un leadership au sein de la communauté et du gouvernement pour faire du handicap une priorité pour le Canada. Pour parvenir à l'équité en matière de soins de santé dans le cadre d'une Stratégie nationale sur l'autisme, nous devons examiner l'intersectionnalité entre l'autisme et les déterminants clés de la santé. De plus, pour s'engager efficacement auprès du gouvernement, des professionnels de la santé et du public, la communauté de l'autisme doit s'efforcer de trouver une voix influente, unifiée et diversifiée. Enfin, la conversation doit mener à des actions.

Keywords
Health Equity, National Autism Strategy, Disparities, Barriers, Disability, Determinants of Health
Mots clés
Équité en santé, stratégie nationale sur l'autisme, disparités, obstacles, handicap, déterminants de la santé

Introduction

Health equity means striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions (The World Health Organization, 2021). The World Health Organization (2021) defines health equity as, "the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically." It implies that no one should be disadvantaged from achieving their full health potential no matter where they live, what health conditions they have, or who they are. Moreover, health equity means each individual is able to receive care that is fair and appropriate to them and their needs (Health Quality Ontario, 2017). The principles of health equity are important for Canada. As is stated in the Accessible Canada Act (2019):

> [a] all persons must have the same opportunity to make for themselves the lives that they are able and wish to have regardless of their disabilities; … [b] laws, policies, programs, services and structures must take into account the disabilities of persons, the different ways that persons interact with their environments and the multiple and intersecting forms of marginalization and discrimination faced by persons; … [and c] persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures (pp. 4 – 5).

At the Canadian Autism Leadership Summit 2020 hosted by the Canadian Autism Spectrum Disorder Alliance (CASDA), health equity was discussed in relation to the policies, programs, services, and structures needed to achieve health equity in a future National Autism Strategy in Canada. The panelists were representatives from the South Asian Autism Awareness Centre (SAAAC), Disabled Women's Network of Canada (DAWN Canada), Weeneebayko Area Health Authority (WAHA), and British Columbia Aboriginal Network on Disability Society (BCANDS) who all advocate for equitable care. They spoke on behalf of key groups including underserviced communities in central Toronto, women with disabilities, remote communities in northern Ontario, and Indigenous Peoples in British Columbia. This article reflects on the equity panel's discussion on (1) the current disparities in health equity for Autistic people, (2) the main barriers to achieving equity, and (3) ways to address these equity challenges and how the larger autism community can be effective and respectful allies in supporting equity in a National Autism Strategy.

Disparities

The panellists and discussants first reflected on where current disparities in health equity exist within the autism community. They identified five factors as major contributors to health inequity that extend from the level of support needs at an individual level and its intersection with several key determinants of health.

1. Level of support needs. As of 2013, the Diagnostic and Statistical Manual Fifth Edition separates an autism diagnosis into three "severity levels" depending on the level of support an individual needs for daily function. In fact, actual levels of need across a variety of domains (e.g. self-help, communication) are far more complex than these categories suggest, and can fluctuate throughout a person's life. Throughout Canada, however, autism funding is often based on a person's age irrespective of their needs, with many more supports available for children under five years of age than for older children, youth, and adults (e.g. "Ontario Autism Program: Childhood Budgets", 2019; "Ministry of Child and Family Development", 2019; "Autism Canada", 2017).

2. Geography and Isolated Communities. The geographical location and jurisdiction of a community impacts the availability of services, leading to disparities in health equity. For example, northern communities in Ontario, such as the Weeneebayko area, are composed of remote and small rural municipalities that do not have the same access to supports that are available in larger cities. In addition to remoteness, Indigenous communities are also faced with jurisdictional issues such that health services might be provided by federal, provincial/territorial, or Indigenous self-governments resulting in a lack of adequate care due to a lack of coordination and communication between the different levels of government, agencies, and stakeholders(Thompson, 2016a, pp. 363-364).

> [T]he biggest challenge is the jurisdictional issue. I think that many organizations and governments… forget that there is a provincial, territorial, and federal jurisdiction here… equity you know is a great word but isn't really a reality.
> - Neil Belanger, BCANDS

3. Diverse Cultural and Racialized Communities. BIPOC communities are more likely to experience both interpersonal and systemic racism, rooted in a history of colonialism, which may erode their confidence in the health care system and impede their access to services (Institute for Canadian Citizenship, 2020). Further, various religious, cultural, and immigrant communities may have specific health beliefs, first languages that are not English or French, and other culturally specific needs that should be considered and integrated into equitable and accessible health care planning.

