April 2025 Volume 5 Issue 1

CANADIAN JOURNAL OF AUTISM EQUITY

REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

Safia Abdulle

McKenna Hart

Emi Linds, Alastair Linds, Ella Shtaif, & Sarah Cooper

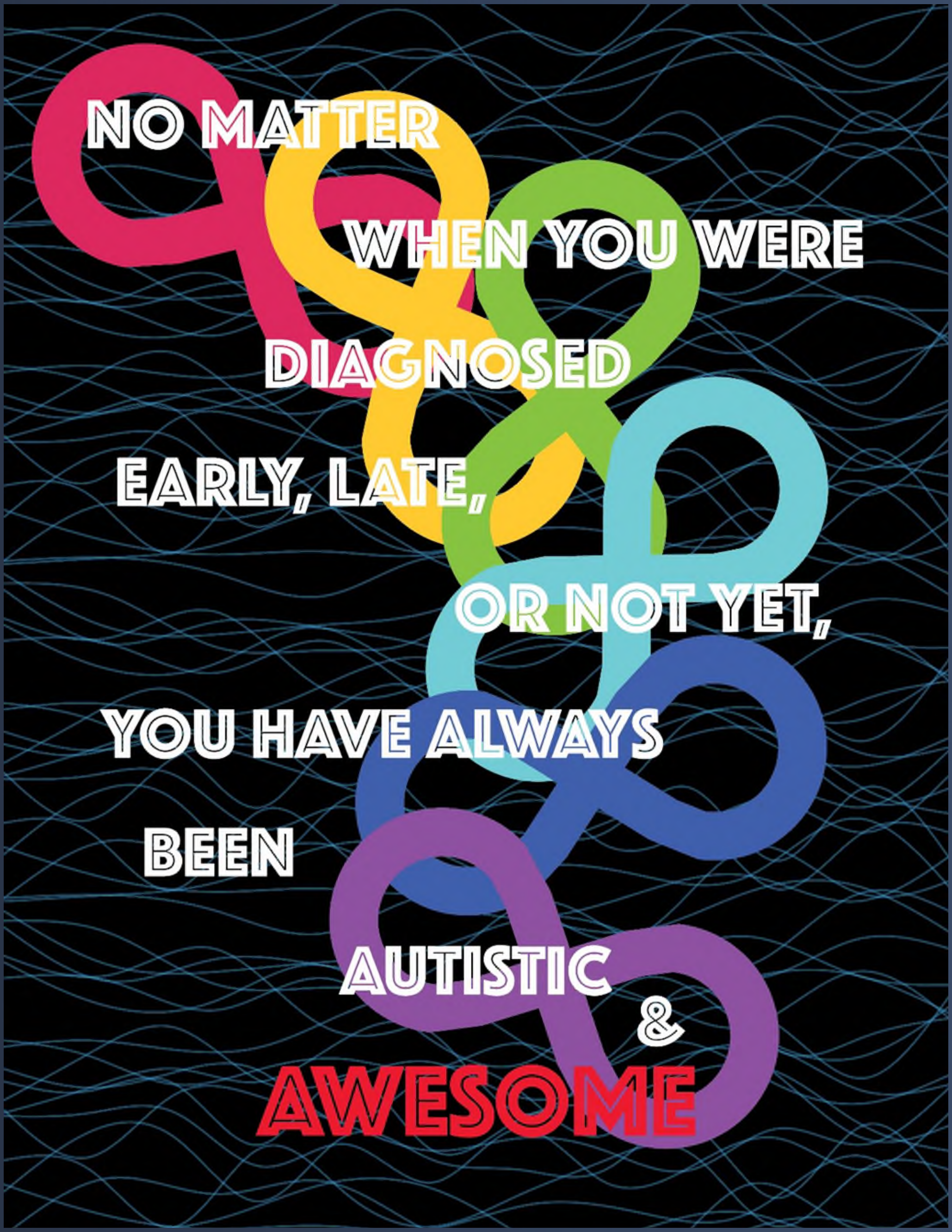
Joy Lu

W. Roberts

Jan A. Wozniak

Jan A. Wozniak & Sue Hutton

MissNatasha Connects



Cover art:
"NO MATTER WHEN YOU WERE DIAGNOSED, EARLY, LATE, OR NOT YET, YOU HAVE ALWAYS BEEN AUTISTIC & AWESOME"

By Joy Lu

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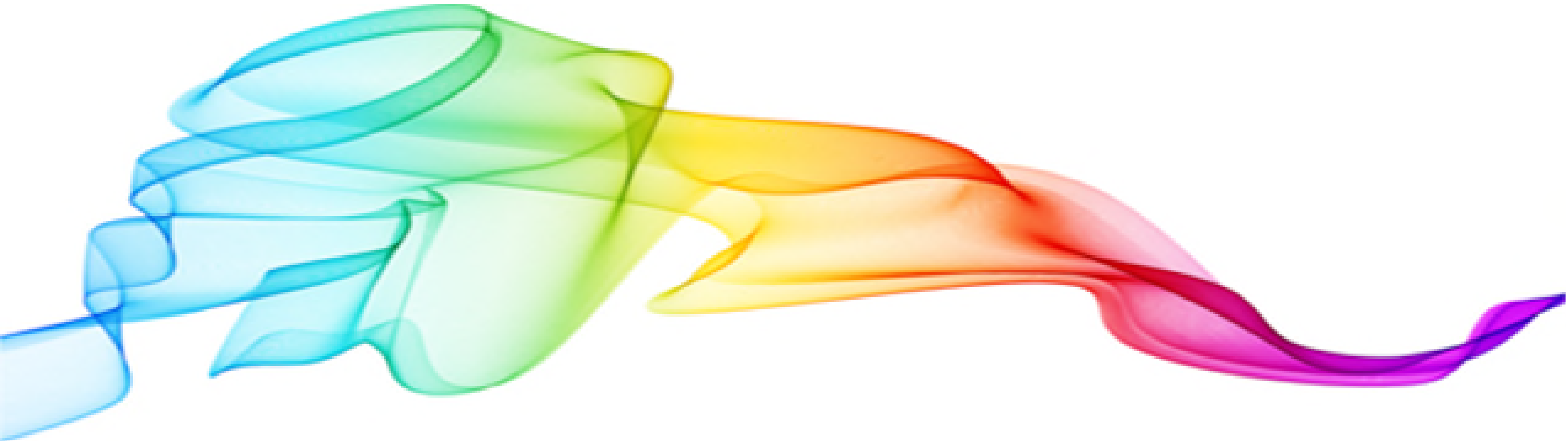


