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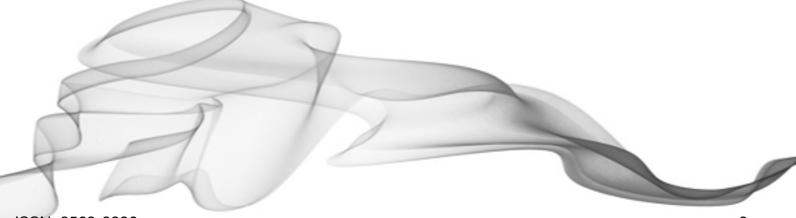Cover art: Lexicon By Elsbeth Dodman

# THE CANADIAN JOURNAL OF AUTISM EQUITY

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## Land Acknowledgement

As Equity-minded members of the Constitutional Democracy of Canada among a Commonwealth of Free Nations, symbolized by honorary monarch, geographically co-situated with the Indigenous Peoples of Northern Turtle Island; we gratefully acknowledge and respect the ancestral relationship between Indigenous Peoples (including over 634 First Nations, Inuit First Peoples, and Aboriginal Métis Peoples) and their Traditional Lands, their Truth of self-narrative, and their Cultural Properties.

## Language Statement

At the Canadian Journal of Autism Equity (CJAE), our goal is amplifying autistic voices and getting them to the attention of researchers, academics, and other policy makers. To that end, we do not impose or enforce a specific language standard on people writing about their experiences. We realize that many in the autistic community may have a preference for certain types of referential language, like identity-first language ('autistic' person) compared to person-first language (person with autism), and that there is also controversy within the autistic community around use of certain terms relating to older diagnostic terms that have been adopted by some in the autistic community ('aspie'). We also understand that there are different beliefs within the autistic community as to which language standards are 'correct'. We feel that to try and impose a language standard upon other peoples' experience and how they refer to themselves would undermine their autonomy and their self-determination. Therefore, we do not prescribe any particular language standard regarding referential language as it relates to submissions wherein autistic authors are referring to their own experiences as we want to amplify their voices, not replace their voices with the voices of others.

## Cover art by Elsbeth Dodman

Elsbeth Dodman is an Autistic woman living in London Ontario with her family and two cats. She has a BA in fine art history and anthroplogy and a post graduate certificate in Autism Behavioral Sciences. When she's not working, Elsbeth loves to make art and tell stories. 'Lexicon' is an image made from alphabet stamps on paper.



*Lexicon, Alphabet stamps on paper*

# Contents

# Foreword

**Whitney Hodgins, BA (Brandon University)**
**Student of Athabasca University**
**2022 Recipient of the Jim and Ginette Munson Autism Leadership Award**

The third issue of the Canadian Journal of Autism Equity is a collection of articles written by and for Autistic people, their families, and decision-makers alike. The major theme of this issue is Autistics in decision-making, the importance of lived experience, and the inclusion of first voice Autistics in policy development. As someone who lives with autism and as an autism advocate, I have spent the last 13 years breaking down barriers for people living with autism and other disabilities in Manitoba, Canada. Over time, this work would later span multiple provinces, which has given me the honour of becoming the first winner of the Jim and Ginette Autism Leadership Award for my vision and impact to build a more inclusive Canada for all Autistic Canadians and their families.

Even today, as I sit in legislative committee hearings speaking against bills that would hurt more than just the autism community, I still see everyday decision-makers making the same mistakes every time they try and tackle the summit that is inclusive policies and legislations. The decisions they make on behalf of the communities they swore to serve are being impacted negatively due to the lack of lived experience being properly consulted at the time of the policy being developed. I see policies get copy and pasted and maybe a couple of words changed to check off the inclusion box. However, in reality, this cookie cutter approach never actually works.

By the time you read this journal, there will be one renowned autism researcher named Johnny Matson, who will have had 24 articles retracted by Elsevier because of issues with their research. The reasons for the retraction of research are because of undisclosed conflicts of interest and compromising the peer review processes in place (*Retraction Watch Database User Guide* 2023). On these articles, you will find redaction notices that state, "This article has been retracted at the request of the Editor in Chief, after review by an independent panel of experts, due to evidence of a compromised peer review process and the failure of one author to disclose significant conflicts of interest" (Turygin et al., 2023). Matson is an autism researcher who does not live with autism. By doing these things in their push for progress, with over 800 academic pieces published, they unequivocally hurt not only the autism community but also their co-authors.

I will never know the individual's reasons for why ethics got lost in translation in the pursuit of academia. However, this entire situation explains why this journal issue is so important to discuss. It is simply not enough to say you are an autism researcher when you yourself do not live with the condition. We are not people you can use as pawns to put yourself ahead in the research field when we are the only reason some researchers sit in their positions today. Taking the intellectual property of Autistics, who bravely put themselves out there so that you can reap the rewards you wanted, is unethical when proper credit is not being given. The articles in this issue are written by those in the Autistic community and thus they should bear more weight than others regardless of one's academic title. These are pieces written with a compassionate lens of a person who lives on the pulse of what its like to live with autism. These articles call to light issues in current policy development and how the only way to rectify that is to involve us in creating that change. These articles are doing the exact things as what I am doing on the ground every single day, advocating for changes to the current environments occupied by Autistic individuals.

The first article, written by Adora Wong, titled "The Past, Present and Future of Early Childhood Inclusion in Canada," discusses that as we begin to leave behind seclusion and segregation of children living with disabilities in our policy development, the push for policies endorsing inclusive practices in early childhood education very rarely involved those living with autism. Furthermore, it looks at how modern, inclusive policies may hurt children living with disabilities rather than help them. Finally, the article also emphasises the importance of listening to those with lived experience so that we can begin to care for children living with disabilities so that they can reach their full potential as individuals.

The second and third articles written by Heather Gillespie, "Autism Spectrum Disorder: Difficulty in Adult Diagnosis" and "Heuristics in Medicine: How Cognitive Biases Influence Decision Making and Diagnosis," discuss the current barriers that exist in receiving a diagnosis of autism in adulthood. One essay discusses the internal biases that can be presented when medical professionals use heuristics in their practice. These biases in decision-making about a diagnosis can also present greater challenges when paired with the other socioeconomic factors that can make receiving a diagnosis of autism challenging for adults. Factors such as gender, financial costs, age, and the diagnostic tools used and the limitations within them all play into the challenges that medical professionals can face, in addition to unconscious biases of medical professionals when seeking a diagnosis of autism.

The overall outcomes of these challenges faced by individuals living with autism are highlighted in Kai E. Forcey-Rodriguez's article titled "The Risk Factors and Preventative Methods of Self-Harm and Suicidality for Autistic People." People living with autism experience the long-term impacts of a society that does not recognize the need for fully inclusive policies, legislation, and programming that are mental illnesses in addition to autism. If left untreated, an individual's mental health can decline, putting them at risk for self-harming behaviours and ultimately dying by suicide at a greater rate than their neuro-typical peers.

Finally, the series ends with Rebekah Kintzinger's personal essay on "Teaching Strategies for Autistic Students". Whereby Rebekkah provides a personal account of the strategies that worked for them and their family while navigating the school environment. This account both highlights and proves that education can be a place to foster inclusion in its purest forms. It also proves that a lot of the inclusion that one needs is during the most important time in one's life, during their K-12 education.

In conclusion, I wish to thank the editorial board for granting me the honour and privilege of being the foreword for the third edition of the Canadian Journal of Autism Equity. As we navigate through one of the most historical moments of our nation's collective memory with the future adoption of Bill S-203, "An Act Respecting a Federal Framework on Autism Spectrum Disorder," it is going to be a time of much celebration for many activists like myself who have spent a good chunk of our adult lives fighting for autism equity in many aspects of our lives. However, it also means that journals such as this one, which work to amplify our voices, will be looked up to as those who will helped pave the way to this historic moment because the autistic voice is the foundation of this journal. As you read through the pages of this journal, I hope you too will see why these issues are so important to address in literature from the compassionate lens that only one who lives in those shoes can bring to the discussion.

## Avant-propos:

Le troisième numéro de la Revue canadienne de l'équité en matière d'autisme propose une collection d'articles écrits pour un public autiste par des personnes autistes, leurs familles et des décideurs du domaine. Le thème principal de ce numéro est la participation des autistes à la prise de décision, l'importance de l'expérience vécue et l'inclusion des expériences des autistes dans l'élaboration des politiques. En tant que personne autiste et en tant que militant pour les droits des personnes autistes, j'ai passé les 13 dernières années à faire tomber les barrières pour les personnes qui vivent avec l'autisme et d'autres handicaps dans la province canadienne du Manitoba. Au fil du temps, ce travail s'est étendu à plusieurs provinces, ce qui m'a valu l'honneur de devenir le premier lauréat du Prix Jim et Ginette pour le leadership en matière d'autisme pour ma vision et mon impact sur la création d'un Canada plus inclusif pour tous les Canadiens autistes et leurs familles.

Même aujourd'hui, alors que je participe à des audiences de commissions législatives pour m'opposer à des projets de loi qui feraient du tort à la communauté de l'autisme et au-delà, je vois les décideurs politiques commettre toujours les mêmes erreurs chaque fois qu'ils essaient de s'attaquer au défi immense que constituent les politiques et législations inclusives. Les décisions qu'ils prennent au nom des communautés qu'ils ont juré de servir sont affectées négativement en raison de l'absence de consultation appropriée au moment de l'élaboration de la politique. Sans tenir compte de nos expériences vécues, ils ne font que copier-coller des politiques auxquelles ils changent quelques mots pour prétendre répondre à la notion d'« inclusion ». En réalité, cette approche à l'emporte-pièce ne fonctionne jamais.

Au moment où vous lirez cette revue, un chercheur renommé du domaine de l'autisme, Johnny Matson, aura vu 24 de ses articles retirés par le groupe éditorial Elsevier en raison de problèmes liés à ses recherches. La rétractation de ces articles serait motivée par des conflits d'intérêts non divulgués et la compromission des processus d'évaluation par les pairs en place (Retraction Watch Database User Guide 2023). Sur ces articles, vous lirez l'avis suivant : « Cet article a été rétracté à la demande du rédacteur en chef, après examen par un groupe d'experts indépendants, en raison de preuves d'un processus d'examen par les pairs compromis et de l'incapacité d'un auteur à divulguer d'importants conflits d'intérêts » (Turygin et al., 2023). Matson est un chercheur sur l'autisme qui n'est pas autiste. Il a publié plus de 800 articles savants. En agissant de la sorte dans sa quête d'avancement, il a porté atteinte non seulement à la communauté de l'autisme, mais aussi à ses coauteurs.

Je ne connaîtrai jamais les raisons pour lesquelles les notions d'éthique se sont perdues dans ses études savantes. Cependant, toute cette situation explique pourquoi il est très important de discuter des sujets abordés dans ce numéro. Se dire chercheur sur l'autisme ne suffit tout simplement pas quand on ne vit pas soi-même avec cette condition. Nous ne sommes pas des personnes à utiliser comme des pions pour se valoriser dans le domaine de la recherche, alors que nous sommes la seule raison pour laquelle certains chercheurs occupent leur poste aujourd'hui. S'approprier la propriété intellectuelle des autistes, qui se sont courageusement mis en avant pour que vous puissiez récolter les fruits que vous souhaitiez, est contraire à l'éthique lorsque le mérite n'en est pas dûment reconnu. Les articles de ce numéro sont rédigés par des membres de la communauté autiste et devraient donc avoir plus de poids, quel que soit leur titre universitaire de leurs auteurs. Ces articles sont rédigés avec la perspective compatissante d'une personne qui comprend bien ce que c'est que de vivre avec l'autisme. Ces articles mettent en lumière les problèmes liés à l'élaboration des politiques actuelles et montrent que la seule façon de rectifier le tir est de nous impliquer dans la création de ces changements. Ces articles font exactement la même chose que ce que je fais sur le terrain chaque jour, en plaidant pour des changements dans les milieux occupés actuellement par les personnes autistes.

Le premier article, écrit par Adora Wong et intitulé « The Past, Present and Future of Early Childhood Inclusion in Canada » (Le passé, le présent et l'avenir de l'inclusion dans la petite enfance au Canada), explique qu'au moment où nous cessons d'isoler et de ségréguer les enfants en situation de handicap dans l'élaboration de nos politiques, les personnes vivant avec l'autisme ne sont que très rarement impliquées dans la mise en place de politiques soutenant des pratiques d'inclusion dans l'éducation de la petite enfance. En outre, l'article examine comment les politiques modernes et inclusives peuvent nuire aux enfants en situation de handicap au lieu de les aider. Enfin, l'article souligne l'importance d'écouter les personnes ayant une expérience vécue du handicap afin de pouvoir commencer à mieux s'occuper des enfants dans la même situation et de les aider à atteindre leur plein potentiel.

Les deuxième et troisième articles rédigés par Heather Gillespie, « Autism Spectrum Disorder: Difficulty in Adult Diagnosis » (Trouble du spectre de l'autisme : difficultés du diagnostic chez l'adulte) et « Heuristics in Medicine: How Cognitive Biases Influence Decision Making and Diagnosis » (Heuristique en médecine : comment les biais cognitifs influencent la prise de décision et le diagnostic), traitent des obstacles actuels à l'obtention d'un diagnostic d'autisme à l'âge adulte. L'un des essais traite des préjugés internes qui peuvent apparaître lorsque les professionnels de la santé utilisent des hypothèses heuristiques dans leur pratique. Ces préjugés dans la prise de décision concernant un diagnostic peuvent également présenter des défis plus importants lorsqu'ils sont associés à d'autres facteurs socio-économiques qui peuvent rendre difficile l'obtention d'un diagnostic d'autisme pour les adultes. Des facteurs tels que le sexe, les coûts de traitement, l'âge, les outils de diagnostic utilisés et leurs limites jouent un rôle dans les difficultés auxquelles les professionnels de la santé peuvent être confrontés, en plus des biais inconscients des professionnels de la santé lorsqu'ils cherchent à obtenir un diagnostic d'autisme.

L'article de Kai E. Forcey-Rodriguez, intitulé « The Risk Factors and Preventative Methods of Self-Harm and Suicidality for Autistic People » (Les facteurs de risque et les méthodes de prévention de l'automutilation et de la suicidalité chez les personnes autistes), met en lumière les résultats globaux de ces défis auxquels sont confrontées les personnes vivant avec l'autisme. Les personnes autistes subissent les conséquences à long terme d'une société qui ne reconnaît pas la nécessité de politiques, de législations et de programmes pleinement inclusifs qui tiennent compte des maladies mentales en plus de l'autisme. Si elle n'est pas traitée, la santé mentale d'une personne

peut se dégrader, ce qui l'expose à des comportements d'automutilation et, en fin de compte, mener à un taux de mortalité par suicide plus élevé chez les personnes autistes que chez les pairs non autistes.

Enfin, notre numéro se conclut avec l'essai personnel de Rebekah Kintzinger sur les « Teaching Strategies for Autistic Students » (Stratégies d'enseignement pour les élèves autistes). Rebekah y présente un compte rendu personnel des stratégies qui ont fonctionné pour elle et sa famille en milieu scolaire. Son récit met en évidence que l'éducation peut être un lieu qui favorise l'inclusion dans sa forme la plus pure. Il prouve également qu'une grande partie de l'inclusion dont on a besoin se fait pendant la période la plus importante de la vie d'une personne, c'est-à-dire pendant son éducation de la maternelle à la fin du secondaire.

En conclusion, je souhaite remercier le comité de rédaction de m'avoir accordé l'honneur et le privilège de rédiger la préface du troisième numéro de la Revue canadienne de l'équité en matière d'autisme. Nous traversons l'un des moments les plus historiques de la mémoire collective de notre pays avec l'adoption future du projet de loi S-203, la Loi sur le cadre fédéral relatif au trouble du spectre de l'autisme, et de nombreux militants (moi y compris), qui ont passé une bonne partie de leur vie d'adulte à lutter pour l'équité en matière d'autisme dans de nombreux aspects de notre vie, pourront enfin se réjouir. Cela signifie également que l'on considérera que des revues comme celle-ci ont contribué à ouvrir la voie à ce moment historique, car l'amplification des voix des autistes est le fondement de notre approche. En lisant les pages de cette revue, j'espère que vous comprendrez vous aussi pourquoi il est si important d'aborder ces questions dans les ouvrages savants, avec la compassion que seule une personne qui vit dans ces conditions peut contribuer.

Turygin, N., Matson, J. L., & Tureck, K. (2023). Retraction notice to "ADHD symptom prevalence and risk factors in a sample of toddlers with ASD or who are at risk for developmental delay" [Research in Developmental Disabilities 34/11 (2013) 4203–4209]. *Research in Developmental Disabilities*, *134*, 104448. https://doi.org/10.1016/j.ridd.2023.104448

New York: The Center for Scientific Integrity. (2023, February 22). *Retraction Watch Database User Guide*. The Retraction Watch Database. Retrieved March 2, 2023, from https://retractionwatch.com/retraction-watch-database-user-guide/#:~:text=Should%20you%20wish%20to%20reference,The%20Center%20for%20Scientific%20Integrity.

# The Risk Factors and Preventative Methods of Self-Harm and Suicidality for Autistic People

Kai E. Forcey-Rodriguez

## Abstract

Non-suicidal self-injury (NSSI) and suicide are not new concepts. However, prevention and intervention strategies are evolving. This paper explores NSSI/Self-Harm and suicidality in the context of autism spectrum disorders (ASD), starting with neurotypical children and adolescents aged 10-24 to compare differences. Suicide is a leading cause of death in adolescents and young adults and is disturbingly high in the autistic community. While evidence about causes and risk factors for NSSI, self-harm, and suicidal behavior in autistic people exist, a comprehensive review of peer-reviewed publications revealed significant gaps in research about severe mental health concern prevention. With high chances of developing mental health disorders, autistic people have higher rates of experiencing self-injury of various types throughout their lives and increased cases of suicide than neurotypical people. Four major risk factors for autistic people: Demographics/SES, ableism and otherness, autism camouflaging, and autistic burnout. Three recommendations for educators are provided on how to support autistic mental health. The implicit focus on causation and behavior identification in research needs to be addressed instead of comprehensive preventative strategy creation. If educators and mental health practitioners know mental health literacy methods and risk factors for suicide and self-harm, specifically for neurotypical students, neurodivergent students deserve equitable support and attention.