4. Gender. Women and girls with disabilities, including Autistic women, are underserviced. Generally, gender inequities in health equity are related to inequities in employment or income (Thompson, 2016b, p. 80), but women are also overrepresented in difficult situations (e.g. violence, abuse) which affects health equity. Important for a National Autism Strategy, health inequity due to gender arises due to a lack of knowledge about how autism presents itself in girls and extends to variability in autism diagnosis (with girls more likely to be under-diagnosed or diagnosed later). This, in turn, impacts the age at which they can qualify for support and therapy services. Members of LGBTQ+ communities also face discrimination, including homophobia and transphobia, which can compound challenges accessing care.

5. Socioeconomic Status (SES). In addition, socioeconomic status compounds with these four identified disparities, as the added cost required to travel for health care services, either due to geography or residence in an underserviced area, is not financially feasible for many individuals and their families. Further, as many autism therapies and services are not provided for sufficiently in the public realm, families who can afford to purchase supports privately often do, enabling earlier access and better outcomes for families with higher SES, and further widening the chasm between income groups (McLaughlin & Schneider, 2019, pp. 26-28). In the absence of comprehensive public services, different levels of SES amounts to two-tiered health care for many Autistic Canadians, from access to timely diagnosis (which can be purchased privately by some but not others) onward.

Intersectionality

The concept of intersectionality reflects that components of identity and determinants of health often compound and overlap, and cannot be considered in isolation. For example, those who experience racial or gender discrimination are also more likely to have lower SES. In fact, several of the listed disparities align with the key determinants of health as have been identified by the Public Health Agency of Canada in 2001 (Thompson, 2016b, pp. 71-80). For example, physical environment, culture, gender, and income and social status are all listed as key determinants of health. These can overlap with other determinants, such as social support networks, education and literacy, biology, social environment, and health services availability. With this in mind, we must consider the intersectionality of health equity for Autistic individuals with these key determinants of health and recognize each Autistic person's overlapping identities and experiences in order to understand the complexity of health challenges they face.

> ... the future is [about] partnerships that move us across those intersectional questions and begin to understand that [i.e., the intersectionality of autism].
> - Bonnie Brayton, DAWN

Barriers

To achieve health equity, how the key determinants of health interact with health care for Autistic individuals needs to be recognized, and therefore, equity in health care access, availability, and administration needs to be addressed. From the discussion at the equity panel, the major barriers to achieving health care equity in underserved communities can be grouped into four categories, with an overarching lack of theme.

1. Lack of awareness. Underserviced communities themselves are not necessarily aware of the extent of inequity and the supports available for Autistic people. Often, people are not aware of available services unless they seek out those supports. This issue can arise for a variety of reasons, including intergenerational trauma that can affect trust in health care providers (particularly for Indigenous communities), language barriers, level of education (which can affect health-related conversations when heavy jargon is used), and/or access to the internet.

> … these communities themselves are not aware of this inequity, to them longer wait times [and] limited access is just the norm and when it comes specifically to autism-related services, evidence has shown that [for example] immigrant and newcomers receive a later diagnosis, which can lead to delayed access to interventions and then in turn poor outcomes.
> - Dr. Shivajan Sivapalan, SAAAC

2. Lack of research and knowledge. A lack of research, specifically intersectional research, results in a lack of knowledge and evidence-based practice that can be applied variably depending on the needs of the individual. First, autism in women is under-researched. Differences in the presentation of autism in women affects diagnosis, medication, and interventions, and may also limit how and to what extent individuals and caregivers seek-out support. Second, there is a lack of culturally diverse knowledge about ASD and how preferred supports may vary based on culture. Third, is the lack of community-based research and knowledge; assumptions are made about what is needed for various communities and having evidence directly from those communities would help individuals in the communities to support proposed initiatives.