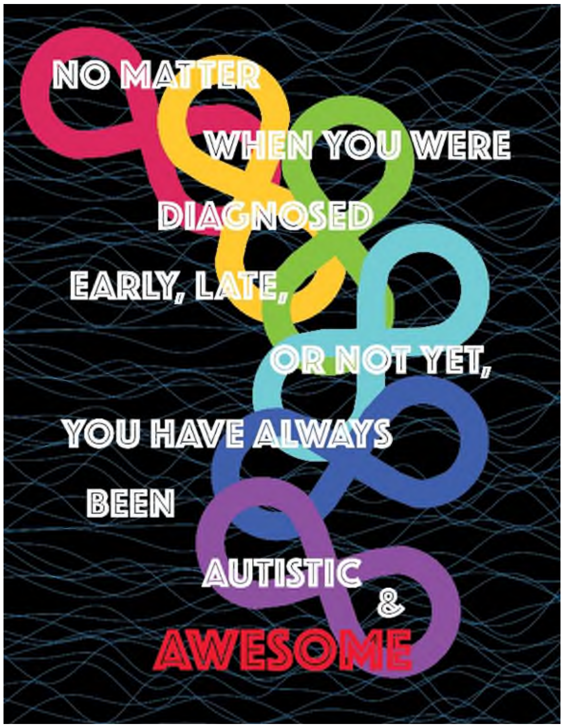
Land Acknowledgement

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 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.

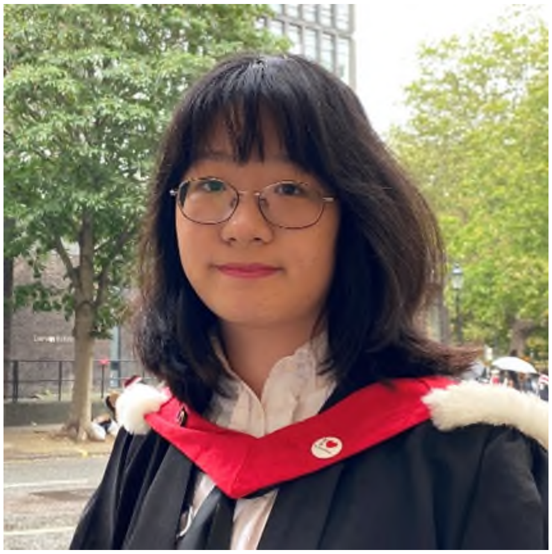
Cover art by Joy Lu



NO MATTER WHEN YOU WERE DIAGNOSED, EARLY, LATE, OR NOT YET, YOU HAVE ALWAYS BEEN AUTISTIC & AWESOME

2024, Adobe Illustrator, Figma

For far too long the conversations around autism and autistic people have been negative and full of resentment, anguish, and misery. But this doesn't have to be the case, since there are things to be celebrated for being autistic, and for discovering one is autistic. There is also much debate over how an autism diagnosis can affect someone whether: an early diagnosis would guarantee support, a late diagnosis equals trauma, or a self-diagnosis is valid (the eternal question). But for this special edition of the "Canadian Journal of Autism Equity" under the theme of "autism and diagnosis", I didn't want the cover artwork to reflect the negativity and controversy surrounding autism diagnoses. I want something positive, affirming, and unifying, as a change! I wish that an autism diagnosis could be a validating and empowering thing, that unites instead of divides autistic people. Which is why I created this text-based artwork that somewhat resembles a manifesto, drawing focus to the one-sentence affirmation. The rainbow-coloured infinity signs symbolise the diversity of autistic people and their experiences, while the thin undulating lines represent the negativity and judgement that autistic people might face surrounding their autism diagnosis. I want all the readers to know that "no matter when you were diagnosed, early, late, or not yet, you have always been autistic & awesome".



Photograph by Joy Lu

Joy Lu is an award-winning autistic designer, artist, and writer, bilingual in both English and Mandarin Chinese. A multicultural Chinese Canadian based in Toronto, she holds a background in Industrial Design from Rhode Island School of Design, USA, and an MA in Design Products from the Royal College of Art, UK. Her work centres on amplifying neurodivergent voices and talents. In 2023, before graduating from the RCA, Joy won the Helen Hamlyn Design Award for her inclusive design 'We Are in This Together', addressing challenges faced by disabled individuals in navigating higher education in art and design. She passionately believes that neurodivergent individuals should not only be the subjects of design but also reclaim their agency as designers, creating solutions that serve their own communities.