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## Résumé

L'automutilation non suicidaire (AMNS) et le suicide ne sont pas des concepts nouveaux. Cependant, les stratégies de prévention et d'intervention évoluent. Cet article explore l'automutilation non suicidaire et la suicidalité dans le contexte de l'autisme, en commençant par les enfants et les adolescents qui ne sont pas en situation de handicap âgés de 10 à 24 ans, afin de comparer les différences. Le suicide est l'une des principales causes de décès chez les adolescents et les jeunes adultes, et son taux est inquiétant dans la communauté autiste. Bien qu'il existe des preuves des causes et facteurs de risque de l'AMNS, de l'automutilation et du comportement suicidaire chez les personnes autistes, un examen complet des publications évaluées par les pairs a révélé des lacunes importantes dans la recherche sur la prévention des problèmes de santé mentale graves. Les personnes autistes, qui ont de fortes chances de développer des troubles mentaux, présentent des taux plus élevés d'automutilation de différents types tout au long de leur vie et des cas de suicide plus nombreux que les personnes n'étant pas autistes. Quatre facteurs de risque majeurs pour les personnes autistes sont 1) la démographie et le statut social ; 2) la discrimination fondée sur la capacité et l'altérité ; 3) le camouflage social ; et 4) le burnout autistique. Trois recommandations sont formulées à l'intention des éducateurs sur la manière de soutenir la santé mentale des personnes autistes. Il est nécessaire de se pencher sur l'accent implicite que la recherche met sur la causalité et l'identification des comportements plutôt que sur la création de stratégies préventives globales. Si les éducateurs et les praticiens de la santé mentale connaissent les méthodes d'éducation à la santé mentale et les facteurs de risque de suicide et d'automutilation, en particulier pour les élèves n'étant pas sur le spectre, les élèves issus de la neurodiversité méritent un soutien et une attention équitables.

## Introduction

### Overview

Non-suicidal self-injury (NSSI) and suicide are not new concepts. However, prevention and intervention strategies are evolving. This paper explores NSSI/Self-Harm and suicidality in the context of autism spectrum disorders (ASD), starting with neurotypical adolescents to help explain differences. The definition of self-injurious and NSSI behavior occurring in typically developing people is the intentional and harmful mutilation of someone's own anatomy without suicidal intent (Nock, M.K., 2009). Also, this paper defines self-harm as a prevalent internalized disorder exacerbated by many external factors.

### Prevalence for Neurotypical Adolescents

The prevalence of suicide, suicidal ideation, non-suicidal self-injury (NSSI), and other forms of self-harm among neurotypical people is disquieting. Suicide is the third leading cause of death for people aged 10-24 and research suggests that the occurrence is high among adolescents (17.2%) and young adults (13.4%) (Swannell et al., 2014). Furthermore, suicide attempts are more

common, with 1 in 5 teenagers seriously considering suicide and 1 in 12 making a suicide attempt (Carson, G.S., 2015). The long list of risk factors for NSSI for neurotypical adolescents is disturbing.

### Risk Factors

Any form of self-harm or suicide is disturbing and therefore, it is important to know some of the circumstances research attributed to such acts. Risk factors for NSSI and suicide include psychological/mental health conditions, treatment history, history of NSSI/Suicide, demographics, socio-economic-status (SES), family environments, and whether they witnessed or know someone who took their own life (Wolfe et al., 2014). These risk factors are alarming for a variety of reasons. The first of many reasons is that a non-quantifiable number of experiences in an individual's life connected to each situation can lead someone to self-harm and suicidal behavior. Therefore, this paper briefly analyzes the two major risk factors of mental health/psychological conditions and demographics to provide evidence about why these factors are disturbing and how they can be attributed to self-harm and suicidal behavior.

### Mental Health/Psychological Conditions

Psychological conditions are a major factor to be considered when exploring causes for self-harm and suicidal acts. For example, mood disorders and depression are most often connected with people fatally hurting themselves (Wolfe et al., 2014). Trauma can exacerbate environmental impacts, and mental health situations and intergenerational trauma can have a harmful effect on the mental health situations of those far removed from the initial event. Therefore, if someone with a history of adverse life situations experiences intense stressful life encounters, the individual may view NSSI or suicide as a way to relieve their pain when all other options fail (Baetens et al., 2021). Also, Wolfe and colleagues (2014) state that individuals with additional psychological diagnoses experience more difficulty. This risk factor can be particularly disturbing because if schools, mental health professionals, or teachers are unaware of or cannot access the individual's mental health history, the individual may not receive support.

### Demographics

The variety of stressors unique to each of the diverse individual identities someone carries can contribute to their likelihood of self-harm and suicidality. For example, a person's privilege can lessen or increase the gravity of these stressors. The societal construct of privilege and oppression derives from colonial practices where people are segregated based on social status, with authority inequitably allocated (Paradies, Y. C., 2006). Therefore, privilege can help or hinder access to essential resources and high-quality supports (e.g., Mental/physical health support, housing, education, etc...). Gholamrezaei and colleagues (2017) state that there are possible merits in further exploring the connection between gender, race, socioeconomic status, and self-harm. However, there is very little available research exploring the connections collectively or individually. Recognizing this limitation, this subsection briefly analyzes the connection between gender and racial background to self-harm and suicide.

### Gender

In the United States, the CDC reported that the male prevalence of suicide is quadruple that of females at a disturbing number of 36,551 people (Centers for Disease Control and Prevention, 2022). The reports Centers for Disease Control and Prevention (2022) and Canada, P.

H. A. (2022) reveal that women are more likely to try to take their own life and harm themselves than men but are less likely to commit suicide successfully.

Also, rates of self-harm, suicidal ideation, and suicide are of significant concern among people who are a gender minority, such as gender non-conforming, transgender, nonbinary, and genderqueer people. Research about the transgender community reveals that the likelihood of suicidal ideation (12 times greater) and intent (18 times greater) is far greater in other communities in the United States (Herman, Brown, & Haas, 2019). Therefore, practitioners need to know how mental health distresses are related to bullying, ostracization, trauma, or fear around their own identity (Liao et al., 2015; Brammer & Ginicola, 2017), when supporting individuals from gender-minoritized populations.

### Race

While there are established distinctions between racially minoritized populations, immigrants, and aboriginal people based on the different statuses they hold. They still face similar difficulties, such as prejudice, poverty, lack of support, and other social disparities that increase their chances of suicide (Troya et al., 2022). Murducca, C. (2013) solely focuses on how aboriginal populations in the United States, Canada, New Zealand, and Australia still endure the long-lasting effects of colonialism through infrastructural problems, illness, loss of identity, discrimination, and intergenerational trauma. These similarly high suicide rates and atrocities faced by indigenous and other minority populations like the Siberian aboriginals, the Japanese Ainu, and China's various oppressed minorities need not go unrecognized. Ongoing oppression in tandem with intergenerational and other forms of trauma contribute to increasing likelihoods of suicide and self-harm, including the probability that these events go underreported by racially minoritized and indigenous populations.

What aids in this is legal structures that have a basis in racism and centuries of oppression. For example, since the 1700s, Canadian policies have frequently continued hosting and maintaining aggression against the Black community (Thornhill, E.M.A., 2008). North America's continental history of oppression of racially minoritized people calls for practitioners to utilize and be familiar with the Conceptualizing and Characterizing Privilege/Oppression as a Determinant of Health Model from Paradies (2006) when exploring exposure to all forms of racism and working to understand their client/students' levels of privilege or oppression.

### Academic Ramifications & Warning Signs

There is a strong body of research covering the negative educational outcomes of emotional distress (Whitley et al., 2018).
Academic ramifications may include:

- · Truancy.
- · Decreased interest in topic areas of prior enjoyment.
- · A drop in grades.
- · School punishment for reactive behavior.

Also, adolescents may be less likely to share that they are engaging in NSSI or are suicidal because of fear, embarrassment, and the risk of being publicly besmirched (Simone & Hamza, 2020) because these behaviors challenge societal concepts of self-preservation.

Noticing warning signs is imperative for ensuring proper support provision and involvement. Warning signs are displayed through art forms like writing, drawings, paintings, or consistently listening to songs or music that connote mental health suffering or pain. Recognizing

the invisibility of self-injurious and suicidal behavior within the school context (Evans & Hurrell, 2016) is pivotal for early intervention. Therefore, the relationship between lived experiences of suicidal ideation and nonsuicidal self-injury calls for preliminary assessments for self-harm for youth suspected of hurting themselves or dealing with tumultuous times (Baetens et al., 2021). After reviewing the causes and effects of NSSI and suicidal behaviors in neurotypical adolescents, this paper explores these aspects in the context of autism.

### NSSI, Self-Injurious Behavior, and Suicide in the Autistic Context

#### *Overview*

Discussions about prevalence, risk factors, and warning signs associated with NSSI and suicide in the context of autism (ASD) are relatively new. In the case of autism, definitions for self-injurious behavior (SIB) and NSSI differ. SIB is considered repetitive behavior due to adaptive behavior functioning, social cognition, and overwhelming emotional processing challenges. Intense and consistent self-injurious behavior is both enervating and prevalent in children and adults on the spectrum, causing drastic effects on physical health, cognitive development, and overall well-being (Summers et al., 2017). NSSI is SIB's emotional and physical effects over time. Since comportment associated with autistic people is sometimes confined to the repetitive behaviors category, the prevalence of NSSI within this population may go unnoticed (Maddox et al., 2017). These distinctions aid in discussing the prevalence of self-injury, NSSI, and suicide in this population.

#### *Prevalence*

With high chances of developing mental health disorders, autistic people have higher rates of experiencing self-injury of various types throughout their lives and increased cases of suicide compared to neurotypical people. Duerden et al. (2012) found that 241 autistic participants aged 2-19 years old (52.3% of study participants) had a lifetime history of self-injury. Oliphant and colleagues (2020) established that 66% of adults with high-functioning autism have life experiences with suicidal ideation, and 35% reported having plans for or having attempted suicide. High rates of NSSI and suicide among autistic people result from numerous factors. The following paragraphs explain what increases these individuals' likelihood of self-harm and suicidality.

#### *Demographics/SES*

The initial factor is demographics. While the literature is very conflicted about how gender relates to suicidality in autistic children, there is evidence of its influence among adults. Specifically, in the adult population, autistic women reported higher rates of suicidality (McDonnell et al., 2020). One of a myriad of rationales for autistic women reporting higher rates of suicidality could be linked to camouflaging and late diagnosis because qualitative research around determining characteristics of autism between genders is still emerging. Lai and colleagues (2017) revealed in their study that, while no autistic person is similar to another, autistic women had a higher chance of camouflaging than men resulting in depression and other mental health concerns based on gender expectations. Concerning race, autistic Hispanic and

BIPOC youth have a higher likelihood of suicidal ideation compared to neurotypicals. Regarding age, it is plausible that later-onset diagnoses of autism are associated with increased rates of self-harm (Licence et al., 2020). Warrier & Baron-Cohen (2021) found autistic people to have a higher likelihood of experiencing childhood trauma such as maltreatment, adverse experiences, abuse, and neglect, making self-harm an attractive coping mechanism.

### Ableism & Otherness

Ableism and otherness can cause significant mental health distress among autistic people. Focusing on how we are different through a negative lens detracts from being able to see the humanity, beauty, outstanding contributions, and talents everyone has and is the antithesis of inclusion. Ableism and otherness exist in many settings, including schools. For example, Baglieri and colleagues (2011) state that similar to other kinds of persecution, historically and currently, the disability community faces persistent imposed segregation, being devalued as human beings, and being taken advantage of. Furthermore, school environments can be one of those challenging places, not only because of the high likelihood of sensory overload for autistic people but also because deficit mindsets can exist among students and educators. This subsection discusses the impacts of Person first language (PFL), the medical narrative of being othered, and the importance of addressing ableism in literature.

### Person first language

Current inclusive language practices like Person first language (PFL) can promote othering mindsets. Special education still places a heavy emphasis on identification and creating names that connotate differences (Ashby, C., 2012). PFL is a prime example that refers to members of the disability community as "people with disabilities." This language is controversial because, like most marginalized groups, labels are thrust upon them by outsiders or influential organizations like the American Psychological Association. Practitioners need to know that labels associated with neurodivergent people often misrepresent how neurodivergent people see themselves because the denomination-creators establish names without input from the community the denomination affects and stigmatizes. Person first language did not come from the disability community, resulting in a lot of division.

Scholars of disability note the problematic aspects of PFL in literature and use, arguing that the continued use of words like "impairment" and "disability" are ideologically loaded terms based on medical discourse. This discourse establishes the notions of perfect human characteristic norms used as forms of control, creating large groups of 'others' when deemed fit (Buettgen & Gorman, 2019). Therefore, despite the aim of PFL being to put the person before the disability, it serves the opposite purpose because calling someone a "person with autism" still puts autistic people in a box, portraying them and others with disabilities as different and unreachable. Imagine two individuals facing each other with one person on either side of a closed door with a fogged-up/ blurry big glass window. Therefore, practitioners must know that just because PFL puts the person before the diagnosis does not mean that members of the disability community are recognized more for their humanity or treated equitably (Gernsbacher, M.A., 2017). For example, it is essential to note that PFL's sole use is for categorizing neurodivergent people and not for neurotypical people. This is an example of ableism. Therefore, asking disability community members whether they prefer person first language (person with a disability) or identity first (disabled person), could actually be inquiring how would they like to conform in society. After unpacking the meaning behind this question, the connotation is othering.

### Medical narrative influence

The medical narrative is at the core of how special educators and practitioners are trainedThe intense focus on resolving a problem or difficulty based on the perception of an individual's ability or problem is reinforced by the social construct of binary opposition: quandary vs. solution. As a result, the medical narrative only sees the elegance of people when the perceived deficits are not there (Healey, D., 2022). This concept is a possible influencer of the curriculum for pre-service teacher training, whereby disabilities are framed as a medical diagnosis that can be "dealt with" through diagnostic procedures and interventions (Ashby, C., 2012). Therefore, the medical narrative's interpretation of good and bad, whereby autism is stigmatized, becomes personified when these perceptions influence behaviors promoting a culture in the larger society and schools of "be cool or be cast out" (Lee et al., 1982). The medical narrative is also very prevalent in academic literature.

### Addressing ableism in literature

Ableist and medicalized language used in the academic literature about autism contributes to societal stigma, can misrepresent the autistic community, and possibly affect an autistic person's self-conception (Bottema-Beutel et al., 2021). Practitioners need to be mindful when using medicalized terms and the perceptions they can create when talking about autistic people and other members of the disability community, like co-morbid, at risk of impairment, and treatment. Possible alternative terms are "supported/diagnosed," which might be used instead of treated/treatment, "in need of support/undiagnosed" instead of untreated, "coexisting/co-related/connected with" instead of co-morbid, "in need of support" instead of at risk, and "has difficulty in/challenges" instead of impaired/impairment. While there are circumstances when an individual on the spectrum can have a coexisting diagnosis or someone has a diagnosis that is both a disability and a chronic illness/medical condition (e.g., Cerebral palsy), it is important to be mindful of what lens from which those labels originate. For example, while, according to the medical narrative, someone may have a diagnosis that is both a disability and a chronic illness/medical condition, the counterargument to the medical perspective and mindset can be reframed into a more humanistic perspective. Rather than focusing on medicalized labels, it may be more prudent to recognize the individual's diverse support needs and how different everyone is from each other, which is the beauty of humanity.

### Impact of othering

Similar to other minoritized populations, people on the spectrum are not strangers to receiving derogatory nicknames or labels that other them. Autistic people are often characterized as weird or different through the language and practices of diagnosis resulting in dehumanizing perceptions from society because of a label created for them and not by them (Hodge et al., 2019). Individuals on the spectrum crave equitable treatment, but often times the lyrics from the song "Subdivisions" by Rush, "growing up it seems all one-sided. Opinions all provided. The future pre-decided. Detached and subdivided in the mass production zone" (Lee et al., 1982) resonates with what is felt when walking into school. A possible explanation of these feelings can be connected to complications in social dynamics between autistic and neurotypical people. Available literature suggests that these scenarios result from students being grouped based on neurologies not by character traits or similar interests (Chen et al., 2021). Like minds understand each other, and different minds do not or struggle to do so, which can make the exchange of information and conversations exhausting or challenging for neurotypical peers to follow

(Crompton et al., 2020). The toll of partial societal acceptance causes anxiety around fitting in and feelings of a need to create camouflage to become neurotypical-passing.

### Autism camouflaging/masking

Autism Masking is a significant influencer of self-harm and suicide. This social atmosphere survival strategy involves hiding someone's authentic self and suppressing their autistic traits. Camouflaging is an exhaustive process that is an everyday necessity for this population to feel safe, avoid stigma, abuse, bullying, remain employed, find a romantic partner, and form friendships and other relationships. They accomplish this through watching and practicing speech patterns to learn social cues from characters on TV shows and practice body language. Some autistic people are so skilled at camouflaging that peers do not realize they are on the spectrum. (Stanborough & Klein, 2021). The quote, "I can't pretend a stranger is a long-awaited friend" (Lee et al., 1981), explains the anxiety autistic people feel when meeting new people because of societal pressures. The constant need to camouflage or repress their autistic tendencies when in public can lead to feelings of loss of self or a need to be someone else to fit in or be loved. Cassidy and colleagues (2019) revealed that prolonged use of camouflaging causes suicidal ideation and eventual suicide because of feelings about being a burden to society.