3. Lack of access to health services. Our panelists identified a lack of access to crucial health services as a major barrier to health equity. A lack of access to resources can arise due to geography, jurisdiction, language, racism, cost, misdiagnosis, level of education, or availability of culturally diverse education and programming. In underserviced areas, often the burden of service falls on a few service providers to cover a large geographical area or large number of underserviced individuals. In order to achieve health equity in a National Autism Strategy, health care equity must be a priority. This focuses on the role of the health care system to provide equitable care and extends to ensuring access to the resources that each Autistic individual requires to achieve their full potential, such as an appropriate diagnosis, services, and supports. In fact, a key determinant of health is the health services offered in a region and their method of delivery (Thompson, 2016b, p. 79).

4. Lack of voice. Underserviced communities should be able to advocate for themselves, especially since everyone's experiences and needs are different. Currently, few attempts have been made to collaborate and consult with the end-users of health services, like the communities SAAAC, DAWN Canada, WAHA, and BCANDS represent. Because of the lack of consultation and engagement directly with communities, there are assumptions made about the service needs of these groups and the barriers they face, resulting in supports that are not reflective of the needs of the community. For example, since there is no consultation with cultural minorities, currently there is an absence of culturally diverse education and programming about health in a format appropriate for the group.

Ways to address health equity challenges

The equity panel concluded by discussing how the described barriers and challenges to health equity for Autistic people can be overcome, and how the broader autism community can be effective and respectful allies in supporting equity for underserviced communities. Four reoccurring themes were identified for how to address inequities in health care for Autistic individuals.

1. Regional or in-community initiatives. The specific allocation of resources for local initiatives spanning engagement, research, education, and services can go a long way in better supporting underserviced groups, by increasing awareness, research, access, and lived-experience input. Engagement at a local level can be improved by setting up local working-groups that can (a) continue discussions on health equity, (b) facilitate community engagement, and (c) manage end-user consultations. Increasing the funding support for in-community research that is intersectional, inclusive, and promotes lived-experience participation will improve knowledge and evidence-based initiatives implemented in the communities. Grassroots initiatives and local workshops can be used to improve knowledge of available resources. Lastly, establishing in-community services, such as respite programs, social/support groups for children or caregivers, therapy, and virtual care, can improve access to some health and social services.

> … in community programming supports which could include things like respite services, even local events to allow children with autism to have some fun, local support, groups for parents, caregivers, and educational workshop opportunities that you know others in more urban destinations would have access to…
> - Robert Gagnon, WAHA

An example of such an initiative is the CARES program run by SAAAC in Toronto, Ontario which is a family support program aimed at increasing caregiver capacity to support the development of Autistic children. The program is delivered through a combination of support group discussions, expert led workshops, and social leisure activities (SAAAC Autism Centre, 2021).

2. Representation and Connection. To achieve representation, the heterogeneity of autism, beyond diagnosis, should be considered. There is a diversity of experiences across marginalized communities and everyone should be able to have a voice when it comes to establishing a strategy for health equity. One step is to ensure diverse representation on panels and in key discussion groups.

Apart from representation, the connection between and among Autistic communities and service or health care providers should be strengthened. There are several ways to improve connection, as discussed by the panelists. One way is to put a stronger focus on client-centred care. The use of cultural liaisons and creating materials in diverse formats can help health professionals connect with the communities they serve. And in response, underrepresented groups will gain an improved awareness of available health services and more readily engage with service providers.

> … working with community organizations and specifically cultural liaison[s] to ensure that strategies that are being developed are actually culturally responsive … [and] dedicating resources to create materials in different languages would help with awareness and outreach into these communities.
> - Dr. Shivajan Sivapalan, SAAAC

For example, WAHA supports families and communities through health education, advocacy and Cree language services, and is committed to providing high-quality health services that include traditional and cultural healing methods (WAHA, 2021). Incorporating cultural sensitivity training into relevant post-secondary education fields (e.g. health professions, law school) through placement and internships will improve the cultural competency of service providers. Moreover, the autism community as a whole can work to improve their cultural knowledge and awareness, which can strengthen the relationships within the ASD community. These relationships can also be strengthened by using storytelling to convey common shared experiences, such as through the creation of “living-libraries”. Storytelling distills complex language, and provides a relatable message, which can also help leaders better understand what it is that individuals with disabilities actually require.