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Foreword

David B. Nicholas, PhD, RSW
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I am pleased to welcome you to this special issue focused on diagnosis. The issue consists of research, narrative, poetry and art that reflect on, and unpack, the diagnostic process and resulting outcomes such as seeking services or accommodations. A diagnosis may be illuminating, helpful, delayed or difficult. Sadly for some, a diagnostic assessment may be unattainable due to barriers such as unaffordability.

Like authors and artists in this issue, for me, diagnosis is not just an academic or theoretical topic, but also is deeply personal. As a caregiver in the autism community, my world changed with the diagnosis of autism of close family members. The day of diagnosis propelled our family on a life journey that has brought depth of meaning and purpose—that I couldn't have anticipated in those early days. But that doesn't discount struggle on that day and on some days since. My partner and I reflect on our diagnosis encounter as one that seemed unnecessarily harsh, and offered seemingly little space or support to figure out, with gentle humanity, where we were and what was to come. In hindsight, we would have appreciated a broader perspective: that while autism results in challenges, ones largely reflective of a society rife with ableism, it predominantly brings an identity of pride, authenticity, depth, love and humanity. For us, autism has offered an unparalleled gift of better recognizing what truly matters and increasingly letting go of what doesn't. If that's not a profound gift, I don't know what is.

But on that day of diagnosis, I didn’t yet know that, nor what was to come. I couldn’t have anticipated the rough patches in schools and community, nor could I have anticipated the goodness of others and how connected some of our relationships in the autism community would become. Friendships have been forged in the common landscape and camaraderie of this community. The experience of more than twenty years of caregiving, along with dear family, friends and colleagues, and especially in the presence of Autistic loved ones who are among my most treasured relations, have not just enriched my life, but have left me with gratitude for the autism community and all that it is doing and striving for in its determination and work to create a better and more just world!

Yet while being celebratory, I’m dismayed by how far we need to go, and in some cases, how we, in some ways, have seemingly moved backward! Diagnostic assessments and services waitlists in many jurisdictions are much too long. Some attitudes in society seem increasingly polarized with respect to equity, diversity, inclusion and accessibility. Ableism continues. So we must resolutely push forward for change! And that is the spirit within the impressive works in this issue. These papers and art collectively situate diagnosis as one area, among critically important others, to reflect on and advance.

In a moving piece of poetry entitled, “The Vestiges of Disability”, Jan A. Wozniak poignantly conveys a shift from disability to empowerment, with pre-diagnosis experiences of struggle, to evolving post-diagnosis identity and authenticity. This work leads the reader along the author’s passage of change and hope. It presents a journey over time and experience—an evolving trajectory of self awareness, despite layers of imposed ableism and marginalization, to increased empowerment and resilience. This work offers hope yet presents pressing challenge in moving forward.

In “The Bastard”, W. Roberts presents a powerful poem that conveys a circuitous path of self-discovery amidst obstacles. The tenacity and persistence of the author, as so eloquently portrayed in this poem, is a testament and encouragement to push forward even in the face of injustice and inequities. And it calls for systemic change so children (and others) are not left to suffer and struggle as many sadly do. I was moved by the poetic acumen and generosity of this author to share his path to and through diagnosis, as it pertains to journeying life and self-discovery.

In her piece, “Embracing Neurodivergence: A Personal Journey”, MissNatasha Connects offers an insightful account of transformation from imposed ableism and stigma to the realization and recognition of neurodivergent ability, authenticity, self-love and understanding. Along with this rich descriptive narrative account, Miss Nathasha offers artwork that creatively and thoughtfully contrasts a backdrop of ableism and barriers with an overlaying and contrasting message that supplants the negative and offers inspiration and challenge.

Papers in this special issue address intersectionality as it relates to diagnosis and related experience. Several examine co-existing areas of marginalization and imposed inequity. In a reflective commentary, Joy Lu shares perspectives as an Autistic Chinese Canadian, bringing an important and under-represented account of lived experience. Concerning issues of racial bias and underrepresentation are identified, inviting critical reflection and advocacy for racial justice and autism awareness cross-culturally. This paper further illustrates ingenuity and leadership by the author in nurturing awareness, understanding and acceptance within a cultural context.

In “An Intersection of Race and Disability: A Critical Analysis of the Racial Inequities in Autism and Neurodivergent Disability Diagnoses for Black Children”, Safia Abdulle importantly presents trends among Black Autistic children, based on research indicating disproportionately less access to diagnoses and higher risk for misdiagnosis. This review amplifies the need for racial justice in disability, and calls us to deeply reflect on, and redress, racial inequity in diagnostic assessment and support access.

McKenna Hart generously reflects on co-existing mental health and autism diagnoses. Experience and insight are offered, culminating in a call for diagnostic precision and caution in professional languaging related to diagnosis and care. Critical reflection is offered in the use of terminology, and how labels and ‘labelling’ matter and can be harmful. The author offers important considerations for diagnostic practices and compassion in care.

A caregiver’s perspective is offered by Emi Linds in “It Begins with a Diagnosis: Our Journey and the Promise of Canada’s Autism Strategy”. This article celebrates a child and their family in their journey together and conveys family engagement in caregiving. The author expresses hope in Canada’s Autism Strategy (https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/canada-autism-strategy/canada-autism-strategy.pdf) for improved diagnostic assessment and service access in Canada.

These various papers remind us that diagnosis is an important ‘moment’, but it is not a discrete or disconnected entity; rather, diagnosis looks back in reflecting on experience, and looks forward toward understanding and support. Diagnosis needs to be in the service of support, accommodations and resources. Reflecting on a support initiative, Jan A. Wozniak offers an experiential commentary entitled, “Autism-Informed Mindfulness: Collaborative

Practitioner Experiences". This paper reflects on the delivery of a mindfulness initiative. An important message in the paper is the need for services and resources to be neuroaffirming; in this case, facilitated by an Autistic co-lead.