### Autistic burnout

Although autistic burnout has been a longstanding topic discussed by the autistic community in public forums online, this topic is barely conversed about in the academy (Higgins et al., 2021). The lack of literature about autistic burnout is disturbing because it hinders the creation of needed professional support. This form of burnout results from the combination of life stressors, the cumulative load they experience, and obstacles to support, creating an inability to find relief (Raymaker et al., 2020). Autistic burnout is a more intense version of the standard form of burnout. Higgins and colleagues (2021) revealed that while fatigue was similar for both autistics and non-autistics, autistic people with tendencies to be more pessimistic about social encounters would go into self-imposed seclusion and feel immobilized due to major anatomical and psychological fatigue. It is essential to notice initial signs of immobilization because that could be a warning sign of autistic burnout (Mantzalas, Richdale, & Dissanayake, 2022). Allowing autistic people to take sensory and other kinds of brain breaks can help with diminish the likelihood of burnout.

### Academic ramifications

The paucity of literature discussing the academic ramifications of autistic self-injurious behavior needs to be addressed. A significant rationale for why there is a gap in research could be related to how no single autistic person is the same. However, an initial academic ramification can be prolonged absences and disrupted learning due various factors. Absenteeism could be provoked by a particular event or caused by prolonged rejection by peers or self-deprecation (Lowri, C., 2021). An added factor is the set-up of academic settings is not suitable for all people on the spectrum. For example, the misalliance of the learning environment can be difficult to adjust to and provoke interfering behavior (Goodall, C., 2018). These behaviors can include self-injurious acts and physical or verbal aggression toward others because of stress and anxiousness.

# How Can We Support Autistic Mental Health Needs?

## Overview

Autistic people can struggle to articulate what they need, which leaves them without often-needed support. Also, there is no self-harm behavior assessment tailored specifically for this population. Schools face another challenge because mental health professionals are not always fully trained in ASD. Therefore, these services are unprepared to adapt their support for this group (Raja, 2014), making it difficult for autistic people to self-advocate because they may feel nobody will understand. This paper provides three recommendations for educators on how to best support autistic students.

## Flexibility & Autism

Educators, practitioners, and community members need to know the importance of not using the blanket statement of "be flexible" with people on the spectrum without considering the mental health impact, processing time, and amount of energy required to be flexible. Mentally and behaviorally adapting to change requires a lot of executive functioning, is draining, and done consistently, can lead to autistic burnout and the fostering of heavy resentment towards society. Also, the pressures associated with expectation of autistic people mental flexibility and adapting to changes singular or numerous can provoke a fight or freeze response due to its overwhelming nature. Ways to help this population adapt to change, create classroom environments/school cultures, and demonstrate flexibility include the Structured TEACCHing method and other modalities to reestablish structure. This empirically supported practice assists with organizing the classroom environment allowing learners to know the agenda and how to prepare (Mesibov & Shea, in Buron et al., 2014). Positive and inclusive classroom cultures are when educators maintain the schedule in the classroom, use consistent instructional language, provide enough processing time, and use Carol Dweck's Praise Model. It is more important to modify or adapt a classroom to the learner on the spectrum than to require them to adapt themselves. These approaches are adaptable for other settings.

## Therapeutic educational strategies

Therapeutic methods in social-emotional learning curricula promote inclusion and enhance student mental health. Trauma-informed Cognitive Behavioral Therapy and Dialectical Behavior Therapy (DBT) are evidence-based approaches effective in assisting autistic people demonstrating self-harm behaviors to learn effective communication, regulate emotions, and handle frustrating situations. Even though DBT is ineffective with most children with ASD exhibiting SIB, it is possible to utilize similar strategies for these children (Shkedy et al., 2019). Another method is Emotion-Focused Therapy (EFT). Practitioners utilize EFT methods by demonstrating focal point tapping (Emotion Freedom Technique) and using metacognitive and mindfulness strategies to foster emotional acceptance and acknowledgement. Frequently, autistic people recount painful experiences resulting from miscommunications and misinterpretation of feelings with their typically developing classmates (Robinson, A., 2018). Therefore, focal point tapping can be a secret signal of SOS for practitioners and others to be on the lookout for when autistic people are in overwhelming or distressing situations providing opportunities for essential professional support in emotion regulation and processing.

### Strategies for teachers & schools

Educators have many tools at their disposal to assist autistic students in avoiding getting into trouble because of misunderstandings around restricted and repetitive behaviors. Helping others recognize that some behaviors are more related to difficulties with emotion regulation-- not intentions to inflict harm or discomfort-- creates environments around autism acceptance. Utilizing whole class approaches (Tier 1) like EMPOWER-ASD promotes understanding of autism and neurodiversity to parents and children (Leadbitter et al., 2021). This method teaches neurotypical students to form positive views of their neurodivergent peers and establish supportive and caring relationships.

Concurrent with the EMPOWER-ASD approach, the teacher can use peer support or peer-mediated strategies known to be successful with autistic people. A key factor when educators utilize peer support learning methods in the class is that the peers matched with their autistic classmates demonstrate a higher understanding of autism than those who do not (Laghi et al., 2018). For example, in Black and colleagues (2022), autistic participants defined friendship in five categories: "They would always look after me," "They understand," "Grow to become friendly," "Like the things I like," and "people like me." Creating peer groups where the culture fulfills the criterion mentioned above is paramount.

Sosnowy and colleagues (2019) found that autistic people have better connections with others when their mannerisms are accepted. In different friendships, autistic people feel obligated to behave by societal parameters displaying difficulty and hesitancies with how to be in particular settings while finding comrades who were not mandating such comportment enhanced their feelings of comfort (Sosnowy et al., 2019). It is a universal fact that everyone wants and deserves to be loved and accepted despite their shortcomings. Educators can also give opportunities for autistic students to gain experience making friendships in class where neurotypical peers learn how to provide constructive and honest feedback to help their classmates on the spectrum grow. Part of this is tackling the issue of autism camouflage can be done by making the classroom and school a designated unmasking zone. Students learn universal self-care methods and teachers could model stimming as an excellent example of a calming mechanism.

### Conclusion

As autism awareness and acceptance increases, it is important to recognize the empirical evidence indicating the immediate need to explore and comprehend the increasing risks, nature, and causes of suicidality in autistic people to provide support and establish preventative intervention strategies (Oliphant et al., 2020). Effects of demographics/SES, ableism, autism masking, and autistic burnout on autistic people are often overlooked in the literature and discourse and ignored by society. Acknowledging and working to change that reality saves lives. Educators and mental health practitioners can employ strategies suited for school and therapeutic settings by teaching helpful coping mechanisms and supporting populations susceptible to suicidal ideation as a foundation to addressing systemic issues. In conclusion, if educators and practitioners know mental health literacy methods and risk factors for suicide and self-harm, specifically for neurotypical students, neurodivergent students deserve equitable support and attention.

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**References**

Ashby, C. (2012). Disability studies and inclusive teacher preparation: A socially just path for teacher education. *Research and Practice for Persons with Severe Disabilities*, *37*(2), 89–99. https://doi.org/10.1177/154079691203700204

Baetens, I., Greene, D., Van Hove, L., Van Leeuwen, K., Wiersema, J. R., Desoete, A., & Roelants, M. (2021). Predictors and consequences of non-suicidal self-injury in relation to life, peer, and school factors. *Journal of Adolescence, 90*, 100–108. https://doi.org/10.1016/j.adolescence.2021.06.005

Baglieri, S., Valle, J. W., Connor, D. J., & Gallagher, D. J. (2011). Disability studies in education: The need for a plurality of perspectives on disability. *Remedial and Special Education, 32*(4), 267–278. https://doi.org/10.1177/0741932510362200

Berger, E., Hasking, P., & Martin, G. (2013). "Listen to them": Adolescents' views on helping young people who self-injure. *Journal of Adolescence, 36*(5), 935–945. https://doi.org/10.1016/j.adolescence.2013.07.011

Black, M., Kuzminski, R., Wang, J., Ang, J., Lee, C., Hafidzuddin, S., McGarry, S. (2022). Experiences of friendships for individuals on the Autism Spectrum: A scoping review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-022-00332-8

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood, 3*(1), 18–29. https://doi.org/10.1089/aut.2020.0014

Bottema-Beutel, K., Park, H., & Kim, S. Y. (2018). Commentary on social skills training curricula for individuals with ASD: Social interaction, authenticity, and stigma. *Journal of autism and developmental disorders, 48*, 953-964. https://doi.org/10.1007/s10803-017-3400-1

Brammer, R., & Ginicola, M. M. (2017). Counseling transgender clients. In *Affirmative Counseling With LGBTQI+ People* (pp. 183–212). American Counseling Association. https://doi.org/10.1002/9781119375517.ch14

Buron, K. D., Wolfberg, P. J., & Gray, C. (2014). Teaching a different way of behaving: Positive behavior supports. In *Learners on the Autism Spectrum: Preparing Highly Qualified Educators and Related Practitioners* (pp. 152-174). AAPC Publishing.

Buron, K. D., Wolfberg, P. J., & Gray, C. (2014). Structures Teaching and Environmental Supports. In *Learners on the Autism Spectrum: Preparing Highly Qualified Educators and Related Practitioners* (pp. 265-288). AAPC Publishing.

Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts, and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders, 49*(5), 1899-1911. doi: http://dx.doi.org/10.1007/s10803-018-03878-x

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental healthdifficulties, self-injury, and suicidality. *Autism, 23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders, 50*(10), 3638-3648. http://dx.doi.org/10.1007/s10803-019-04323-3

Centers for Disease Control and Prevention. (2022). Suicide data and statistics. Centers for Disease Control and Prevention. Retrieved October 13, 2022, from https://www.cdc.gov/suicide/suicide-data-statistics.html

Chen, Y.-L., Senande, L. L., Thorsen, M., & Patten, K. (2021). Peer preferences and characteristics of same-group and cross-group social interactions among autistic and non-autistic adolescents. *Autism, 25*(7), 1885-1900. https://doi.org/10.1177/13623613211005918

Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism, 24*(7), 1704–1712. https://doi.org/10.1177/1362361320919286

Culpin, I., Mars, B., Pearson, R. M., Golding, J., Heron, J., Bubak, I., … Rai, D. (2018). Autistic traits and suicidal thoughts, plans, and self-harm in late adolescence: Population-based cohort study. *Journal of the American Academy of Child and Adolescent Psychiatry, 57*(5), 313-320. .https://doi.org/10.1016/j.jaac.2018.01.023

Duerden, E. G., Oatley, H.K., Mak-Fan, K. M., McGrath, P.A., Taylor, M.J., Szatmari, P., Roberts, S.W. (2012). Risk factors associated with self-injurious behaviors in children and adolescents with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(11), 2460–2470. https://doi.org/10.1007/s10803-012-1497-9

Evans, R., Hurrell, C. (2016). The role of schools in children and young people's self-harm and suicide: systematic review and meta-ethnography of qualitative research. *BMC Public Health. 16*(1), 1-16, 401. https://doi.org/10.1186/s12889-016-3065-2

Foley, K. R., & Trollor, J. (2015). Management of mental ill health in people with autism spectrum disorder. *Australian Family Physician, 44*(11), 784–790.

Fuld S. (2018). Autism Spectrum Disorder: The impact of stressful and traumatic life events and implications for clinical practice. *Clinical Social Work Journal, 46*(3), 210–219. https://doi.org/10.1007/s10615-018-0649-6

Gernsbacher, M. A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry, 58*(7), 859-861. https://doi.org/10.1111/jcpp.12706

Gholamrezaei, M., De Stefano, J., and Heath, N.L. (2017), Nonsuicidal self-injury across cultures and ethnic and racial minorities: A review. *International Journal Psychology, 52*(4), 316-326. https://doi.org/10.1002/ijop.12230

Goodall, C. (2018). 'I felt closed in and like I couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people. *Autism & Developmental Language Impairments, 3.* https://doi.org/10.1177/2396941518804407

Haas, A. P., Rodgers, P. L., & Herman, J. (2014). *Suicide attempts among transgender and gender non-conforming adults: Findings of the national transgender discrimination survey.* American Foundation for Suicide Prevention. https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-GNC-Suicide-Attempts-Jan-2014.pdf

Haddad, F., Gerson, R., & Carson, G. S. (2015). Suicide and self-injurious behaviors. In *Helping kids in crisis: Managing psychiatric emergencies in children and adolescents* (2nd ed., Vol. 1, Ser. 1, pp. 35-51). essay, American Psychiatric Publishing.

Healey, D. (2022). DisAppearing blindness… with a twist. In Titchkosky, T., Cagulada, E., DeWelles, M., & Gold, E. (eds) *DisAppearing: Encounters in Disability Studies* (1st ed., Vol. 1). Canadian Scholars.

Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism, 25*(8), 2356–2369. https://doi.org/10.1177/13623613211019858

Hodge, N., Rice, E. J., & Reidy, L. (2022). 'They're told all the time they're different': how educators understand development of sense of self for autistic pupils. *Disability & Society, 34*(9-10), 1353-1378. https://doi.org/10.1080/09687599.2019.1594700

Jokiranta-Olkoniemi, E., Gyllenberg, D., Sucksdorff, D., Suominen, A., Kronström, K., Chudal, R., & Sourander, A. (2020). Risk for premature mortality and intentional self-harm in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 51*(9), 3098–3108. https://doi.org/10.1007/s10803-020-04768-x

Jones, E. K., Hanley, M., & Riby, D. M. (2020). Distraction, distress, and diversity: Exploring the impact of sensory processing differences on learning and school life for pupils with autism spectrum disorders. *Research in Autism Spectrum Disorders, 72*, 101515. https://doi.org/10.1016/j.rasd.2020.101515

Kiekens, G., Claes, L., Demyttenaere, K., Auerbach, R. P., Green, J. G., Kessler, R. C., … Bruffaerts, R. (2016). Lifetime and 12-month nonsuicidal self-injury and academic performance in college freshmen. *Suicide and Life-Threatening Behavior, 46*(5), 563–576. https://doi.org/10.1111/sltb.12237

Laghi, F., Lonigro, A., Pallini, S., & Baiocco, R. (2018). Peer buddies in the classroom: The effects on spontaneous conversations in students with autism spectrum disorder. *In Child & Youth Care Forum, 47*(4), 517-536. Springer US. https://doi.org/10.1007/s10566-018-9449-y

Lai, M.-C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., Happé, F., Baron-Cohen, S. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism, 21*(6), 690–702. https://doi.org/10.1177/1362361316671012

Lee, G., Lifeson, A., Peart, N. (1981). Limelight [Song]. On Moving Pictures [Album]. Mercury Records

Lee, G., Lifeson, A., Peart, N. (1982). Subdivisions [Song]. On Signals [Album]. Mercury Records

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology, 12*, 1-7. https://doi.org/10.3389/fpsyg.2021.635690

Liao, K. Y.-H., Kashubeck-West, S., Weng, C.-Y., & Deitz, C. (2015). Testing a mediation framework for the link between perceived discrimination and psychological distress among sexual minority individuals. *Journal of Counseling Psychology, 62*(2), 226–241. https://doi.org/10.1037/cou0000064

Licence, L., Oliver, C., Moss, J., & Richards, C. (2020). Prevalence and risk-markers of self-harm in autistic children and adults. *Journal of Autism and Developmental Disorders, 50*(10), 3561-3574. http://dx.doi.org/10.1007/s10803-019-04260-1

Lowri, C. (2021). Issues in persistent nonattendance at school of autistic pupils and recommendations following the reintegration of 11 autistic pupils. *Good Autism Practice (GAP), 22*(2), 12–20.

Maddox, B. B., Trubanova, A., & White, S. W. (2017). Untended wounds: non-suicidal self-injury in adults with autism spectrum disorder. *Autism, 21*(4), 412–422. https://doi.org/10.1177/1362361316644731

Mantzalas, J., Richdale, A. L., & Dissanayake, C. (2022). A conceptual model of risk and protective factors for autistic burnout. *Autism Research, 15*(6), 976–987. https://doi.org/10.1002/aur.2722

McDonnell, C. G., DeLucia, E. A., Hayden, E. P., Anagnostou, E., Nicolson, R., Kelley, E., Georgiades, S., Liu, X., & Stevenson, R. A. (2020). An exploratory analysis of predictors of youth suicide-related behaviors in autism spectrum disorder: Implications for prevention science. *Journal of Autism and Developmental Disorders, 50*(10), 3531-3544. http://dx.doi.org/10.1007/s10803-019-04320-6

Michalko, R. (1999). The Two-in-one: walking with Smokie, walking with blindness. Philadelphia: Temple University Press.

Murdocca, C. (2013). Persistence and Memorialisation: Self-harm and suicide in reparation politics in Canada. *Australian Feminist Law Journal, 38*(1), 93–107. https://doi.org/10.1080/13200968.2013.10854485

Nock, M. K. (2009). Why do people hurt themselves? New insights into the nature and functions of self-injury. *Current Directions in Psychological Science, 18*(2), 78–83. http://www.jstor.org/stable/20696002

Oliphant, R.Y. K., Smith, E. M., & Grahame, V. (2020). What is the prevalence of self-harming and suicidal behaviour in under 18s with ASD, with or without an intellectual disability? *Journal of Autism and Developmental Disorders, 50*(10), 3510-3524. http://dx.doi.org/10.1007/s10803-020-04422-6

Paradies, Y. C. (2006). Defining, conceptualizing, and characterizing racism in health research. *Critical Public Health, 16*(2), 143–157. https://doi.org/10.1080/09581590600828881

Staniland, L., Hasking, P., Boyes, M., & Lewis, S. (2021). Stigma and nonsuicidal self-injury: Application of a conceptual framework. *Stigma and Health, 6*(3), 312–323. https://doi.org/10.1037/sah0000257

Strauss, P., Cook, A., Watson, V., Winter, S., Whitehouse, A., Albrecht, N., Wright Toussaint, D., & Lin, A. (2021). Mental health difficulties among trans and gender diverse young people with an autism spectrum disorder (ASD): Findings from trans pathways. Journal of Psychiatric Research, 137, 360-367. http://dx.doi.org/10.1016/j.jpsychires.2021.03.005

Summers, J., Shahrami, A., Cali, S., D'Mello, C., Kako, M., Palikucin-Reljin, A., Savage, M., Shaw, O., & Lunsky, Y. (2017). Self-injury in autism spectrum disorder and intellectual disability: Exploring the role of reactivity to pain and sensory input. *Brain sciences, 7*(11), 140. https://doi.org/10.3390/brainsci7110140

Swannell, S. V., Martin, G. E., Page, A., Hasking, P., & St John, N. J. (2014). Prevalence of nonsuicidal self-injury in nonclinical samples: Systematic review, meta-analysis, and meta-regression. *Suicide and Life-threatening Behavior, 44*(3), 273–303. https://doi.org/10.1111/ sltb.12070.