> What do they want, not us deciding what they want… let’s have a conversation and start with the person who we’re thinking [about]... equity means all of us working together.
> - Bonnie Brayton, DAWN

3. Establish a community of allies. Unity, respect, and trust within the broader ASD community needs to be a priority. In order to effectively engage with the government, health professionals, and the public, we must try to find a unified and diverse perspective within the autism community.

> [W]e need to work together as a disability community, not just within autism or women with disabilities or newcomers or Indigenous. We have to start supporting each other better and get the pressure on the government and we work together as a community cohesively to move our priorities.
> - Neil Belanger, BCANDS

Beyond the autism community, collaboration with underserved communities and organizations with similar barriers can be strengthened. By engaging the broader community, the shared-collective capacity to promote equity can be increased.

4. Leadership at all levels of government. To effectively promote health equity and make disability a priority for Canada, leadership at the federal, provincial/territorial, and municipal or community levels of government need to be engaged. Educating the public, health professionals, and the broader autism community, improving representation and connection, and establishing a community of allies will all increase the autism community’s ability to engage with policymakers and politicians.

> … but we have to understand … anything we do is going to cost money … disability is expensive and we need to have supportive governments. [T]he federal government is great but the provincial and territorial government is where things are going to happen. They have to be at the table, they have to be prepared to step up and that

> comes back again to who do we have in leadership positions and what is their priority of disability.
> - Neil Belanger, BCANDS

In addition to these four themes, to achieve health equity in a National Autism Strategy, the criteria for "good service" should be reconsidered: what are the criteria for good service based on, who decides what those criteria are, who evaluates the criteria, and what is the purpose of the criteria (e.g. cost)? Re-evaluation needs to occur with a diverse set of lived-experience contributors by collaboratively consulting with various groups, and taking into account regional priorities and the priorities of leadership.

Conclusions and Considerations

The ways to address health equity challenges and promote change discussed in the Canadian Autism Leadership Summit 2020 equity panel reflect a broader national conversation. For instance, in the last five years, the Wellesley Institute for Health Quality Ontario (2016, p. 4), and Health Quality Ontario (2016, pp. 17 - 20; 2017, pp. 7 – 12) have identified similar actions to be taken to achieve health equity in Canada including: addressing the wide-ranging social determinants of health; access to care; empowering communities; leadership; collaboration, engagement, multi-sectoral actions; cultural and linguistic competency; and data, research and evaluation.

> [M]ost important to anything … the conversations need to turn into action. And they need …to turn into implementation plans ... It's not only to talk about it, but to also have a coordinated strategy of how to make it happen ... no matter how many of these conversations we have, if there's no movement towards getting this towards implementation you know we're going to be lost.
> - Robert Gagnon, WAHA

The panellists urged that for progress to occur, now conversation must turn to action. For example, in a policy compendium published by CASDA (2020), policy briefs were created that complement suggestions made in this equity panel and represent a step towards action. To improve regional access to services, it was recommended to create a taskforce which could guide the provinces and territories to provide universal services according to neighbourhood SES (see Affordability and Access Brief #5, pp. 32 - 34). To increase connection between Autistic individuals and service providers, the Affordability and Access Brief #3 (pp. 27 – 29), recommends a comprehensive training program for professionals in a wide range of sectors to expand their capacity to work with Autistic people. Establishing a community of allies with a shared, diverse voice could be achieved by encouraging and ensuring that Autistic people and service providers who are women, Indigenous, from rural and remote communities, racialized immigrants and newcomers, and from the LGBTQ+ community be prioritized as members of the board of the proposed advisory panel or organization for the National Autism Strategy (see Research and Governance Brief #3, pp. 15 - 18). Recommendations to improve leadership at all levels of government included creating a cross-government leadership coordination commission (see Research and Governance Brief #1, pp. 9 - 12) and building a collaborative framework of intergovernmental partnership in sharing knowledge and resources regarding autism (see Information Brief #2, pp. 62 - 63).

In conclusion, the Canadian Autism Leadership Summit 2020 equity panel comprised of diverse voices discussed how to strive for health equity in a National Autism Strategy and represents progress toward consultation and collaboration. This article highlights some of the key voices from this panel. However, the panel discussion and this article should only be the beginning of these sorts of collaborations. As several of the panelists inferred – dialogue, while essential, is most helpful if it leads to action. We hope that this article spurs additional conversation, and ultimately action, on the topic of health equity for Autistic people in Canada.

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