This special issue illustrates that diagnosis can be fraught with layers of complexity, including being situated in an overarching context of societally-imbued ableism, barriers to diagnostic and support access, and a myriad of factors that can hinder thriving. To redress challenges, neuroaffirming ways of thinking and being, policy, and supports and services are needed. The papers in this issue offer a helpful glimpse into what currently is, but also what yet needs to be! As such, the authors convey important considerations and priorities of Autistic people. I appreciate the intersectionalities addressed in the issue, and agree with issue contributors as well as other authors who convey the importance of addressing intersectionality in diagnostic assessment and service access as well as in other important areas such as community engagement (Lopez et al., 2022; Maroney & Horne, 2022), school (Cohen et al., 2022) and employment (Doyle et al., 2022). Examining diagnosis in the context of sex, gender, co-existing health or mental health issues, socioeconomic status, ethnocultural context, region (e.g., rurality), and other areas of diversity is critical.

Finally, in writing this foreword, I was struck by what seemed like my repetitive use of summarizing notions like 'challenge', 'moving forward' and 'call for action'. It occurred to me that the impressive authors, poets and artists in this issue illustrate a reflective and insightful path forward, and in so doing, I wonder if they might, through their writing, invite and inspire us, as readers, to such intentionality in pushing forward for needed change. At the time of this special issue's publication, the month of April has been declared World Autism Acceptance Month. Drawing on the insights offered by these authors, poets and artists, may the learning gained and challenges issued in this issue, indeed inspire greater acceptance and brave conversations in our collective aim of transformative action and change!

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

Avant-propos

David B. Nicholas, PhD, RSW

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J'ai le plaisir de vous présenter ce numéro spécial consacré au diagnostic, composé d'études, de récits, de poèmes et d'œuvres d'art qui examinent et décortiquent le processus de diagnostic et les résultats qui en découlent, tels que la recherche de services ou d'accommodements. Un diagnostic peut être éclairant, utile, retardé ou difficile. Malheureusement, pour certain·es, une évaluation diagnostique peut être inaccessible en raison d'obstacles tels que l'inabordabilité.

À l'instar des auteurs et autrices et des artistes de ce numéro, je ne vois pas seulement le diagnostic comme un sujet universitaire ou théorique, mais comme une expérience profondément personnelle. En tant qu'aidant au sein de la communauté de l'autisme, mon univers a changé lorsque des membres de ma famille proche ont reçu un diagnostic d'autisme. Ce jour-là, ma famille s'est retrouvée sur un chemin de vie qui lui a apporté un sens et un but profonds que je n'aurais pas pu anticiper à l'époque. Cela n'enlève toutefois rien aux difficultés rencontrées à ce moment-là et certains jours depuis. Mon partenaire et moi nous souvenons que notre expérience du diagnostic nous a semblé inutilement dure et qu'on nous a offert peu d'espace ou de soutien pour comprendre, avec une douce humanité, où nous en étions et ce qui nous attendait. Avec le recul, nous aurions apprécié une perspective plus large : si l'autisme entraîne des difficultés qui sont en grande partie le reflet d'une société où règne le capacitisme, il donne surtout accès à une identité empreinte de fierté, d'authenticité, de profondeur, d'amour et d'humanité. Pour nous, l’autisme nous a permis de mieux reconnaître ce qui compte vraiment et de délaisser de plus en plus ce qui n’a pas d’importance. Si ce n’est pas un cadeau précieux, je ne sais pas ce que c’est.

Le jour du diagnostic, toutefois, je ne le savais pas encore, pas plus que je ne savais ce qui m’attendait. Je n’aurais pas pu prévoir les moments difficiles à l’école et dans la collectivité, ni la bonté des autres et la façon dont certaines de nos relations dans la communauté de l’autisme allaient se resserrer. Des amitiés se sont forgées dans le paysage commun et la camaraderie de cette communauté. L’expérience de plus de vingt ans de soins, en compagnie de familles, d’amis et de collègues très chers, et surtout en présence de proches autistes qui font partie de mes relations les plus chères, a non seulement enrichi ma vie, mais m’a aussi laissé avec de la gratitude pour la communauté de l’autisme et tout ce qu’elle fait et s’efforce de faire pour créer un monde meilleur et plus juste!

Pourtant, tout en me réjouissant, je suis consterné par le chemin qu’il nous reste à parcourir et, dans certains cas, par nos reculs! Dans de nombreuses juridictions, les listes d’attente pour les évaluations diagnostiques et les services sont beaucoup trop longues. Certaines attitudes dans la société semblent de plus en plus polarisées en ce qui concerne l’équité, la diversité, l’inclusion et l’accessibilité. Le capacitisme persiste. Nous devons donc résolument aller de l’avant pour changer les choses! C’est dans cet esprit que s’inscrivent les travaux impressionnants présentés dans ce numéro. Ces articles et ces œuvres d’art situent collectivement le diagnostic comme un domaine parmi d’autres, d’une importance capitale, sur lequel il convient de réfléchir et de progresser.

Dans un poème émouvant intitulé « The Vestiges of Disability », Jan A. Wozniak décrit de manière poignante le passage entre handicap et autonomisation, entre une vie de luttes avant le diagnostic et l’évolution de l’identité et de l’authenticité après le diagnostic. Ce texte conduit le lecteur sur le chemin du changement et de l’espoir emprunté par l’auteur. Il présente un voyage au fil du temps et de l’expérience — une trajectoire évolutive de prise de conscience de soi, malgré le capacitisme et la marginalisation, vers une autonomisation et une résilience accrues. Cette œuvre offre de l’espoir tout en présentant des défis pressants pour aller de l’avant.