Thornhill, E. M. A. (2008). So Seldom for Us, So Often Against Us: Blacks and Law in Canada. *Journal of Black Studies, 38*(3), 321–337. https://doi.org/10.1177/0021934707308258

Troya, M. I., Spittal, M. J., Pendrous, R., Crowley, G., Gorton, H. C., Russell, K., Byrne, S., Musgrove,R., Hannam-Swain, S., Kapur, N., & Knipe, D. (2022). Suicide rates amongst individuals from ethnic minority backgrounds: A systematic review and meta-analysis. *EClinicalMedicine, 47*. https://doi.org/10.1016/j.eclinm.2022.101399

Warrier, V., & Baron-Cohen, S. (2021). Childhood trauma, life-time self-harm, and suicidal behaviour and ideation are associated with polygenic scores for autism. Molecular *Psychiatry, 26*(5), 1670–1684. https://doi.org/10.1038/s41380-019-0550-x

Whitley, J., Smith, J.D., Vaillancourt, T., Neufeld, J. (2018). Promoting mental health literacy among educators: A critical aspect of school-based prevention and intervention. In: A. W. Leschied, D. H. Saklofske, G. L. Flett (Eds.), *Handbook of School-Based Mental Health Promotion: An Evidence-Informed Framework for Implementation* (pp. 143-165). Springer International Publishing. https://doi.org/10.1007/978-3-319-89842-1_9

Wolfe, K. L., Foxwell, A., & Kennard, B. (2014). Identifying and treating risk factors for suicidal behaviors in youth. *International Journal of Behavioral Consultation and Therapy, 9*(3), 11-14. doi: http://dx.doi.org/10.1037/h0101634

Wood-Downie, H., Wong, B., Kovshoff, H., Mandy, W., Hull, L., & Hadwin, J. A. (2021). Sex/gender differences in camouflaging in children and adolescents with autism. *Journal of Autism and Developmental Disorders, 51*(4), 1353-1364. http://dx.doi.org/10.1007/s10803-020-04615-z

Zangeneh, M., & Al-Krenawi, A. (Eds.). (2019). *Culture, Diversity and Mental Health-Enhancing Clinical Practice*. Springer Nature. https://doi.org/10.1007/978-3-030-26437-6_3

# Autism Spectrum Disorder: Difficulty in Adult Diagnosis

Heather L. Gillespie

## Abstract

Adults have a significantly harder time being diagnosed with autism, and this is due to many reasons, such as the paucity of information about adults with autism, their diagnosis being missed as a child, lack of providers who feel confident in their knowledge to diagnose autism in adults, and an autistic adult's ability to mask and cope in a neurotypical world since childhood, among others. Few tests are available and specifically target adult diagnosis. Most tests are created for children or youth and may not account for the difference in the presentation of autism in adults and the coping skills and masking they have required to develop throughout their lives. This paper talks about the need for adequate knowledge and testing for autism in the adult population.

## Resumé

Il est beaucoup plus difficile de diagnostiquer l'autisme chez les adultes, et ce, pour de nombreuses raisons, notamment le manque d'informations sur les adultes autistes, le fait que le diagnostic n'ait pas été posé pendant l'enfance, le manque de prestataires qui ont confiance en leur capacité à diagnostiquer l'autisme chez les adultes, et la capacité de nombreux adultes autistes à faire preuve de camouflage social et à se débrouiller dans un monde neurotypique depuis l'enfance, entre autres. Il existe peu de tests ciblant spécifiquement le diagnostic chez l'adulte. En effet, la plupart des tests sont conçus pour les enfants ou les adolescents et peuvent ne pas tenir compte de la différence de présentation de l'autisme chez les adultes et des capacités d'adaptation et de camouflage qu'ils ont dû développer tout au long de leur vie. Cet article traite de la nécessité d'une connaissance et d'un dépistage adéquats de l'autisme dans la population adulte.

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## Introduction

Autism Spectrum Disorder, hereafter referred to as ASD, is a lifelong neurodevelopmental condition that was only recognized in children for many years. Recently, there has been a notable increase in the availability of ASD-focused services for children and an improvement in the early diagnosis and intervention for young people with autism — to the extent that doctors can correctly diagnose ASD as young as infancy (Adams, 2016[CW1] ). The issue in clinical psychology is the paucity of screening and diagnostic testing designed for adults, even though research shows similar rates of the disorder reported in this population as in children (Magiati, 2016). Another issue is the limited number of professionals who treat and are trained in diagnosing ASD in the adult population (McKenzie, 2015).

This paper defines ASD according to multiple diagnostic publications. It discusses some reasons ASD may be overlooked in children and the effect growing up undiagnosed can have. The paper also compares some of the available screening and testing methods developed for children and examines whether these measures are helpful for adults. Furthermore, it indicates the need to develop more accurate screening, diagnostic, and treatment options for those over 18.

## History

The diagnostic criteria for ASD are continuously being adapted. Before Kanner described *the infantile autistic disorder* in his 1943 paper, the syndrome was viewed not as a neurodevelopmental disorder but as a result of poor parenting. This is noted in his paper; according to the Freudian viewpoint, children whose mothers were cold and un-nurturing (refrigerator mothers) were more likely to develop the syndrome. It was also viewed as something children outgrew (Kanner, 1943; Sponheim, 1996). Moreover, Kanner differentiated autism from schizophrenia, yet until the 1970's, they were still mistaken for each other (Kanner, 1943; Green et al., 1984).

## Diagnostic Criteria

With the DSM-5 and the IDC-10, there is a consensus on a diagnosis. The DSM-5 has two symptom categories: social communication/interaction and restricted/repetitive interests (Adams, 2016; American Psychological Association, 2013). Deficits in social communication are broken down into groups: problems with social initiation and response, problems with non-verbal communication, and problems with social awareness and insight, as well as general concepts of social relationships. Restricted/repetitive patterns of behaviour, interests, or activities are broken down into four categories; Atypical speech, movement or play, rituals and resistance to change, preoccupations with objects or topics, and atypical sensory behaviours (APA, 2013).

To receive a diagnosis, the symptoms must be present in early childhood [but may not manifest fully until social demands become more than the individual can cope with]. The combined symptoms must also impair the individual's everyday functioning. Furthermore, according to the DSM-5, ASD has three severities. Level 1 [sometimes referred to as "high functioning" autism] requiring support, level 2 requiring substantial support, and level 3 requiring very substantial support (APA, 2013).

The DSM-5 views Autism as a spectrum and has included Asperger's syndrome within this

spectrum (APA, 2013), whereas the IDC-10 differentiates between Asperger's and what it terms "Childhood Autism" (APA, 2013; WHO, 2003). In the DSM-5, the previous diagnosis of Asperger's is lumped in with ASD. This is a better indication of autism being a spectrum because every person with autism struggles in different ways and with different aspects of their lives. Furthermore, Asperger's is named after the Nazi, Hans Asperger, and the DSM moved away from using this term which is an improvement on the original name of ASD-1. ASD as a spectrum allows for a complete picture when diagnosing because it includes many different factors degrees of the disorder while still including a number (1-3) for the "severity" of the disorder. In the IDC-10, 'communication' and 'social' impairments are separated into two categories (WHO, 2003). These are not the only two areas in which autism affects an individual, and thus is less inclusive than the DSM-5 for this particular disorder. It is important to understand how the disorder is classified to understand what measures are necessary to diagnose it accurately.

## Factors Contributing to Underdiagnosed ASD

The reason ASD is so frequently overlooked is multifaceted. Gender can play a role (Murray, 2016). There is a distinct difference in how symptoms of ASD are presented between sexes. Wilson studied adults who were being diagnosed with ASD for the first time, trying to assess why their diagnosis had been delayed (Wilson, 2016). He explains that women are more likely to find the ability to mask their symptoms as they age and do not always act on symptoms in the same way as males, which leads to females being left untreated or misdiagnosed at a higher volume than their male cohorts (Wilson, 2016). For instance, girls may have different types of obsessive or repetitive behaviour, and their 'special interests' tend to be more socially acceptable — thus, even though they display symptoms of autism, they are not recognized until later in life (Wilson, 2016). There is also an unconscious bias, where a doctor may have a template for what autism looks like and base their diagnosis on this instead of on the actual diagnostic criteria. This happens in all areas of healthcare but is very prevalent when it comes to a diagnosis of Autism Spectrum Disorder.

A family's income may also play a role; there is a significant out-of-pocket expense for these assessments, which many families cannot afford. In addition to the initial assessment, the responsibility of paying for subsequent treatment and support is also placed on the caregiver or family. Race is another factor. A study which looked at children being screened and diagnosed with ASD. Although there is no known difference in the prevalence or presentation of ASD between different races, Mandell found that African American children were diagnosed approximately 1.4 years later than white children, and the diagnosis time was prolonged for these individuals as well (Mandell, 2007). The availability of screening methods for ASD sensitive to social-cultural differences needs to increase, as well as intervention programs for these children once ASD has been identified. Some evidence also shows that cultural factors may also affect a parent's ability to recognize or interpret the signs of ASD in their children (Mandell, 2007). Parents who view a child's actions as negative are more likely to seek help for the child, compared to parents who view the child's behavior as part of the child's personality and do not see the need to seek help (Barahona-Corrêa, 2017). The severity of symptoms also plays a role in the age of diagnosis as well. The traits of having an IQ lower than 70, being male, and having developmental regression are all associated with the individual receiving an earlier diagnosis (Adams, 2016).

Another reason that children often are not diagnosed until they go to school is that there are very few pediatricians who will diagnose ASD (Campbell & Sceil, 2016); this can be due to a lack of knowledge of the disorder itself, or lack of confidence in their ability to screen/test for it. However, even though the number of doctors has increased from 8% to 50% in the past few years (Campbell & Sceil, 2016), it still leads to a problem. With increased awareness of ASD and the characteristics of the disorder, more people seek a diagnosis. There is then an increase in people both seeking an ASD diagnosis and an increase in specialist referrals due to physicians' inability to diagnose this disorder, and patients are then sent to specialists. The waiting list for these doctors becomes longer, and because of this, the wait time for patients also increases significantly. Subsequently, there ends up being a bottleneck in the service flow. Not only does this ensure that individuals who need prompt assessment are unable to receive it, but it also extends the diagnostic process for everyone seeking a diagnosis. A system that can handle the large increase in ASD referrals is vital to ensuring children are accurately screened and diagnosed with ASD.

## Adults With ASD

A study looked at adults being assessed for ASD for the first time. The differences between the individuals who received a diagnosis of ASD at their assessment and those who did not receive a diagnosis of ASD at their assessment were examined (Geurts, 2011). One difference was that adults who received the diagnosis reached out to the clinic much earlier (Geurts, 2011), which may suggest that their symptoms became more noticeable or an increased issue at an earlier age. Furthermore, despite both groups having similar exposure to mental health services in the past, those who received an ASD diagnosis had fewer previous diagnoses than those who did not receive an ASD diagnosis (Geurts, 2011).

It is recommended that adults seek assessment for ASD when they experience difficulties in social interaction and social communication or experience rigid and inflexible behaviours; resistance to change, and restricted interests, and if symptoms are affecting major areas of their life (i.e., work, school, relationships) (NICE, 2012). Nevertheless, adults have difficulty being diagnosed; for instance, clinicians find it more difficult to diagnose ASD in adults because they may present with less obvious impairments (Eriksson, 2013). Additionally, as individuals get older, they are sometimes misdiagnosed with another disorder, like OCD or ADHD which can have overlapping symptoms with ASD (McKenzie, 2015).

Little research has looked at ASD in the elderly population (Campbell & Sceil, 2016). Elderly patients presenting with ASD likely did not receive a diagnosis because the strong awareness of the disorder did not exist as it does now. Just a few decades ago, an individual presenting with symptoms of ASD may have been institutionalized (Hirota, 2018; Nierkerk, 2011). The lack of awareness, coupled with the fact that Asperger's syndrome and higher functioning forms of ASD were not acknowledged in the DSM until the 1990s, has led to many individuals being missed as children and seeking a diagnosis as an adult (APA, 1994[CW2] ).

## Available Screening and Diagnostic Tools

The lack of diagnostic tools for adults remains a serious methodological challenge for researchers and clinicians. A study done in 1989 is evidence that psychologists have been looking into testing adults for ASD for more than three decades (Mesibov, et al., 1989) and that this has

been an issue for an extended period of time. There were doctors showing concern and awareness around the disorder even before the heightened awareness around it, not just in the population it was increasingly being diagnosed in but also thinking ahead to adults[CW3] . The Childhood Autism Rating Scale (CARS) has been found to have higher validity than other childhood rating scales (Morgan, 1988); however, studies point to CARS being unreliable and having unsatisfactory measurement values (Baghdadli, et al., 2017). Researchers compared scores on the Childhood Autism Rating Scale (CARS) obtained by patients before age ten with results collected from the same children again after age thirteen (Mesibov et al., 1989). They found an improvement in the children's overall scores in almost every category. They concluded that if the measure were to be used in adolescents or adulthood, it would be more accurate to use a cut-off score lower than that used with children (suggested cut of scores: children: 30; adults: 27) (Mesibov, et. al., 1989). The improvement in scores shows a difference in the overall presentation of the disorder as one ages, and tests need to be adapted to fit this change. Mesibov points out the irony in the fact that the one score that did significantly increase was the "general impressions" category which translates to 'how autistic a person seems.' (Mesibov, et. al., 1989). This score goes up because many behaviours that may be acceptable as children seem increasingly unnatural as the individual ages. Thus, as these children age, their behaviour is more likely to stick out and to be noticed more by others – and possibly by the individual (Mesibov, et al., 1989[CW4] ). The individual becoming more aware of their symptoms, or having symptoms become an increased issue as they grow older, may lead to the individual seeking a diagnosis (Lewis, 2016a).

## Screening Measures

The author of an article reviewing nine different ASD screening methods found that most yielded unsatisfactory results, stating that "only the AQ-50, AQ-s, RAADS-R, and RAADS-14 had satisfactory or intermediate values for their psychometric properties" (Baghdadli, et al. 2017). The original Ritvo Autism Asperger's Diagnostic scale (RAADS) was developed to address the need for more ASD screening services for adults. Before the RAADS, the only peer-reviewed measure for adults was the Autism Spectrum Quotient (AQ) (Ritvo, 2010). The AQ is another screening test for adults, which is mailed and sent back by post (Magiati, 2016). People often use it as a self-diagnosis tool, although it is not intended to diagnose independently, regardless of who administers it (Magiati, 2016). The RAADS-R is a revised version of the RAADS scale that includes a self-report section for clients to complete. This version contains 80 questions and is completed in a clinical setting (Ritvo, 2010). The self-rating questionnaire in the RAADS-R has proven helpful when working with individuals with suspected comorbidities that may otherwise lead to a prolonged, unclear diagnosis (Eriksson et al., 2013). The RAADS-14 is a shortened version of the Ritvo Autism Asperger's Diagnostic scale, which may be helpful in clinical outpatient settings. This measure should be used in individuals without suspected comorbidity due to its shortened length and less ability to screen for differential diagnoses (Ritvo, 2010).

## Diagnostic Measures

Although both the Autism Diagnostic Observation Scale (ADOS) and Autism Diagnostic Interview (ADI) were developed for children, they both can be used in adults (Baghdadli et al., 2017). A revised version of the Autism diagnostic interview, ADI-R, which took out many

unnecessary or misleading questions, requires the interviewer to have specialized training to perform the test. The ADI-R takes 2 hours, can be used on children or adults with a mental age above 2, and is usually done in a clinical setting (Hirota, 2018). The test is best used on those without suspected comorbidity. While this is a well-respected diagnostic test, some disadvantages are that it is very long to conduct, is costly to administer, and requires the interviewer to be trained in administering it (Russel, 2016). Some clinicians may be hesitant to use it because of this (Joshi et al., 2011). There is also a shorter 40-question true or false informant survey, which corresponds with the ADI-R and signals a need for conducting the entire test. The ADOS-2 is an instrument created by the same authors and requires only 40-60 minutes to complete. It is a list of observations a licensed examiner should look for as different scenarios are conducted (Joshi et al., 2011). The ADOS is sometimes considered a gold standard, as is the ADI-R; however, they both tend to be more costly, labour intensive, and require the examiner to have extensive training, which limits who can administer them (Joshi et al., 2011; Magiati, 2016; Russel, 2016).

The Adult Asperger's assessment (AAA) is an emerging diagnostic tool for adults. However, it is relatively new, so few professionals are trained in administering and scoring this test (Kuenssberg & McKenzie, 2011). Additionally, it takes a long time to administer. The AAA includes two components; the empathy quotient (EQ) and the autism quotient (AQ). It includes two self-report questionnaires and a clinical interview with the client and possibly an informant (Kuenssberg & McKenzie, 2011). The AAA is administered via computer, not mailed to the client, and sent back (Ritvo, 2010). The test has been reported as having good content validity (Baron-Cohen et al., 2011). The authors of one of the few studies which looked at the AAA found that the test tends to overweight social and communication factors (Baron-Cohen et al., 2006). Because social and communication are measured separately, some symptoms may be counted twice, leading to overdiagnosis. The findings from this study correspond to the DMS-5 more so than the IDC-10 because it shows that separating these two categories, can lead to overdiagnosis of the disorder.