Dans « The Bastard », W. Roberts présente un poème puissant qui décrit un chemin détourné de découverte de soi au milieu d’obstacles. La ténacité et la persistance de l’auteur, telles qu’elles sont décrites avec éloquence dans ce poème, sont un témoignage et un encouragement à aller de l’avant, même face à l’injustice et aux inégalités. Elles appellent à un changement systémique afin que les enfants (et les autres) ne soient pas abandonnés à leur souffrance et à leur lutte, comme c’est malheureusement le cas pour beaucoup d’entre eux. J’ai été touché par la perspicacité poétique et la générosité de l’auteur, qui a partagé son parcours jusqu’au diagnostic et à travers celui-ci, dans le cadre de son cheminement dans la vie et de la découverte de soi.

Dans son article intitulé « Embracing Neurodivergence: A Personal Journey », MissNatasha Connects offre un compte-rendu perspicace d’une transition entre la stigmatisation et de l’incapacité imposées par la société et la réalisation et à la reconnaissance de ses capacités neurodivergentes, de l’authenticité, de l’amour de soi et de la compréhension. Parallèlement à ce riche récit descriptif, Miss Natasha présente des œuvres d’art qui contrastent de manière créative et réfléchie avec la toile de fond de la discrimination fondée sur la capacité et les barrières, en y superposant un message qui supplante le négatif et offre une source d’inspiration et de défi.

Les articles de ce numéro spécial traitent de l'intersectionnalité dans le cadre du diagnostic et de l'expérience qui en découle. Plusieurs examinent les domaines coexistants de marginalisation et d'inégalité imposée. Dans son commentaire réflexif, Joy Lu partage ses perspectives en tant que Sino-Canadienne autiste, apportant un témoignage d'expérience vécue important et sous-représenté. Les enjeux relatifs aux préjugés raciaux et à la sous-représentation sont identifiés, invitant à une réflexion critique et à un plaidoyer pour la justice raciale et la sensibilisation à l'autisme au niveau interculturel. Cet article illustre en outre l'ingéniosité et le leadership de l'autrice pour favoriser la prise de conscience, la compréhension et l'acceptation dans un contexte culturel.

Dans « An Intersection of Race and Disability: A Critical Analysis of the Racial Inequities in Autism and Neurodivergent Disability Diagnoses for Black Children », Safia Abdulle présente de manière importante les tendances chez les enfants autistes noirs, sur la base de recherches indiquant un accès proportionnellement plus faible aux diagnostics et un risque plus élevé d'erreur de diagnostic. Cette étude amplifie le besoin de justice raciale dans le domaine du handicap et nous invite à réfléchir en profondeur sur les inégalités raciales en matière d'évaluation diagnostique et d'accès au soutien, et à y remédier.

McKenna Hart se penche sur la coexistence des diagnostics de santé mentale et d'autisme. Son expérience et sa perspicacité se traduisent par un appel à la précision diagnostique et à la prudence dans le langage professionnel lié au diagnostic et aux soins. L'autrice se livre à une réflexion critique sur l'utilisation de la terminologie et sur la manière dont les étiquettes et l'« étiquetage » sont importants et peuvent être préjudiciables. Elle présente aussi des considérations importantes pour les pratiques de diagnostic et la compassion dans les soins.

Emi Linds présente le point de vue d’une soignante dans « It Begins with a Diagnosis: Our Journey and the Promise of Canada's Autism Strategy ». Cet article célèbre le parcours commun d’un enfant et de sa famille et témoigne de l’engagement de la famille dans la prestation de soins. L’autrice exprime l’espoir que la Stratégie pour l’autisme au Canada (https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/canada-autism-strategy/canada-autism-strategy.pdf) améliorera l’accès aux évaluations diagnostiques et aux services au Canada.

Ces différents écrits nous rappellent que le diagnostic est un « moment » important, mais qu’il ne s’agit pas d’une entité discrète ou déconnectée ; au contraire, le diagnostic se tourne vers les expériences passées ainsi que vers l’avenir en vue d’une compréhension de soi et d’un soutien. Le diagnostic doit être fait au service du soutien, des mesures d’accommodement et des ressources. Réfléchissant à une initiative de soutien, Jan A. Wozniak propose un commentaire expérimental intitulé « Autism-Informed Mindfulness: Collaborative Practitioner Experiences ». Ce document porte sur la mise en œuvre d’une initiative de pleine conscience. Son message important porte sur la nécessité pour les services et les ressources d’être « neuroaffirmatifs » et, dans ce cas, facilités par un coresponsable autiste.

Ce numéro spécial illustre le fait que le diagnostic peut s’avérer très complexe, notamment parce qu’il s’inscrit dans un contexte général de discrimination fondée sur la capacité, de barrières à l’accès au diagnostic et au soutien, et d’une myriade de facteurs susceptibles d’entraver l’épanouissement des personnes concernées. Pour relever ces défis, il est nécessaire d’adopter des modes de pensée et d’action, des politiques, des aides et des services neuro-affirmatifs. Les articles présentés dans ce numéro offrent un aperçu utile de ce qui existe actuellement, mais aussi de ce qu'on doit encore mettre sur pied! Ainsi, les auteurs et autrices transmettent des considérations et des priorités importantes pour les personnes autistes. J'apprécie les intersectionnalités abordées dans ce numéro et je suis d'accord avec les contributeurs et contributrices du numéro ainsi qu'avec d'autres auteurs et autrices qui soulignent l'importance d'aborder l'intersectionnalité dans l'évaluation diagnostique, l'accès aux services et d'autres domaines importants tels que l'engagement communautaire (Lopez et al., 2022 ; Maroney et Horne, 2022) ; l'école (Cohen et al., 2022) ; et l'emploi (Doyle et al., 2022). Il est essentiel d'examiner le diagnostic dans le contexte du sexe, du genre, des problèmes de santé physique ou mentale coexistants, du statut socioéconomique, du contexte ethnoculturel, de la région (p. ex., la ruralité) et d'autres domaines de la diversité.

Enfin, en rédigeant cet avant-propos, j'ai été frappé par ce qui m'a semblé être un usage répétitif des notions de « défi » et d'« appel à l'action » et du besoin d'« aller de l'avant ». Il m'est apparu que les auteurs et autrices, les poètes et les artistes de ce numéro dessinent une voie réfléchie et perspicace vers l'avenir. Ce faisant, je me demande s'ils ne pourraient pas, par leurs écrits, nous inviter et nous inspirer, en tant que lecteurs et lectrices, à faire preuve d'une telle intentionnalité en poussant vers l'avant les changements nécessaires. Au moment de publier ce numéro spécial, le mois d'avril a été déclaré Mois mondial de l'acceptation de l'autisme. En s'inspirant des points de vue de ces auteurs et autrices, poètes et artistes, espérons que les connaissances acquises et les défis lancés dans ce numéro inspireront une plus grande acceptation et des conversations courageuses dans notre objectif collectif d'action et de changement transformateurs!

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An Intersection of Race and Disability: A Critical Analysis of the Racial Inequities in Autism and Neurodivergent Disability Diagnoses for Black Children

L'intersection de la race et du handicap : une analyse critique des inégalités raciales dans les diagnostics d'autisme et de handicap neurodivergent chez les enfants noirs

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Abstract

Black children face racial inequities when it comes to autism and neurodevelopmental disability diagnoses. As we know, autism and related neurodevelopmental disabilities have historically been pathologized, stigmatized, and discriminated against. As a result, Autistic self-advocates created the neurodiversity movement, as a direct oppositional force to this historical, and present-day, harm. However, even within the context of this civil rights movement, Black, and other minoritized people have consistently been left at the margins. This marginalization is evident throughout the diagnosis process, where Black children and youth who meet the diagnostic criteria for autism and related neurodevelopmental disabilities face, on average, diagnostic inequities. This includes incorrect diagnoses, later diagnoses, and receiving no diagnoses at all. It is critical to analyze and examine the harmful mechanisms which facilitate the marginalization and inequitable treatment of Black Autistic, neurodevelopmentally disabled youth from a young age.

Keywords

Autism, neurodiversity, neurodevelopmental disability, special education, racial disparity, race, Blackness, disability

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Résumé

Les enfants noirs sont confrontés à des inégalités raciales en ce qui concerne les diagnostics d'autisme et de troubles du développement neurologique. Comme nous le savons, l'autisme et les troubles neurodéveloppementaux connexes ont été historiquement pathologisés, stigmatisés et discriminés. C'est pourquoi les militant·es pour l'autisme ont créé le mouvement de la neurodiversité, en tant que force d'opposition directe à ces préjudices historiques et actuels. Cependant, même dans le contexte de ce mouvement pour les droits civiques, les personnes noires et les autres minorités ont toujours été laissées en marge. Cette marginalisation est évidente tout au long du processus de diagnostic, où les enfants et les jeunes Noir·es qui répondent aux critères de diagnostic de l'autisme et des troubles neurodéveloppementaux connexes sont généralement confrontés à des inégalités en matière d'évaluation : diagnostics, tardifs ou complètement absents. Il est essentiel d'analyser et d'examiner les mécanismes néfastes qui facilitent la marginalisation et le traitement inéquitable des jeunes noir·es autistes ou ayant des troubles neurodéveloppementaux dès leur plus jeune âge.

Mots-clés

Autisme, neurodiversité, handicap neurodéveloppemental, éducation spéciale, disparité raciale, race, noirceur, handicap

Introduction

In a study of over 400 children—all of whom met the diagnostic criteria for Autism—only 58% of Black children received an autism diagnosis, while 72% of White children received an autism diagnosis upon initial visit to a specialized mental health clinic (Mandell et al., 2002). This indicates a clear discrepancy in the diagnosis rates and processes for Black children. The mechanisms and reasonings behind these disparities are complex. Overall, the social understanding of autism and related neurodevelopmental disabilities has vastly changed over time, resulting in a variety of perspectives and social shifts in understanding and existence. However, many of these changes have neglected to fully recognize the intricate considerations of intersectionality, particularly when it comes to race. As a Black clinician working primarily with Autistic and neurodivergent youth, these are complexities I witness regularly. As such, this paper seeks to problematize the ways in which diagnosis processes often pathologize the existence of autism and/or neurodivergence when presented in a racialized, or otherwise 'othered' body.

A Note to Readers

It should be noted that this paper utilizes person-first and identity-first language interchangeably, in solidarity with Autistic (and neurodivergent) self-advocates who have long indicated the importance of using identity-first language (Shakespeare, 2006; Sinclair, 1999; see also Brown, 2011; Pripas-Kapit, 2020), and in opposition to widespread service-provider rhetoric which problematizes its use. Language is an incredibly powerful tool for conveying meaning, concepts, and identity. Person-first language implores individuals to utilize language which emphasizes the individual before the disability (i.e., "a person with a disability") while identity-first language emphasizes language which situates the disability first, as part of the individual's identity (i.e., "Autistic person") (Shakespeare, 2006; Sinclair, 1999; see also Brown, 2011; Pripas-Kapit, 2020). The use of both interchangeably in this paper seeks to recognize the critical importance of analyzing the stigmatization of identity-first language, while recognizing the diverse autonomous perspectives and preferences of disabled people.