One researcher created a DSM-based structured diagnostic interview comprising 16 questions with a sensitivity of 94% (Frazier et al., 2012). The author suggests it could be a quick, cost-effective assessment tool. Although there was a change to the DSM during the study, they retained the diagnostic criteria of DSM-III-R and then, after the study was complete, checked the results with the DSM-IV criteria, and there was a high correspondence (Frazier et al., 2012).

The AMSE (Autism Mental Status Exam) was created for clinicians who were knowledgeable about the disorder but were not trained to give standardized assessments (Grodberg, 2014). Administering this test requires little training; the training can be done online, and itis to be done in a clinical setting (Grodberg, 2014). The AMSE is also shown to compare well to a diagnosis of ASD when looking at DSM-5 (Magiati, 2016). However, it should not be a substitute for a more comprehensive examination. No single measure should be used alone during the diagnostic process (Mazefsky et al., 2010). Results can be misleading for many reasons; underestimation (Frazier et al., 2012) and overestimation (Gładysz et al., 2018).

## Why Addressing ASD in Adults is Important

Delayed and underdiagnosis of ASD is common and can impact the individual's quality of life. A common symptom of ASD is alexithymia, which is difficulty coming up with words to

express oneself (Lewis, 2016b). This leads to an increased issue with assessment as an adult, where the diagnosis is based more on the patients' descriptions of childhood. Individuals with undiagnosed ASD or whose diagnosis has been delayed until adulthood are at a higher risk of depression, anxiety, and suicide (Lewis, 2016b). Reports have stated that two-thirds of adults with newly diagnosed Asperger's reported having considered suicide, and half of those individuals had made a plan or attempted it (Lewis, 2016b). Sadly, the number could be even larger. There have been findings that alexithymia can also lead to underdiagnosis and untreated depression in individuals with ASD (Lewis, 2016b). This can be due to the individual's inability to accurately describe the severity and impact of the symptoms they're experiencing on their life (Lewis, 2016b).

Adults with ASD also tend to be more anxious and have a higher rate of depression than the public (Russel, 2016). Sensory over-responsivity has been shown to lead to anxiety (Tavossoli, 2014). This increased sensory response and anxiety can further compromise someone's ability to function daily. Individuals can present as being more irritable, aggressive, violent, or suicidal (Tavossoli, 2014). Self-harm is also a dangerous symptom of ASD. These symptoms can produce problems with the patient and their family and occasionally result in hospitalization (Russel, 2016). Notwithstanding high rates of comorbid anxiety disorders, psychological intervention treatment for adults with ASD has been shown to be effective (Russel, 2016; Howlin, 2015). It is so important for physicians to look into the possibility of ASD when treating individuals for other suspected ailments.

## Conclusion

Remaining undiagnosed, if an individual has ASD, can be detrimental, and it is always best to try for early intervention. Some tools developed for adults, like the AAA and AMSE, though more research needs to be done into their validity. More testing methods inclusive of sex, race, culture, and socio-economic status are vital in individuals receiving proper diagnosis and care. However, it will not be perfect regardless of what is done in an attempt at early intervention. The fact that children continue to be missed being diagnosed further validates the need for more adult-focused treatment. Not every person with autism spectrum disorder will be diagnosed in early childhood, and the resources need to be there to help support those individuals seeking a diagnosis at a later age.

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## References
Adams, H. L. (2016). History and Purpose of Assessment and Diagnosis of Autism. In J. L. Matson (Ed.), *Handbook of Assessment and Diagnosis of Autism Spectrum Disorder* (pp. 1-9). Springer International Publishing. https://doi.org/10.1007/978-3-319-27171-2_1
American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.
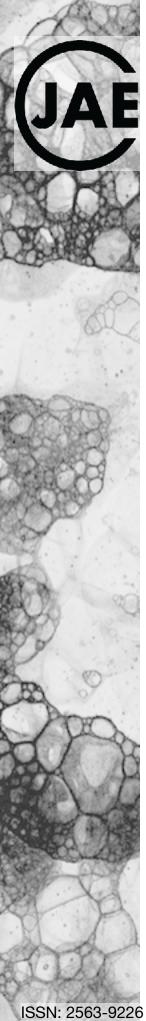
Baghdadli, A., Russet, F., & Mottron, L. (2017). Measurement Properties of Screening and Diagnostic Tools for Autism Spectrum Adults of Mean Normal Intelligence: A Systematic Review. *Journal of European Psychiatry, 44,* 104-124. https://doi.org/10.1016/j.eurpsy.2017.04.009

Barahona-Corrêa, B. (2017). The High Functioning Group: High-Functioning Autism and Asperger's Syndrome in Adults. In B. Barahona Corrêa & R.-J. van der Gaag (Eds.), Autism Spectrum Disorders in Adults (pp. 129–178). Springer International Publishing. https://doi.org/10.1007/978-3-319-42713-3_5

Baron-Cohen, S., Wheelwright, S., Robinson, J., & Woodbury-Smith, M. (2005). The Adult Asperger's Assessment (AAA): A diagnostic method. *Journal of Autism and Developmental Disorders*, 807-819. https://doi.org/10.1007/s10803-005-0026-5

Campbell, J. M., Sceil, K. A., & Hammond, R. K. (2016). Screening Methods. In J. L. Matson (Ed.), *Handbook of Assessment and Diagnosis of Autism Spectrum Disorder* (pp. 65-86). Springer International Publishing. https://doi.org/10.1007/978-3-319-27171-2_5

Eriksson, J. M., Andersen, L. M., & Bejerot, S. (2013). RAADS-14 Screen: Validity of a screening tool for autism spectrum disorder in an adult psychiatric population. *Molecular Autism*, 4(1), 49. https://doi.org/10.1186/2040-2392-4-49

Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., Findling, R. L., Hardan, A. Y., & Eng, C., (2012). Validation of Proposed DSM-5 Criteria for Autism Spectrum Disorder. *Journal of American child and Adolescent Psychiatry, 51*(1) 28-40.

Geurts, H. M. (2011). A Retrospective Chart Study: The Pathway to a Diagnosis for Adults referred for ASD Assessment. *Autism, 16*(3) 299-305. https://doi.org/10.1177/1362361311421775

Grodberg, D., Weinger, P. M., Halpern, D., Parides, M., Kolevzon, A., & Buxbaum, J. D. (2014). The Autism Mental Status Exam: Sensitivity and Specificity Using DSM-5 Criteria in Verbally Fluent Adults. *Journal of Autism and Developmental Disorders, 44*(3) 609-614. https://doi.org/10.1007/s10803-013-1917-5

Hirota, T., So, R., Kim, Y. S., Leventhal, B., & Epstein, R. A. (2018). A systematic review of screening tools in non-young children and adults for autism spectrum disorder. *Research in Developmental Disabilities, 80*, 1–12. https://doi.org/10.1016/j.ridd.2018.05.017

Howlin, P., & Taylor, J. L. (2015). Addressing the need for high quality research on autism in adulthood. *Autism, 19*(7), 771–773. https://doi.org/10.1177/1362361315595582

Joshi, G., Petty, C. R., Fried, R., Wozniak, J., Micco, J. A., Henin, A., Doyle, R., Galdo, M., Kotarski, M., Caruso, J., Meller, B., Faraone, S. V., & Biederman, J. (2011). Discriminant and concurrent validity of a simplified DSM-based structured diagnostic instrument for the assessment of autism spectrum disorders in youth and young adults. *BMC Psychiatry, 11*, 204. https://doi.org/10.1186/1471-244X-11-204

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous child, 2*(3), 217-250.

Kuenssberg, R., & McKenzie, K. (2011). Confirmatory factor analysis of the Adult Asperger Assessment: The association of symptom domains within a clinical population. *Research in Developmental Disabilities, 32*(6), 2321–2329. https://doi.org/10.1016/j.ridd.2011.07.034

Lai, M.-C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., Happé, F., & Baron-Cohen, S. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism, 21*(6), 690–702. https://doi.org/10.1177/1362361316671012

Lewis, L. F. (2016a). Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorder in Adults. *Archives of Psychiatric Nursing, 30*(5), 575–580. https://doi.org/10.1016/j.apnu.2016.03.009

Lewis, L. F. (2016b). Realizing a diagnosis of autism spectrum disorder as an adult. *International Journal of Mental Health Nursing, 25*(4), 346–354. https://doi.org/10.1111/inm.12200

Magiati, I. (2016). Assessment in Adulthood. In J. L. Matson (Ed.), *Handbook of Assessment and Diagnosis of Autism Spectrum Disorder* (pp. 191–207). Springer International Publishing. https://doi.org/10.1007/978-3-319-27171-2_11

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in Diagnoses Received Prior to a Diagnosis of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1795–1802. https://doi.org/10.1007/s10803-006-0314-8

McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., & Irvine, L. (2015). Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults. *Research in Developmental Disabilities, 45-46*, 300–306. https://doi.org/10.1016/j.ridd.2015.07.033

Mesibov, G. B., Schopler, E., Schaffer, B., & Michal, N. (1989). Use of the Childhood Autism Rating Scale with Autistic Adolescents and Adults. *Journal of the American Academy of Child & Adolescent Psychiatry, 28*(4), 538–541. https://doi.org/10.1097/00004583-198907000-00012

Morgan, S. (1988). Diagnostic Assessment of Autism: A Review of Objective Scales. *Journal of Psychoeducational Assessment, 6*(2), 139–151. https://doi.org/10.1177/073428298800600205

Murray, A. L., Allison, C., Smith, P. L., Baron-Cohen, S., Booth, T., & Auyeung, B. (2017). Investigating diagnostic bias in autism spectrum conditions: An item response theory analysis of sex bias in the AQ-10: ASD fair screening. *Autism Research, 10*(5), 790–800. https://doi.org/10.1002/aur.1724

Ritvo, R. A., Ritvo, E. R., Guthrie, D., Ritvo, M. J., Hufnagel, D. H., McMahon, W., Tonge, B., Mataix-Cols, D., Jassi, A., Attwood, T., & Eloff, J. (2011). The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): A Scale to Assist the Diagnosis of Autism Spectrum Disorder in Adults: An International Validation Study. *Journal of Autism and Developmental Disorders, 41*(8), 1076–1089. https://doi.org/10.1007/s10803-010-1133-5

Russell, A. J., Murphy, C. M., Wilson, E., Gillan, N., Brown, C., Robertson, D. M., Craig, M. C., Deeley, Q., Zinkstok, J., Johnston, K., McAlonan, G. M., Spain, D., & Murphy, D. G. (2016). The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report. *Autism, 20*(5), 623–627. https://doi.org/10.1177/1362361315604271

Sponheim, E. (1996). Changing criteria of autistic disorders: A comparison of the ICD-10 research criteria and DSM-IV with DSM-III-R, CARS, and ABC. *Journal of Autism and Developmental Disorders, 26*(5), 513–525. https://doi.org/10.1007/BF02172273

Stoddart, K., Burke, L., & King, R. (2012). *Asperger syndrome in adulthood: A comprehensive guide for clinicians*. WW Norton & Company.

Tarbox, J., La Cava, S., & Hoang, K. (2016). Types of Assessment. In J. L. Matson (Ed.), *Handbook of Assessment and Diagnosis of Autism Spectrum Disorder* (pp. 11–26). Springer International Publishing. https://doi.org/10.1007/978-3-319-27171-2_2

Tavassoli, T., Miller, L. J., Schoen, S. A., Nielsen, D. M., & Baron-Cohen, S. (2014). Sensory over-responsivity in adults with autism spectrum conditions. *Autism, 18*(4), 428–432. https://doi.org/10.1177/1362361313477246

The National Institute of Clinical Excellence, NICE. (2012). *Guidelines for the Recognition, Diagnosis, and Management of Adults with ASD.*

Van Niekerk, M., Groen, W., Vissers, C., Van Driel-de Jong, D., Kan, C., & Oude Voshaar, R. (2011). Diagnosing autism spectrum disorders in elderly people. *International Psychogeriatrics, 23*(5), 700-710. doi:10.1017/S1041610210002152

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (2014). Practice Parameter for the Assessment and Treatment of Children and Adolescents With Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*(2), 237–257. https://doi.org/10.1016/j.jaac.2013.10.013

Wilson, C. E., Murphy, C. M., McAlonan, G., Robertson, D. M., Spain, D., Hayward, H., Woodhouse, E., Deeley, P. Q., Gillan, N., Ohlsen, J. C., Zinkstok, J., Stoencheva, V., Faulkner, J., Yildiran, H., Bell, V., Hammond, N., Craig, M. C., & Murphy, D. G. (2016). Does sex influence the diagnostic evaluation of autism spectrum disorder in adults? *Autism, 20*(7), 808–819. https://doi.org/10.1177/1362361315611381

Wilson, C. E., Roberts, G., Gillan, N., Ohlsen, C., Robertson, D., & Zinkstok, J. (2013). The NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum. *Advances in Mental Health and Intellectual Disabilities, 8*(1), 3–14. https://doi.org/10.1108/AMHID-05-2013-0035

World Health Organization (Ed.). (2004). *International statistical classification of diseases and related health problems* (10th revision, 2nd edition). World Health Organization.

# Heuristics in Medicine: How Cognitive Biases Influence Decision Making and Diagnosis

Heather L. Gillespie

## Abstract

Heuristics, or mental shortcuts, are used by everyone to make decision making easier and quicker in daily life. In jobs such as medicine, however, using heuristics can lead to biased decision making and, in turn, misdiagnosis of patients. Doctors are not immune to being biased, or stereotyping. In fact, many healthcare professions have implicit bias training to try and minimize this. Knowledge about one's own bias can make a difference short term, but the person will be thinking more about whether they are being biased and less on how they can solve the problem in front of them. Bias is, unfortunately, something that must be acknowledged in all corners of society. So, how do we accommodate our biases to get the best results — knowing that we will fall back on heuristics and stereotyping?

## Resumé

L'heuristique (aussi appelée « raccourci mental ») est utilisée par tout le monde pour faciliter et accélérer la prise de décision dans la vie quotidienne. Toutefois, dans des professions telles que la médecine, l'utilisation de l'heuristique peut conduire à une prise de décision partiale et, par conséquent, à un diagnostic erroné des patients. Les médecins ne sont pas à l'abri des préjugés ou des stéréotypes. En fait, de nombreuses professions du domaine de la santé ont mis en place des formations sur les préjugés implicites afin d'essayer de minimiser ce phénomène. Le fait de connaître ses propres préjugés peut faire une différence à court terme, mais il existe un risque que la personne passe plus de temps à se demander si elle a des préjugés qu'à tenter de résoudre le problème qui se présente à elle. Les préjugés sont malheureusement une réalité qu'il faut reconnaître dans tous les domaines de la société. Alors, comment est-il possible de tenir compte de nos préjugés pour obtenir les meilleurs résultats possibles, tout en sachant que nous risquons de retomber dans le piège de l'heuristique et des stéréotypes?

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Through quasi-systematic review, Whelehan et al. (2020) explore many of the common heuristics used every day by physicians during clinical decision-making. The insight from this paper--in addition to relevant empirical work--will allow me to explore how cognitive biases and heuristics affect decision-making overall, and then relate the findings to the context of medical diagnosis and clinical decision-making. Dual process decision making relies on the idea that there are two types of cognition used in decision making: intuitive and deliberate thinking. Type I, or intuitive processes, are where the majority of heuristics come into play, because these are automatic shortcuts made to speed up every-day decisions (Pennycook et al., 2015). Type II, or analytic thinking, takes a lot more effort on the part of the individual, is conscious, deliberate, and often more accurate/rational. Studies looking at the dual-process model of decision-making have found that individuals move from one type of processing to the other quite quickly (Croskerry, 2014). The problem with using analytical processes all of the time is that the abundance of information available to filter through when making the decision, and the inability to multitask, are often too much and can lead to cognitive fatigue (2015). This happens easier with analytic processing than with intuitive thinking processes, which are able to work in parallel with one another (2015).

Intuitive processing has been historically seen to be as faster, and taking less effort than analytic processing (Pennycook et al., 2015; McDonald, 1996; Kahneman & Tversky, 1974); however, there is evidence that some heuristics--which are typically viewed as intuitive in nature--actually take more mental effort due to attentional control and search costs in certain conditions (Bobadilla-Suarez & Love, 2018). Bobadilla-Suarez & Love (2018) continue by researching the effects of time-pressure on participants' use of heuristics and conclude that, when under time-pressure, heuristics that were accurate in previous studies now hindered performance (2018). Their research suggests that a greater number of heuristics should be looked at in detail, focusing on which cognitive processes they rely on (Bobadilla-Suarez & Love, 2018). The fact that time-pressure influences heuristics to such a great extent is an important factor when looking at the medical community, and clinicians who are making diagnostic decisions, because these are often fast paced environments which require quick thinking.

According to Arkes et al. (1986), the representativeness heuristic, where an individual estimates prevalence based on mental representations, often accounts for how psychologists make clinical-decisions; this is in line with earlier empirical studies conducted by Kahneman & Tversky (1974), which show that judgements and decision-making in everyday life can often be described using the availability and representativeness heuristics, and are shaped by cognitive-biases. Clinicians are not immune to these cognitive biases, and research has shown that there is a high level of "bias blindspot" within the medical community (Croskerry, 2014). Blindspot bias has a positive correlation with overconfidence bias, which is described by erroneously high levels of confidence in one's decision, leading to biased decision making and misdiagnosis (Croskerry, 2014). A study by McCormick and colleagues found that out of the 661 participants in their study, only one claimed to be more biased than the average person (McCormick et al., 2015).