Autism and Neurodiversity

To fully contextualize the racial inequities and disparities which exist in the diagnosis processes of autism and related neurodevelopmental disabilities, it will be important to understand both the historical, and the present-day, accounts of these disabilities.

The Historical Conceptualization of Autism

In 1911, the term ‘autism’ was first coined by a German psychiatrist, Eugen Bleuler, to describe what he theorized was the most ‘severe’ form of childhood schizophrenia (Evans, 2013; Wright, 2019). This theorization of Autism—characterized by “hallucinations” and “extreme detachment” in childhood—remained popular throughout the early 1900s, as did violence against the bodies and minds of Autistic people, including eugenics, institutionalization, and forced sterilization (Evans, 2013; Wright, 2019). Further, it was largely argued that ‘bad mothering’ was the “cause” of autism in children (Waltz, 2020). By the 1940s, Leo Kanner (an Austrian-American psychiatrist) began theorizing that autism was a cognitive and biological “deficit”, rather than a form of mental illness (Jaarsma & Welin, 2012). Kanner proposed the term ‘autistic aloneness’, arguing against the notions of ‘extreme hallucinations’ and suggesting that Autistic individuals were “deficient” and overall, had a lack of consciousness and ability (Jaarsma & Welin, 2012; Waltz, 2020). This new theorization shifted the focus away from ‘bad parenting’ and towards a biological ‘reasoning’ for neurological disability (Jaarsma & Welin, 2012; Waltz, 2020). As a result, however, the social construction of the “normal child” and the “abnormal child” began to gain prominence in society—literature indicates that this type of pathologization, i.e., construction of the ‘normal’ child, has only existed for approximately the past 100 years (Fenton & Krahn, 2007; Waltz, 2020; see also Aries, 1962; Burman, 2007; Foucault, 1965).

By the 1970s and 1980s, a social shift emerged as first-wave disability theorists began to criticize the medical and biomedical fields for applying this type of medical model approach to disabilities (Scully, 2008). Additionally in the 1980s, the deinstitutionalization movement gained momentum, as many so-called ‘mentally disabled’ individuals left institutional facilities, symbolizing another historical social shift in the perspectives around cognitive and neurodevelopmental disabilities. Yet, because of society’s medical model, deficit-based perspectives on disability, people with neurodevelopmental disabilities were still left unsupported, and unable to reintegrate back into communities (Wright, 2019).

Introducing the Neurodiversity Movement

Overall, Autistic and neurodevelopmentally disabled individuals would have been previously labelled as ‘mentally disabled’ or ‘mentally deficient’ throughout history, and as a result, they experienced significant stigma, discrimination, and violence (Acevedo & Nusbaum, 2020; Aries, 1962; Evans, 2013; Fenton & Krahn, 2007; Foucault, 1965; Singer, 1999; Waltz, 2020). Individuals with autism and neurodevelopmental disabilities were viewed as abnormal and were pathologized—seen as a ‘problem’ in society (Jaarsma & Welin, 2012; Waltz, 2020; Wright, 2019). In the 1990s, the neurodiversity movement was created in direct opposition to the historical discrimination and oppression against autism and neurodevelopmental disabled people.

What is Neurodiversity?

Neurodiversity is a term which states that all human brains have neurological variations and thus, all function differently (Kapp, 2020; Singer, 1999; Walker, 2023). The term neurodivergence specifically describes individuals whose minds deviate from the 'expected' neurological make-up society has deemed as "normal" (Rosqvist et al., 2020) and can describe individuals diagnosed with Autism, Attention-Deficit Hyperactivity Disorder (ADHD), and many more. It is important to note that there is currently no clear consensus on the exact parameters of who is included and excluded from a 'neurodivergent' diagnosis or label (Botha & Gillespie-Lynch, 2022; Dekker, 2020; Gillespie-Lynch et al., 2020; Legault et al., 2021; Kapp, 2020; Kapp, 2023; Rosqvist et al., 2020; Russell, 2020; Singer, 1999; Singer, 2017). However, within the context of the medical model and/or using the Diagnostic Manual of Mental Disorders (DSM-5) as a categorization method, neurodivergence largely includes individuals meeting the criteria of a 'Neurodevelopmental Disorder' (which includes Intellectual Disabilities, Communication Disorders, Autism Spectrum Disorders, ADHD, Learning Disorders/Disabilities, and Motor Disorders like Tourette's). Neurodivergent diagnoses can also include individuals meeting criteria for Schizophrenia Disorder, Obsessive-Compulsive Disorder (OCD), and Neurocognitive Disorders as well.