There are other biases to be aware of in the medical community; both intrinsic and extrinsic factors can play a role in bias so internal cognitive factors, as well as external, environmental factors can change the way clinicians decide on treatment. Stereotyping, attributional biases, affective biases, in addition to cognitive biases affect clinicians

(Featherstone et al., 2020). For instance, in the emergency department — where decisions need to be made particularly quickly — if a doctor sees a patient frequently complaining of pain, they may write it off as drug-seeking, or malingering, when this patient could have a chronic condition and be in chronic pain. This is further exasperated when a patient has a pre-existing mental health condition, or previous drug abuse (O' Sullivan & Schofield, 2018). Heuristics also play a role in under-diagnosing some rarer conditions; there is a saying in the medical community, "if you hear hoof beats think horses, not zebras." What this means is that when a physician sees a set of symptoms, they should be looking for a more common illness that could be responsible, because those are more likely to occur than a rare condition. This goes hand in hand with the availability heuristic because more common illnesses or diseases are seen on a more regular basis, and thus are in the clinicians' conscious thoughts more than something briefly learned in medical school, or something they see very rarely. There are many biases seen in daily life which can have an influence in medicine as well, one example is stereotype bias, where a medical professional has a set of cognitive over-generalizations—expectations or beliefs about certain groups of people—and these stereotypes remain in their mind, unchanging, even if an individual does not fit the stereotype held by the doctor (Featherstone et al., 2020).  When characteristics and qualities of social categories or members of a group are not altered, even when interacting with an individual whose qualities are incongruent with the stereotype, it can lead to mistreatment of these groups of people (2020). This can be the case when looking at diagnosing based on age, gender, race, socioeconomic factors, weight, disability, or previous drug use/mental health diagnosis (2020).

There is a discrepancy in how doctors and clinicians treat male versus female patients; with male patients, pain is taken more seriously, and a male patient is less likely to be dismissed and told they are being dramatic or that their ailments are caused by anxiety. In fact, in Featherstone et al.'s 2020 analysis, gender bias was almost double that of any other bias studied. There are many reasons why this could be; firstly, female patients have historically been viewed as having psychological manifestations of illness — from the early days of medicine, women were treated differently, and psychosomatic illnesses — now known as conversion disorders — were diagnosed at a far greater rate than in men (Hamburg, 2008; McDonald, 1997). Secondly, men and women have differences in how they explain their symptoms to the practitioner, which could bias their treatment (Ruiz & Verbrugge, 1997). Furthermore, many studies of disease have been done on solely men, and the results of these studies are then carried over to treat female patients, whose symptoms may differ from those shown in these studies — meaning their treatment and assessment is based on how men present with the illness and, as such, their symptoms could be dismissed (Ruiz & Verbrugge, 1997; Hamburg, 2008).

Age can be another factor in biases toward patients; with COVID 19, the disease was seen to affect mostly older adults, which, before adequate testing was implemented, meant that younger patients were systemically seen as more resistant to the illness, and thus not treated or assessed at the same level as older adults (Hammond et al., 2021). The same is true for many illnesses. Looking at autism, it is generally seen as a disorder affecting children, and as such there are limited testing methods available for the adult population (Baron-Cohen, 2004).

Being aware of one's biases has shown to improve them in the short-term, but there have been few studies looking at the long-term retention of these bias reductions, and knowledge of biases alone is not enough to counter cognitive-biases effectively (Satya-Murti & Lockhart, 2018).

Focusing on overconfidence bias and how to mitigate its effects is important in reducing the current estimated 10-15% diagnostic failure rate (Croskerry, 2013).

Physicians' decision-making processes are often guided by heuristics due to the biological evidence available being insufficient to guide every decision doctors make every day (McDonald, 1996). *Anchoring* can be frequently seen in medical decision-making when doctors focus on one particular symptom that they view to be the most pertinent, leading them to overlook other, as or more important symptoms (Satya-Murti & Lockhart, 2018). Another heuristic described by Kahneman & Tversky (1974), *the representativeness heuristic,* is where people estimate the prevalence of something occurring by comparing it with a mental prototype, (McDonald, 1996; Kahneman & Tversky 1974; Bowes et al., 2020). For example, when assessing someone with Autism Spectrum Disorder (ASD), clinicians bring to mind a "prototype" of their view of someone with the diagnosis and then compare the individual with this mental prototype (Garb, 1996). This is problematic because these prototypes do not always align with standardized diagnostic guidelines (Whelehan et al., 2020). This is the case particularly with an ASD diagnosis due to the paucity of research on females who have ASD. Due to the disparity in available research between sexes, the mental prototypes that doctors form of individuals who have ASD tend to be biased and are similar to the "stereotypical" presentation of the disorder, which was based on studies only including boys (Baron-Cohen, 2004). Research by Garb (1996) showed that, even if clinicians appeared to be referring to the DSM criteria for a diagnosis, that their decisions did not match the criteria verbatim, with only 18 of the 67 clinicians making consistent diagnosis which align with DSM criteria.

Heuristics can lead to doctors misdiagnosing patients, and, as such, can lead to subpar or inaccurate treatment for these patients. While teaching physicians about the biases found in the field can help improve bias toward patients to some degree, for a limited amount of time, doctors and patients should still be aware that biased diagnoses are bound to continue. Physicians need to be open to the possibility that their thinking is biased, and that they are more likely than they think to misdiagnose patients. Less common conditions need to be in their mind as well when looking at differential diagnosis, and doctors must understand that presentation of disorders and illness can differ between patients. Patients need to advocate for themselves and object when they believe they are not being listened to or have their insight into what could be happening to them ignored. For physical, and mental health conditions, the patient knows their symptoms best, and thus sometimes may need to explain, reiterate, and push for doctors to listen to them and take them seriously.

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**References**
Arkes, H. R., Dawes, R. M., & Christensen, C. (1986). Factors influencing the use of a decision rule in a probabilistic task. *Organizational Behavior and Human Decision Processes, 37*(1), 93–110. https://doi.org/10.1016/0749-5978(86)90046-4

Baron-Cohen, S. (2004). The cognitive neuroscience of autism. *Journal of Neurology, Neurosurgery & Psychiatry, 75*(7), 945–948. https://doi.org/10.1136/jnnp.2003.018713

Bobadilla-Suarez, S., & Love, B. C. (2018). Fast or frugal, but not both: Decision heuristics under time pressure. *Journal of Experimental Psychology: Learning, Memory, and Cognition, 44*(1), 24-33. https://doi.org/10.1037/xlm0000419

Bowes, S. M., Ammirati, R. J., Costello, T. H., Basterfield, C., & Lilienfeld, S. O. (2020). Cognitive biases, heuristics, and logical fallacies in clinical practice: A brief field guide for practicing clinicians and supervisors. *Professional Psychology: Research and Practice, 51*(5), 435–445. https://doi.org/10.1037/pro0000309

Croskerry, P. (2013). From Mindless to Mindful Practice—Cognitive Bias and Clinical Decision Making. *New England Journal of Medicine, 368*(26), 2445–2448. https://doi.org/10.1056/NEJMp1303712

Croskerry, P. (2014). Bias: A normal operating characteristic of the diagnosing brain. *Diagnosis, 1*(1), 23-27. https://doi.org/10.1515/dx-2013-0028

Featherston, R., Downie, L. E., Vogel, A. P., & Galvin, K. L. (2020). Decision making biases in the allied health professions: A systematic scoping review. *PLOS ONE, 15*(10), e0240716. https://doi.org/10.1371/journal.pone.0240716

Garb, H. N. (1996). The representativeness and past-behavior heuristics in clinical judgment. *Professional Psychology: Research and Practice, 27*(3), 272–277. https://doi.org/10.1037/0735-7028.27.3.272

Hamberg, K. (2008). Gender Bias in Medicine. *Women's Health, 4*(3), 237-243. https://doi.org/10.2217/17455057.4.3.237

Kahneman, D., Slovic, P., & Tversky, A. (Eds.). (1982). *Judgment under uncertainty: Heuristics and biases.* Cambridge University Press.

McDonald, C. J. (1996). Medical Heuristics: The Silent Adjudicators of Clinical Practice. *American College of Physicians, 124*, 56-62.

O'Sullivan, E., & Schofield, S. (2018). Cognitive Bias in Clinical Medicine. *Journal of the Royal College of Physicians of Edinburgh, 48*(3), 225–232. https://doi.org/10.4997/jrcpe.2018.306

Pennycook, G., Fugelsang, J. A., & Koehler, D. J. (2015). Everyday Consequences of Analytic Thinking. *Current Directions in Psychological Science, 24*(6), 425–432. https://doi.org/10.1177/0963721415604610

Ruiz, M. T., & Verbrugge, L. M. (1997). A two way view of gender bias in medicine. *Journal of Epidemiology & Community Health, 51*(2), 106–109. https://doi.org/10.1136/jech.51.2.106

Satya-Murti, S., & Lockhart, J. J. (2018). Diagnosing Crime and Diagnosing Disease- II: Visual Pattern Perception and Diagnostic Accuracy. *Journal of Forensic Sciences, 63*(5), 1429-1434. https://doi.org/10.1111/1556-4029.13735

Scopelliti, I., Morewedge, C. K., McCormick, E., Min, H. L., Lebrecht, S., & Kassam, K. S. (2015). Bias Blind Spot: Structure, Measurement, and Consequences. *Management Science, 61*(10), 2468–2486. https://doi.org/10.1287/mnsc.2014.2096

Whelehan, D. F., Conlon, K. C., & Ridgeway, P. F. (2020). Medicine and heuristics: Cognitive biases and medical decision-making. *Irish Journal of Medical Science, 189*(4), 1477-1484. Springer. https://doi.org/10.1007/s11845-020-02235-1

# Teaching Strategies for Autistic Students

**Rebekah Kintzinger**

### Abstract
This article explores teaching and the educational environment with the Autistic student in mind. It begins by approaching the medical and social models of disability and discussing the implications of their use in an educational setting, focusing on why a social model of disability best supports the learning of Autistic and neurodivergent students in order to be as inclusive as possible in the education setting. The article then goes into detail on the strategies found within the support tiers of Communication, Visual Aide, and Environment in a classroom setting to bolster the success of Autistic and neurodivergent students. This includes a comprehensive breakdown of best ways to support students in these areas, and why this is important. Focussing on the idea that all behavior is communication, the article discusses the importance of inclusivity in the classroom, and preserving the agency of Autistic students. This article aims to give educators the tools they need to support students who are Autistic and neurodivergent, so that they are experiencing less stress and an improved school experience across their learning journey.

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Resumé
Cet article explore l'enseignement et l'environnement pédagogique dans l'optique de l'élève autiste. Il commence par aborder les modèles médicaux et sociaux du handicap et discute des implications de leur utilisation dans un cadre pédagogique, en se concentrant sur les raisons pour lesquelles un modèle social du handicap soutient mieux l'apprentissage des élèves autistes et issus de la neurodiversité afin d'être aussi inclusif que possible en contexte pédagogique. L'article décrit ensuite en détail les stratégies utilisées en classe dans les domaines de la communication, de l'aide visuelle et de l'environnement pour favoriser la réussite des élèves autistes et issus de la neurodiversité. L'article comprend une analyse détaillée des meilleures façons de soutenir les élèves dans ces domaines et de leur importance. En se concentrant sur l'idée que tout comportement est une forme de communication, l'article discute de l'importance de l'inclusion dans la classe et de la préservation de l'autonomie des élèves autistes. Cet article vise à donner aux éducateurs les outils dont ils ont besoin pour soutenir les élèves autistes et issus de la neurodiversité, afin de réduire le stress des élèves et de leur offrir une expérience scolaire améliorée tout au long de leur parcours d'apprentissage.

I received my autism diagnosis ten years ago as an adult, having grown up in a small town in BC at the base of a provincial park, where we hiked often, and had a musical, close-knit family. I have lived in many cities and towns and attended post-secondary school in Calgary. I am a parent of two sons in middle and high school, respectively, here in the Okanagan. One of my sons has an autism diagnosis, and the other self-identifies as Autistic but does not require the same support as their brother.

As far as working goes, I have done many different things in my life. Now I am a chair of the Autism Alliance of Canada and founding editor of the recently award-winning Canadian Journal of Autism Equity through McMaster University. The Autism Alliance of Canada is a national alliance working together for the rights of Autistic people and their families. We address priority issues that Autistic people and their loved ones face across their lifespan. We do this by facilitating dialogue, advancing research, and working with governments to develop and implement a National Autism Strategy.

Autism is a brain difference that is fundamental to who Autistic people are. Autistic people develop differently compared to non-Autistic people. Autistic individuals think, move, interact, sense, and process differently than what people might expect. They are atypical in a world that expects people to be typical. Autistic people have qualities that make them similar to other Autistic people.

These qualities include differences in communication. Many Autistics communicate with others in ways that aren't typical or usual - in how they experience and display their feelings, interact with others, form and understand their friendships and relationships, engage in the things they are passionate about or experts in, imagine, and play, see patterns and connections, and perceive or sense the world around them. I try never to use the word 'disorder' to describe

Autism - Autistic people talk about themselves as different, not disordered. Autism is not a disease or an illness. So, it is not curable or treatable.

Autism affects communication and interaction with others and can often have many other significant factors that impact an Autistic person's life, such as sensory challenges or other co-occurring conditions. I am usually non-speaking when I feel overwhelmed or am under stress. I experience many sensory sensitivities in my day-to-day life that fluctuate with my stress levels. These include sensitivity to smells, sounds, and too many people, as well as difficulty processing my environment and channeling the expression of my thoughts and ideas. I also have quite a few co-occurring conditions along with being Autistic. This is common and ongoing and it's a part of being Autistic.

Many of the strategies in this paper have worked for me personally. They have helped foster the success of my children and my colleagues. These are evidence-based strategies with research behind them that demonstrate they work. I want to acknowledge that I know teachers work hard with very little support and that there are many students in the classroom. Still a teacher can make a massive positive impact on the confidence and sense of self of neurodiverse students.

In this paper, I use identity-first (Autistic person) language to describe Autistic people and students, rather than person-first language (person with Autism). This is intentional. When we think about identity-first language, we recognize that we use it all the time! We use identity-first language for positive and neutral descriptors without a second thought. For example, I could describe myself by saying: "I am white." "I am Canadian," "I am intelligent." "I am a parent." "I am a hockey fan." What we don't often do is describe ourselves using person-first language. That would be quite awkward: "I have whiteness," "I have Canadianness," "I have intelligence," "I have offspring," or "I have a fan interest in hockey." I use identity-first language to talk about parts of myself, and I feel that my disability deserves the same treatment.

What do we often use person-first language for? Well, we say things like: "I have a cold," "I have the flu," "I have measles," or "I have cancer." It's important to recognize that we often use person-first language for describing undesirable situations. You can also lose things that you can have - they can usually go away at some point. Autism is not like that.

For a long time, professional fields were using person-first language to talk about certain people, saying "person with autism," "person with a disability," and so on. They felt this need to separate autism, or the disability from the person - to appreciate the person separately from their being Autistic or disabled. But we know now this is harmful; it is stigmatising. It negatively casts Autism by extending so much effort to disassociate the person from their autism or disability (Botha et al., 2021).

It's perfectly appropriate to ask people which language they prefer, or if not, use the language that is the consensus in that community. The Blind, Deaf, and Autistic communities all prefer identity-first language (Zola, 1993).

There is much empowerment that Autistic people and their families can receive from using strength-based language, and I encourage you to use this type of language when communicating with Autistic students in the classroom (Zola, 1993).

This paper briefly introduces the differences between the medical and social models of disability. It also includes some strategies that can be employed in the classroom to improve the learning environment and student experience.

In my opinion, autism is not a medical condition, not a disorder. There is no correct way to develop neurologically. Finding out that I am Autistic brought me an overwhelming sense of relief. I could look back on many of my childhood and adolescent experiences in a way that was

clarifying. Autism is a different way of thinking (and more), and Autistic people contribute to the diversity of cognitive thinking. These differences in neurology should be respected, celebrated, and given as many opportunities as those who are not Autistic in their neurology.

There are two main lenses through which people in the professional and medical sectors tend to look at autism. They are the medical and social models of disability.

In the medical model of disability, disability is diagnosed as the disabled person having an abnormality or a deficiency. Typically, this deficiency needs to be treated, cured, or otherwise requires a plan to be put in place for the individual. In this case, autism is seen as something that needs to be treated and cured, and autistic behaviours are seen as symptoms that should be reduced or eliminated (Waltz, 2008).

In the social model of disability, however, disability is seen as neutral; it is considered just a difference. The person is not disabled by their Autism, for example, but rather by the barriers in the environment and society around them. Disability Rights advocates, including autistic advocates, are trying to move the world towards the social model of disability. In the social model of disability, barriers are removed, rather than disabled people needing to be changed. When barriers are removed, people are more independent and have equal societal opportunities.

Jac den Houting is a Postdoctoral Research Fellow at Macquarie University in Sydney, Australia, where they investigate structural and systemic inequities in autism research. In a TEDx talk, Jac described a shopping mall to compare the social and medical models of disability in the context of autism (den Houting, 2019). They describe being Autistic in a shopping mall. The malls are loud, they're brightly lit, they're unpredictable, and they're full of people.

The medical model of disability says that people are disabled because there's a problem with how their brain processes that input because that person is Autistic. In the social model of disability, the person doesn't struggle in a shopping mall because there is something wrong with them. They struggle because the shopping mall is not designed in a way that meets their needs. If we started designing shopping malls that were quiet, dimly lit, predictable, and sparsely populated, people would still be Autistic. Still, they might not be disabled by shopping malls anymore.

Why should people be thinking about the social model of disability? There are a few main reasons. One of them is that when we approach autism from the social model of disability it empowers the disabled person and promotes their independence.

We should strive to create an inclusive environment for disabled students every day. An inclusive environment happens when we address how disabled students are being denied **full participation**, exposed to **prejudicial attitudes**, and inaccessible **social activities**. These are real issues that create the current barriers that disable Autistic students.

Education and training are important to reduce stereotypes of autism and to increase understanding of the complex needs of Autistic students to include students in school settings where proper accommodations are currently not in place. Inclusion is about offering the same activities to everyone while providing support and services to accommodate people's differences. What inclusion means for any one student will be different because autistic people are different. Autism affects our communication and interactions with others. Although Autistic students can share common traits, strategies that work on one Autistic student *may not work* on all Autistic students. **Therefore, it's important to find support strategies that fit each student rather than trying to fit the student into a support strategy.**
**The strategies that we apply in the classroom for Autistic students can work for all**

**neurodiverse students, even students who are not yet diagnosed, and they help everyone in the classroom.** That makes strategies like these even more valuable for students and teachers.

A great strategy is to use the student's focused interests to benefit learning. Many autistic people have one or more interests that are very important to them, and often a teacher is able to motivate the Autistic student to work on classroom activities relevant to their focused interest and increase their learning. Working with focused interests can help the student be more engaged, complete a larger volume of work, stay motivated, and hopefully focus across a range of subjects. It helps teachers to establish relationships with the student and encourage student engagement. It's helpful to talk with parents to determine what focused interests the student might have. These focused interests **should** be written into the individualised education plan, or IEP, and not just forgotten about but utilised in lesson planning.

For example, suppose the teacher is doing a unit on Japanese culture and the student has a focused interest in trains. In that case, the teacher might encourage the student to explore the rail systems of Japan. Or if the teacher is teaching about Ancient Rome and the student's focused interest is the Marvel character Thor, have the student write a script of Thor interviewing Julius Caesar.

Teachers can also use focused interests to motivate the student by allowing them to experience their focused interests after getting some classwork done. For example, if there are ten questions in a textbook to get through, and the student likes trains, perhaps at the end of the ten questions, they can watch the YouTube video on the trains they like.

We can break down support into three broad categories: Communication support, Visual Support, and Environmental Support.

When we think about **communicating** with students, we must remember that each student will process information at their own pace and in their own way. This is especially true for Autistic students. For most Autistic students, receiving information verbally can be challenging, especially for extended periods. Oral communication is a powerful tool, but it can be draining to have to consciously interpret what another person is saying and decide on an appropriate response. In addition to the verbal content, one must consider tone, vocal inflections, facial expression, and body language and filter out confusing sensory input. Some students will find it helpful to give themselves extra time to process verbal information or have some of their interactions take place in less overwhelming environments.

To best support Autistic students, teachers should limit lecture times if possible. Giving too much verbal information at once is difficult for any student to process; for an Autistic student, this difficulty is magnified. Allowing the student time to respond is important, as Autistic students will often need more time to process and form a response to questions. Inserting breaks or the use of visual supports can help a lot. Some Autistic students find it helpful to doodle or stim (physical motions that reduce stress and aid in sensory regulation) while listening to a teacher speak, as that helps to process verbal input. It's important to find out what works for the individual student in processing verbal information and make accommodations.

Working one-on-one with students to keep them engaged will benefit the student's learning experience. **I understand that working one on one might feel next to impossible in the classroom when there are so many students per class, and so much content to get through. It must feel like there is a lack of resources to apply the strategies needed to provide the proper support for the students, and for this, I don't have an answer.** I just know that the times when teachers are able to engage with the student one on one, those times are much more productive and less stressful for the student, and provide an opportunity to build a relationship

between the student and teacher which helps in future interactions and the student's learning.

Before beginning to communicate with the student, make sure their name is used. Often, Autistic students will be so engaged in what they're doing that simply talking to them will not turn their attention to you. So, first, use their name to secure their attention, and wait for their attention before saying what you need to say.

When giving instructions, understand that for most Autistic students, it can be hard to process oral directions. What can make it easier for the student is to receive instructions one step at a time. **This might feel overwhelming for the teacher because of the time it takes to deliver classroom instructions this way, but if possible, give steps out one by one because it will allow time to process the information and allow the student to respond if necessary,** such as if the student gets stuck on the first step.

This looks like instructing the student and allowing them to complete the step before going on to the next instruction or step. Let the student ask questions during this time. It can be overwhelming otherwise, and the student can lose interest in what they're doing – all the steps at once are simply too much! After this, you can move on to subsequent instructions similarly. **Again, a strategy like this in the classroom will help not only the Autistic students but all those neurodiverse and those who are yet to be diagnosed.**

Using concrete language is important, especially when describing abstract concepts. **Autistic students have a difficult time understanding abstract ideas.** For example, a teacher saying to the student something like "I will be with you in a minute" can easily be misinterpreted, especially if it takes the teacher longer than a minute to get back to the student. Saying instead, "I will be with you as soon as I finish this task" is going to be processed and understood much more easily.

Another example of when something should be worded more concretely is when my Autistic son had some instructions for an assignment that said, "Type your answers in full sentences." When I looked at his work, I noticed that this is what he did. He bluntly answered each question, sometimes just saying "No." Or "They were always there." My son didn't realise the teacher meant for the answer to be worded in a way that included part of the question so that whoever was marking it would understand both the question and the answer in the sentence. Some students might know that this is what the teacher meant when they said, "type your answers in full sentences," but for my son, that was not clear. He was following the instructions and answering properly. What would be more helpful is to have the instructions be worded more clearly, saying exactly what was expected in the assignment.

One way to create communication opportunities for students is by assigning classroom roles. Roles in the classroom promote independence and empower the Autistic student. Another technique is giving the student an option of choices in communication, like saying, "would you like this or that?" A sense of choice and control empowers an Autistic student in the classroom because so much about the school environment feel the opposite! School can feel like an out-of-control experience.

It is important, however, to never pressure or insist on a verbal response. In fact, if possible, it's very helpful to learn to use alternative ways of communicating. **For me, the less I have to communicate verbally during the day, the less I am drained by the end of the day,** so I really appreciate it when people allow me space to communicate non-verbally. I'm typically fine being spoken to, it's responding verbally all the time that I find particularly draining. The use of waves, a thumbs up or down, or other uses of concrete body language, and using texting apps are all helpful communication tools for me. Unfortunately, I never learned sign language. This is

something I can improve upon, but as I said, I typically use texting platforms when I am non-speaking as well as basic gestures.

Visual supports are important because, as I just explained, verbal processing information can be exhausting! Anything that helps a student with processing that input is important in managing stress levels and increasing learning outcomes. As I wrote earlier, oral communication can be a powerful tool. .However, most Autistic students have difficulty understanding spoken direction and instruction, which is why visual supports are so important to integrate into the classroom.

Visual supports can effectively address social, behavioural, cognitive, communicative, academic, and outcomes surrounding school readiness. **They can provide students with an alternative mode of communication, often reducing frustration for the student because it improves their understanding in the area where visual support is used.**

Visual supports help with changes and transitions and help students make choices and express their needs. Visual supports provide structure for students who need it and help all students, not just Autistic students.

When I talk about visual supports, I am talking about photos, drawings, symbols, and lists. I am talking about objects, written words, visual timetables, now and next cards, and the arrangement of the environment. **I am talking about anything that removes the need for verbal language.** The more visual supports like these are used in the classroom, the more engaged your Autistic students can be and the less stress they are likely to experience during their day.

**Visual supports are so beneficial because they present information in a way that helps Autistic students focus on key elements.** They can increase on-task behaviour and the independence of Autistic students.

When presenting visual support, it can be more helpful to stand behind the student than be in front of the student so that they are looking at the visual rather than the teacher. The language the teacher uses to describe the visual support should be clear yet concise so that the use and function of the support are well understood.

Some visual supports that are used in the classroom **could** be accessible to all students, and some visual supports might be just for the individual student. The teacher should discuss the visual with the student or students by introducing the visual and explaining what they're going to be using it for. I don't recommend having visuals in the classroom with no explanation of them.

I would recommend having a timetable for the day displayed in the classroom and now and next board. These are incredibly helpful on a couple of levels. They are visual reminders and are easy for the student to access in times of forgetfulness. They ensure a routine, order, and schedule of the day, which can help the student self-regulate.

For visual supports for social outcomes, having a word list of simple conversation starters can be helpful for Autistic students who find it difficult to communicate with their peer group. An Okanagan group of high school students created a deck of cards for just this purpose – and called it Basecamp Cards. They sell them through Amazon, and there are two levels - depending on whether your student is in higher or lower grades. Such a tool may be appropriate for a visual prompt for social engagement.

When thinking of the classroom **environment**, and how to structure it to be inclusive for Autistic students, a key consideration is how much or how little stress the student will be exposed

to. For example, even a little bit of negative reinforcement can make an Autistic student **shut down**. Employing positive reinforcement strategies instead of negative reinforcement strategies is therefore paramount. Punishing the student will often make the situation worse. **Teaching strategies of affirmation, validation, and praise are key in Autistic students recognizing where their strengths lie and how best to continue applying them to maximise their educational experience.**

One of the keys to productive learning outcomes is reducing stress for the student. Stress can come from many different sources. An Autistic student can become stressed by sensory stimuli, the classroom environment, physical comfort levels, hunger or tiredness, and input from other people. Even a little stress can create larger problems with the learning environment and information processing. Stress makes learning difficult and reducing it should be a priority.

Teachers should be asking themselves, how inclusive is my classroom environment? Are the students getting equal access to activities in the classroom? Is the Autistic student being denied participation in anything, or does the classroom environment limit their independence? **I'd like to see disability rights and inclusive attitudes taught into the curriculum so that all students can learn how to be inclusive and mindful of those different around them, as well as learn about the prejudicial attitudes that might be creating barriers for those who are different.**

The student needs to avoid sensory overload because this is an experience that negatively impacts the Autistic student. However, as much as I've discussed how it's helpful to have visual support in the classroom, there can be a limit to that in terms of how posters and visual displays can create sensory overload. I also recommend including a quiet space in the classroom and considering seating arrangements around loud students or noisy equipment.

Since routines can change, teachers should give time for the student to process these changes and transitions. Transitions need to be as stress-free as possible. For small transitions, referring to a now and next board is appropriate, or verbally referencing the activities and transitions that need to occur prior and giving time for processing would be appropriate.

For major transitions, like class changes, the student should be aware of any transitions or changes happening in their academic or school life as soon as the school has decided that transition is to take place and before the transition is to occur. The student would then be given the appropriate space, time, and accommodation to adjust and respond to the transition. That could look like meeting the previous and new teacher with the resource teacher and appropriate others (such as potential caregivers) to go through the change in class. Discuss what the situation was like before, what it will be like now, and why it needs to change, including how the change will be better. **Lastly, explaining to the student what they can expect after the transition is key.** This process goes a very long way in adjusting to the significant change and moving forward. **Autistic students need to know what they can expect in their environment and what's expected of them.**

Understanding behavioural expectations are important for the learning experience. Teachers can help Autistic students in this area by establishing classroom rules early on and ensuring they are clear and understandable. These classroom rules **could** be available online, visually, or individually handed out to the student.

A structured and routine classroom environment as well as setting time limits on activities

throughout the day is beneficial in reducing this stress and making things move smoothly. This is usually more successful when reminders are given surrounding transitions or the end of certain activities. **Autistic students can become very involved in what they're doing, and when this happens, it can be difficult to transition them to the next subject.** So an emphasis should be placed on early detection of this level of engagement and preparing the student to move on.

The classroom needs strategies around communication, visual support, and an environment to reduce stress and increase learning outcomes. I've been referencing this throughout the session because reducing stress means reducing potential meltdowns and shutdowns that a student might have in the classroom.

When an Autistic student is experiencing a meltdown, it can look like yelling, crying, lashing out, growling, more than typical stimming, and running away, among other things. Meltdowns can be particularly disruptive to the classroom environment. Still, it is important to remember that the experience is especially draining and difficult for the Autistic student, who most certainly does not want to be experiencing a meltdown.

When a student is experiencing a shutdown, it can look like losing focus, becoming detached, losing the inability to express themselves, or being unwilling to continue. These can be less disruptive in the classroom but are not conducive to getting work done and are again, a very draining and a negative experience for the student.

Because both meltdowns and shutdowns are extremely physically and mentally taxing on the Autistic student, they should be avoided if possible. Suppose one of these is occurring for the student. In that case, the teacher must be empathetic and acknowledge their experience without judgement. Autistic people are wired differently, which is part of how they interact with the world.

**A meltdown or shutdown is not the time, to address the negative behaviour occurring because, at that time the behaviour is far from the control of the Autistic student.** Efforts should be made to address what is causing the meltdown or shutdown. Only then can the behaviour be redirected, and only after the student is regulated should the negative behaviour be addressed, in terms of recommitting to classroom rules if they were broken, and so on.

**All behaviour is communication.** Meltdowns and shutdowns are forms of communication. Even behaviour that is difficult to understand, that doesn't come verbally, or that is aggressive is communication. It's important to know that for many Autistic students, what they want most is to be understood by those working with them.

Some Autistic students have more support needs than others, the spectrum is very large, and some students will experience a lot of behaviour that requires support from teachers and staff. These Autistic students still deserve their agency and independence to be appreciated, as well as the opportunity to attend school in a low-stress environment.

Low-stress teaching should be included as a part of the IEP for each Autistic student. Describing and including a list of characteristics and triggers for meltdowns and shutdowns in the IEP is also recommended. I would suggest liaising with parents to determine these triggers and recording them in the IEP. In addition to updating it as the year continues teachers and staff become more familiar with the Autistic student.

Part of a low-stress teaching environment is the flexibility for the student to determine how they will participate in roles and activities, giving them a sense of power and control. As I

said before, there is so much about the school environment where Autistic students feel like they are not in control, just swirling about, or performing, or just surviving, and so giving back some sense of empowerment and control will go a long way with the educational experience of the student.

Part of this flexible environment is also giving more social distance and allowing for refresh and rest breaks when needed. When I write about giving more social distance, that's just what I mean. The constant interaction socially at school can be a lot for Autistic students, who often go home and mentally collapse afterward, unable to do much of anything. Some encouragement to socialise at school should occur. Still, it is my recommendation that this should never cross over into a demand or pressure to socialise.

A refresh break is where the student might be distracted for a few moments. For example, they could take a few deep breaths, wiggle their arms and legs, stretch, or make funny faces, or any activity that helps relieve tension for the student would be acceptable in a refresh break.

A rest break should be given when all other attempts to reduce stress have failed and should be as neutral and non-judgemental as possible. This is not using toys or distractions, but it can be as simple as having the student put their head down on the desk. If a shutdown or meltdown does occur, the student should be given a safe, quiet place to process.

Hopefully, this article is insightful or thought-provoking. As I was developing the article, I knew I wouldn't be able to fit everything I wanted to write about into it.  There is always more that we can talk about when thinking about the complex needs of Autistic students, especially those with higher support needs.

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**References**

Back, L. T., Keys, C. B., McMahon, S. D., & O'Neill, K. (2016). How We Label Students with Disabilities: A Framework of Language Use in an Urban School District in the United States. *Disability Studies Quarterly, 36*(4). https://doi.org/10.18061/dsq.v36i4.4387

Botha, M., Hanlon, J., & Williams, G. L. (2023). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of Autism and Developmental Disorders, 53*(2), 870–878. https://doi.org/10.1007/s10803-020-04858-w

Den Houting, J. (2019, November) Why everything you know about autism is wrong [Video]. TED Conferences. https://www.ted.com/talks/jac_den_houting_why_everything_you_know_about_autism_is_wrong?language=en

Waltz, M. (2008). Autism = death: The social and medical impact of a catastrophic medical model of autistic spectrum disorders. *Popular Narrative Media, 1*(1), 13–23. https://doi.org/10.3828/pnm.1.1.4

Zola, I. K. (1993). Self, identity and the naming question: Reflections on the language of disability. Social Science & Medicine, 36(2), 167–173. https://doi.org/10.1016/0277-9536(93)90208-L

# The Past, Present and Future of Early Childhood Inclusion in Canada

**Adora Wong**

## Abstract

This article examines the roots of inclusion in Canada's educational and early childhood settings as a colonized nation. It discusses how to address the damage done to create inclusive environments where every child is empowered. While we have moved away from exclusion and segregation, inclusion policies are still resisted by parents, educators, and policymakers due to a turbulent past and the lack of coherent programming and funding (Halfton & Friendly, 2015). The author examines the dichotomy of care and education in relation to inclusion, criticizes using children as objects of scientific inquiry, and maintains the importance of upholding a capable image of the child. Modern-day inclusion policies may harm autistic children instead of helping, as they may not truly be in the best interest of children with disabilities.

### Resumé

Cet article examine les fondements de l'inclusion dans les milieux pédagogiques et de la petite enfance au Canada en tant que nation colonisée. Il examine les façons de réparer les dommages causés afin de créer des environnements inclusifs où chaque enfant peut s'épanouir. Bien que nous ayons rompu avec l'exclusion et la ségrégation, les politiques d'inclusion se heurtent encore à la résistance des parents, des éducateurs et des décideurs politiques en raison d'un passé turbulent et de l'absence de programmes et de financements cohérents (Halfton et Friendly, 2015). L'autrice examine la dichotomie qui existe entre les soins et l'éducation en relation avec l'inclusion, critique le traitement des enfants en tant qu'objets d'enquête scientifique et souligne l'importance de maintenir une image capable de l'enfant. Les politiques d'inclusion modernes peuvent nuire aux enfants autistes au lieu de les aider, car elles sont susceptibles de ne pas être véritablement conçues dans l'intérêt supérieur des enfants en situation de handicap.

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This paper focuses on the history of inclusion in Canada as a colonized nation. Learning the roots of inclusion may help educators understand why inclusion policies are still met with resistance and doubt today by parents, educators, and policy makers alike (Brotherson et al., 2001). This is despite the numerous international declarations of rights afforded to children with disabilities and the general acceptance that inclusion policies are the "best practice" for childcare programs (Halfon & Friendly, 2013). Upon reviewing the history of inclusion, we will examine the themes of the dichotomy of care and education, the criticism of using children as subjects of scientific inquiry, and the child's image. We will look at what is currently passed as inclusion today and question whether this is truly in the best interest of children with disabilities. Finally, we will explore two instances where modern-day "inclusion" is harms autistic children instead of helping and discuss how to address these issues to create truly inclusive environments where every child is empowered.

Inclusion in education has a relatively short history, with the movement's roots beginning in the early twentieth century (Bunch, 1994). Western disability history started with a total exclusion of people with disabilities from education (Bunch, 1994). Not only that, but they were also excluded from their communities, being considered "less than human" and "worthy only of death" in several early societies (Bunch, 1994, p. 20). When Canada was colonized in the 1700s, a limited number of children with disabilities could participate in education, and they were tutored only if their families had the resources to do so (Bunch, 1994). Between the mid-1700s to the early 1900s, children with physical disabilities had the option of being educated in special boarding schools that were segregated from public education (Bunch, 1994). At the start of the twentieth century, four societal changes paved the way for more educational rights for people with disabilities. First, society started to see the school system as a way of addressing social issues (Bunch, 1994). Second, education was reformed into a corporate-industrial model of organization to increase "educational efficiency" (Bunch, 1994, p. 26). Third, education was recognized as a path to successful employment and not reserved only for a select few. Fourth, the Intelligence Test (IQ Test) was developed to determine whether a child needed to be placed in special education. With these changes, society began to accept that individuals with disabilities should be exposed to educational services (in the case of physical disabilities) or habilitative services (in the case of intellectual and developmental disabilities). The education available to people with disabilities was still segregated, with specialized administrators, teachers, assessment methods, instructional methods, parent associations, and transportation systems, which paralleled the "regular" education system and competed with it for funds and personnel (Bunch, 1994, p. 23). Segregated education had its roots in the medical model of disability, saw no clear advantages for the children enrolled, and was difficult to exit once a child was placed in the program (Towle, 2015). This system saw those with disabilities as having the challenge or being the problem, rather than reflecting on how their experiences with disabilities were shaped by the environment (Towle, 2015).

In 1970, the *One Million Children* report called for Canadian society to stop isolating and segregating children with disabilities from their peers and families (Towle, 2015). This report addressed pervasive negative attitudes toward people with disabilities. Between 1970 and 1985, several Canadian provinces began to offer the practice of the Least Restrictive Environment, in which a student with disabilities would be placed in either a full-time placement in regular

classrooms with support or a split placement between special and regular classrooms (Bunch, 1994). This model, which was an advance towards what we consider "inclusion" to be today, saw four main opponents: parent groups who saw access to segregated education as a right, policymakers who were concerned about students with disabilities diluting achievement, educators who were concerned about receiving adequate training and support, and educators who believed that segregated education was the best model due to available resources. The history of inclusion began on the opposite end of the spectrum in full exclusion. Only in the last hundred years have children with disabilities slowly extended the right to education. The practice of inclusion in regular classrooms only entered public consideration in the last fifty years.

Today, the right to education is protected by the International Covenant on Economic, Social, and Cultural Rights (1966), the Convention on the Rights of the Child (1989), and the United Nations Declaration of the Rights of Persons with Disabilities (2006). While these treaties outline human dignity and the need for respect, they provide minimal guidance in the implementing policies. In Canada, education is under provincial or territorial jurisdiction. While special education has come a long way from the historical segregation and institutionalization of children with disabilities, educational policies still have "a long way to go before they are truly inclusive" (Towle, 2015, p. 8). Each province currently utilizes different languages to describe disabilities, including "special needs", "exceptionality," and "intensive needs" (Towle, 2015). They also have varying names for similar programs for special educational programming: Individual Student Support Plan, Inclusion and Intervention Plan, Individual Program Plan, or Personalized Learning Program. This lack of cohesion leads to confusion over which supports are available for children with disabilities. Neither Canada as a whole nor individual provinces and territories protect the right to inclusion for children with disabilities in childcare settings. However, the childcare sector has privately led the way in early years inclusion in several ways (Halfon & Friendly, 2013) for children from birth through elementary school. Beginning in the 1980s, community-based childcare centres expanded their mandates to include and support children with disabilities, often without the support of provincial funding (Halfon & Friendly, 2013).

While inclusion in regular childcare programs has become accepted as the "best practice" in Canada (Halfon & Friendly, 2013), the current challenge is to move away from integration systems where a person with a disability adapts to fit into a classroom with non-disabled peers, and into a truly inclusive space which addresses the diverse needs of all participants, including all groups who have been traditionally marginalized and disadvantaged. Disability and inclusion are evolving concepts (Towle, 2015), The modern definition of inclusion means that children with disabilities not only share the same space as children without disabilities but can also participate fully (Halfon & Friendly, 2013). While most educators support inclusion, many are overwhelmed by various perspectives on implementing inclusion policies (Towle, 2015). In early childhood settings, this is exacerbated by the lack of a coherent system that plans, funds, and provides regulated childcare (Halfon & Friendly, 2013). The Dichotomy of Care and Education for Children with Disabilities

The dichotomy of care and education is also present when discussing the meaning of, inclusion in early childcare settings. Here, it becomes important to distinguish between programs that offer integration and inclusion. While these terms are often used interchangeably,

integration focuses primarily on the child with a disability and expects them to adapt. In contrast, inclusion focuses on the benefits for all children when people with disabilities are learn in the same environment (Harman, n.d.). A care perspective seems to satisfy the request for integrationas it provides "social inclusion of children of all abilities" and "allows parents to work and support their families" (Halfon & Friendly, 2013, p. 17). The historical exclusion of people with disabilities may contribute to caregivers looking at early childhood education programs to assist in supervising their child, as access to regulated childcare is a more recent right for children with disabilities (Halfon & Friendly, 2013). However, a better understanding of inclusion calls for equal access to full and meaningful participation in childcare programs (Flanagan & Beach, 2010).  Furthermore, early childhood settings can act as a site for the early identification of learning and developmental disabilities and create opportunities for children to develop to their fullest potential (Halfton & Friendly, 2013), drawing more on the educational aspect of early childcare. Advocates for inclusion often lean in on the educational benefits as well, citing that children in inclusive spaces demonstrate stronger communication and leadership skills, a higher sense of empathy, as well as stronger math and reading skills compared with classrooms without children with disabilities present (Towle, 2015). This definition ensures more than the presence of children with disabilities: it calls for action and responsive teaching (Flanagan & Beach, 2010). The Special Link Early Childhood Inclusion Quality Scale (2009) outlines principles of quality inclusion, which pertain to care and education. On the side of care are the zero-reject principle, where no child is excluded based on disability, the same range of program options principle, where parents of children have the same options that other parents have; and the maximum parent participation principle, where parents are encouraged to participate in the childcare program (Flanagan & Beach, 2010). The full participation principle, where activities and routines are modified and adapted to include all children, and the pro-action for community inclusion principle of advocating for staff training, transportation, funding, and therapeutic support fall on the side of education, as they ensure that children with disabilities can fully participate in the same learning process as other children (Flanagan & Beach, 2010). While care and education are both necessary components in inclusion in early childcare settings, care is associated more with undoing the damages of segregation, whereas education offers a path forward toward true inclusion.

**Children with Disabilities as Subjects of Scientific Inquiry**

Children with disabilities, especially children with learning and developmental disabilities, have historically been the subject of scientific inquiry, beginning with the development of the IQ Test at the turn of the twentieth century (Bunch, 1994). This test determined whether a child would be placed in segregated special education, a system that saw no real benefits to children with disabilities and was difficult to exit (Bunch, 1994). This separated children into two groups: normal or pathological (Varga, 2011). The IQ Test was the start of measuring "normative" child development through a Eurocentric lens (Varga, 2011, p. 138), a process that increasingly structured children's experiences and adult responses (Varga, 2011). Here, we run into the danger of relying so much on our scientific findings of the child, especially in cases of "abnormal development," that we end up disembodying development from the person (Varga, 2011, p. 153) and doing more harm to children with disabilities.

**The Image of the Child**

The image of the child is also important to consider in the history of inclusion, as it can inform our current views on children with disabilities. Until the 1900s, people with disabilities were largely invisible to society, or worse (Bunch, 1994). While reviewing Sorin's ten constructs of the image of the child, only two seem to fit how children with disabilities were viewed in Canada. The first is that of the Evil Child, who is excluded until they can learn to conform to society, which echoes the purpose of segregated education (Sorin, 2005). The second is the Out-of-Control Child, who is offered a negative label ("dysfunctional") and is abandoned by "the system" (Sorin, 2005, p. 16). In present-day inclusion, children with disabilities may hold the image of the Child as a Commodity as adult advocates speak over their voices to obtain sympathy, support, and funding, or the Noble/Saviour child who is there to teach adults a valuable life lesson (Sorin, 2005). By implementing inclusive early childcare programs, we can begin to view children with disabilities as Agentic Children who are social actors that participate in their education and lives (Sorin, 2005). The British Columbia Early Learning Framework calls for educators to view all children as "a gift, as strong and capable in their uniqueness and full of potential, living and growing in complex interdependence with humans and all world relations" (British Columbia Ministry of Education (BCME), 2019, p. 15). Moving away from a history of exclusion and towards true inclusion, we can embrace the image of capable and agentic children in our programs.

**The Future of Inclusion**

With such a recent and turbulent history, most early childhood spaces in Canada have a long way to go before they are truly inclusive (Towle, 2015). While inclusion is accepted as a goal in early childhood education, the terms surrounding disability and accessible education are still vague and disputed among advocates (Towle, 2015). Furthermore, there is no formal system in place to ensure the implementation of inclusive programs (Haflton & Friendly, 2013), nor guidelines on implementing inclusive practices (Towle, 2015). Rather, the implementation of true inclusion in Canada is currently left by chance, determined by whether a child lives in an area where the teachers, schools, and childcare programs welcome students with disabilities (Uditsky, 2019). While Halfton and Friendly (2013) call for "a national, publicly funded, publicly managed universal system of high-quality early childhood education and childcare program that mandates and supports the inclusion of children with disabilities," Nutbrown (2018) offer two practices that parents, educators, and community members can do in the meantime. The first is to move away from a medical model of disability when considering adapting special educational practices and instead towards a social model in which everyone is responsible and can benefit from learning from each other's experiences (Nutbrown, 2018). The second is to ask critically reflective questions about inclusion in early childhood settings: "How do early years practitioners define 'inclusion' in their work? How do young children understand and enact inclusion in their early years setting? What are parents' expectations of inclusion in their children's early years?" (Nutbrown, 2018, p. 10).

As an autistic individual, I have a few suggestions to promote inclusion in early childhood spaces. Due to the colonization of research, most studies on children with developmental disabilities are written from an abled, Eurocentric perspective (Varga, 2011). This means that many currently accepted practices for inclusion are also based on these perspectives, rather than

the lived experiences of people with disabilities, resulting in damaging comparisons and the push toward normalization (Varga, 2011). Suppose inclusion in childcare means that all children have equal access to participate meaningfully (Flanagan & Beach, 2010). In that case, there are two current barriers to true inclusion I would like to personally address in my work as an early childhood educator and disability advocate.

The first is the pervasiveness of Applied Behaviour Analysis (ABA) Therapy in early childcare settings within the inclusion framework. This is concerning because both the autism and the neuropsychology community have exposed the "lasting damage and abuse" this treatment causes (Sandoval-Norton & Shkedy, 2019, p. 1). ABA relies on behavioural modification and intends to modify or diminish unwanted behaviours, to increase language, communication, and social skills in autistic children (Kirkham, 2017). While these appear on the surface level to be commendable intentions, research demonstrates that the prompt dependency on the therapist to control behaviour by having food, candy, toys, or other objects withheld for non-compliance serves to "inhibit or prevent the development of age-appropriate social relationships and interpersonal skills in children, which also contributes to lack of motivation and unsuccessful learning" (Sandoval-Norton & Shkedy, 2019). ABA therapy neglects current research that shows the commonality of comorbid disorders such as anxiety, Attention-Deficit/Hyperactivity Disorder (ADHD), and Obsessive Compulsive Disorder (OCD) in autistic children (Ofner et al., 2018). Given that the Behaviour Analyst Certification Board that certifies ABA therapists does not require any education or training on these comorbid disorders, the practice of applying a blanket approach of implementing behaviorist principles on autistic children is "irresponsible and abusive" (Sandoval-Norton & Shkedy, 2019, p. 5). Autistic and neurodiverse communities have rejected ABA therapy as unethical and unnecessary. They claim it can leave children feeling traumatised and devalued (Kirkhman, 2017). ABA therapy goes against care and the image of the agentic and capable child. It has no place in early childhood settings, much less in those that claim to be inclusive of children with disabilities. In my work as an early childhood educator, I feel a responsibility to educate others about the harm of this popular method of controlling autistic children and to redirect parents toward other resources such as occupational and speech therapy.

A second area of concern was the announcement of the Family Connection Hubs in British Columbia, which was expected to commence in the Okanagan region by 2023 (Britten & Wilson, 2022). This was a swift, top-down decision to have families of children with disabilities access services at a local family connections hub instead of receiving funding for the providers they already had (Weisgarber, 2021). Autism groups were quick to express concern and criticism after the program was released without details of execution, worrying that this system would cause further division within the disability community as families competed for funding. In the program release, the government also announced the end of the Individualized Autism Funding, the At Home Program, and other disability support services by 2025 (Autism BC, personal communication, November 8, 2021). After over a year of criticism from families and autism support and advocacy groups, the BC government paused the plan on November 25, 2022 (Ministry of Child and Family Development, 2022). The name of the program has been changed to "Family Connections Centres." It will not proceed until further evaluation and input from Indigenous peoples (Ministry of Child and Family Development, 2022). However, the program remains for families living in Kelowna, Prince Rupert, Terrace, and Smithers (Ministry of Child and Family

Development, 2022). Both issues of ABA therapy and the release of the 2021 funding model stem from the same place: a failure to listen to people with disabilities and to include them in the decision-making process. These issues can be addressed by accepting a standard of inclusion committed to listening to people with disabilities and their meaning-making process, understanding that this will benefit all children involved in the program.

## Conclusion

Examining the history of inclusion in Canada clarifies the present tension when addressing this topic in early childhood settings. While we have moved away from exclusion and segregation, we can still feel its damaging effects on the limited availability of inclusive programs in Canada (Uditsky, 2018) due to a lack of coherent programming and funding (Halfon & Friendly, 2015). When considering the dichotomy of care and education about children with disabilities, care seems to provide a minimal standard of integration, whereas education moves towards fuller inclusion. In understanding disability history, it is important to note how scientific inquiry into children with disabilities has led to segregation (Bunch, 1994) and modern-day abuse of autistic children (Sandoval-Norton & Shkedy, 2019). As we move into the present and future of inclusion, we can strive to listen to those with lived-disability experiences and to view children with disabilities through an image of a capable, agentic child that is full of potential. Understanding the turbulent history of exclusion and segregation for people with disabilities can help us strive for the opposite today: a world in which all children are accepted and viewed as capable, agentic, important, and valuable.

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## References

British Columbia Ministry of Education. (2019). *British Columbia Early learning framework.* https://www2.gov.bc.ca/gov/content/education-training/early-learning/teach/early-learning-framework

Brotherson, M. J., Sheriff, G., Milburn, P., & Schertz, M. (2001). Elementary school principals and their needs and issues for inclusive early childhood programs. *Topics in Early Childhood Special Education*, *21*(1), 31-45. https://journals.sagepub.com/doi/10.1177/027112140102100103

Bunch, G. (1994). Canadian perspectives on inclusive education from there to here: The passage to inclusive education. *Exceptionality Education Canada*, *4*(3), 19-35. https://inclusion.com/site/wp-content/uploads/2018/10/1994-Canadian-Perspectives-on-Inclusive-Education-From-There-to-Here_The-Passage-to-Inclusive-Education.pdf

Britten, L., & Wilson, J. (2022, November 25). Families express relief as B.C. retracts plan to scrap individualized funding for children with autism. *CBC News*. https://www.cbc.ca/news/canada/british-columbia/bc-autism-funding-1.6665216

Flanagan, K., & Beach, J. (2010). *Examining the human resource implications of emerging issues in early childhood education and care (ECEC)/communications strategy development: Inclusion.* http://ccsc-cssge.ca/sites/default/files/uploads/Projects-Pubs-Docs/EN%20Pub%20Chart/Emerging%20Issues%20-%20Inclusion.pdf

Halfon, S., & Friendly, M. (2013). *Inclusion of Young Children with Disabilities in Regulated Child Care in Canada: A Snapshot: Research, Policy and Practice.* Toronto, ON: Childcare Resource and Research Unit. https://childcarecanada.org/sites/default/files/Occasional%20paper%2027%20FINAL.pdf

Ministry of Child and Family Development. (2022). *Family connections hubs.* Province of British Columbia. Retrieved from https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/family-connections-centres?keyword=family&keyword=hubs

Nutbrown, C. (2018). Inclusion and Diversity in *Early Childhood Education and Care. In Early childhood educational research: International perspectives.* SAGE Publications, Ltd. https://doi.org/10.4135/9781526451811

Ofner, M, Coles, A., Decou, M.L., Do, M. T., Bienek, A. Snider, J. & Ugnat, A.M. (2018). *Autism spectrum disorder among children and youth in Canada 2018: A report of the National Autism Spectrum Disorder Surveillance System.* Ottawa, ON: Public Health Agency of Canada. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html

Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse? *Cogent Psychology, 6*(1), 1-8. https://www.tandfonline.com/doi/full/10.1080/23311908.2019.1641258

Sorin, R. (2005). Changing images of childhood - Reconceptualising early childhood practice. *International Journal of Transitions in Childhood, 1*, 12-21.

Towle, H. (2015). *Disability and inclusion in Canadian education: Policy, procedure, and practice.* Canadian Centre for Policy Alternatives. https://www.policyalternatives.ca/sites/default/files/uploads/publications/National%20Office/2015/07/Disability_and_Inclusion_in_Education.pdf

Uditsky, B. (2018, March 19). The Inclusion Lottery: A game of chance with a child's education – inclusive education. *Inclusive Education Canada.* Retrieved November 12, 2021, from https://inclusiveeducation.ca/2018/03/19/the-inclusion-lottery-a-game-of-chance-with-a-childs-education/

Varga, D. (2011). Look–normal: The colonized child of developmental science. *History of Psychology, 14*(2), 137. https://psycnet.apa.org/doi/10.1037/a0021775

Weisgarber, M. (2021, November 2). Growing concerns over new 'hub' service model for B.C. children with support needs, disabilities. *CTV News.* https://bc.ctvnews.ca/growing-concerns-over-new-hub-service-model-for-b-c-children-with-support-needs-disabilities-1.5649873