The Neurodiversity Movement as Revolution

The term 'neurodiversity' seems to have first been used in literature in 1999 by sociologist Judy Singer, while the neurodiversity movement itself is understood to have begun in the 1990s by autistic self-advocates from prominent online Autism rights groups (Dekker, 2020; Gillespie-Lynch et al., 2020; Kapp, 2020; Rosqvist et al., 2020; Singer, 1999;

Singer, 2017). Online autistic self-advocacy groups began having discussions about how the acceptance of neurological difference should be understood as a new paradigm of thought, asserting that neurological diversity should be treated as biological diversity—natural and essential to human life (Dekker, 2020; Kapp, 2020; Singer, 1999; Singer, 2017). As a social justice movement, the neurodiversity movement asserts that neurodivergence is not a 'defect' and should be reconceptualized as a natural, non-pathological part of human diversity (Leadbitter et al., 2021; O'Dell et al., 2016). Judy Singer (1999) then arguably popularized these revolutionary conversations and the term 'neurodiversity' in her highly influential essay titled "Why Can't You Be Normal for Once In Your Life?" where she spoke of the politics of neurodiversity and further challenged the disability rights movement to better include autistic [and neurodivergent] people. Moreover, around this time in 1999, Jim Sinclair published an essay titled, "Why I Dislike Person-First Language" and highlighted the problematic nature of person-first language as a dehumanizing, deficit-based perspective—further changing the landscape of the neurodiversity rights movement. Sinclair (1999) is noted as one of the first to reject person-first language and advocate for an identity-first stance (see also Brown, 2011; Pripas-Kapit, 2020). Overarchingly, the neurodiversity movement was revolutionary in asserting the rights and humanity of Autistic and neurodevelopmentally disabled (hereby referred to as neurodivergent) peoples.

Critical Analysis of the Neurodiversity Movement

Overall, the neurodiversity movement has been radical and groundbreaking in starting to shift discourse around autism and neurodivergent disabilities. It has begun to change societal understanding, and arguably the acceptance, of neurological, brain-based differences.

An important critique of this movement is outlined by Gillespie-Lynch et al. (2020) as they indicate that while “attributing autism to brain difference can lead to non-pathologized forms of identity and community, it can also conceal intersectional complexities of personhood” (p. 7). As such, even within this revolutionary social justice movement, much of the discourse and research on Autism and neurodiversity has failed to include intersectionality (Botha & Gillespie-Lynch, 2022; Davis et al., 2022). Neurodiversity research, and the neurodiversity movement overall, has largely focused on non-racialized and male bodies, leading to a limited understanding of the presentation of neurodivergence—one that marginalizes identities like race and gender. Often, popularized media or social depictions of Autistic or neurodivergent people include individuals who are White and male. Consequently, I argue that this movement has specifically, albeit inadvertently, left individuals with intersectional identities at the margins, and this can clearly be showcased through the racial disparities which still exist in the diagnosis of autism and neurodivergent disabilities.

Intersections of Race and Disability

To begin, intersectionality is a term coined by Kimberlé Crenshaw which recognizes how social identities, such as race, disability status, class, or gender, are interconnected and intersect with one another, leading to various experiences of oppression and privilege in society (Crenshaw, 1991; Crenshaw, 2018). Intersectionality can be a powerful tool; it is a theoretical perspective which highlights the complexities of the human experience and can be utilized to better understand how disabled people with marginalized identities face unique experiences, barriers, and challenges (Crenshaw, 1991). It can be significant in specifically recognizing how autism and neurodivergence manifest differently across gender identity, sexual orientation, class, race, ethnicity, and various other social identity categories (Davis et al., 2022). However, dominant literature on race and neurodivergence showcases an emergent gap in the intersections between the two concepts. Neurodiversity research has largely over-looked Black individuals by focusing on non-marginalized (primarily White male) bodies which facilitates a narrow societal understanding of neurodivergence—one that, as previously indicated, discounts identities such as race (Davis et al., 2022; Haney, 2018; Rosqvist et al., 2020). The failure to recognize the existence of the intersectional identities of Autistic and neurodivergent people is a problematic and dangerous one, and can lead to outcomes including dehumanization, criminalization, and increased risks of violence (Coles & Powell, 2020; Dumas & Nelson, 2016; Goff et al., 2014; Skiba & Williams, 2014).

As clearly exemplified through the historical account of the treatment of Autistic and neurodevelopmentally disabled people, neurodivergent individuals face stigma, discrimination, pathologization, and consequently, harmful and negative consequences of existence. I argue that the neurodiversity movement has arguably begun to act as a “social shield” against some of this pathologization through conversations of societal acceptance of neurological, brain-based differences. However, the failure to consider the realities of racialized, gendered, and otherwise ‘othered’ bodies within the context of autism and neurodivergence results in this “social shield” not extending to cover all individuals—

meaning that these individuals are, yet again, more susceptible to the consequences of pathologization and discrimination.

Racial Inequities in Autism and Neurodivergent Diagnoses

As previously indicated, the consequences of the marginalization of neurodivergent, racialized can clearly be showcased through the racial disparities which still exist in diagnosis. Autism and neurodevelopmentally disabled children who also identify as Black or racialized receive inequitable rates of appropriate, accurate diagnoses when compared to their non-Black or non-racialized peers (Cameron & Guterman, 2007; Fadus et al., 2020; Mandell et al., 2007; Mandell et al., 2002; Mandell et al., 2009). While the following analysis will primarily focus on Black children and youth, a few diagnostic disparities centering other racialized youth populations will additionally be highlighted.

Inequitable Diagnosis of Black and Racialized Children

Literature consistently showcases that the bodies, brains, and behaviours of Black Autistic and neurodivergent children are extremely misunderstood. When compared to their White peers, Black children who are Autistic and/or neurodivergent are at higher risks of receiving late diagnoses, incorrect diagnoses, and no diagnoses at all (Mandell et al., 2007; Mandell et al., 2002; Mandell et al., 2009). In multiple studies analyzing this phenomenon, researchers reviewed data which analyzed Autistic and neurodivergent children’s interactions with the mental health system. In these studies, all of the children met the criteria for an autism diagnosis or a neurodevelopmental disability diagnosis (like ADHD or

Dyslexia). Importantly, this meant that all children in these studies should have been considered for, and received, an autism and neurodevelopmental disability diagnosis.

Mandell et al. (2009), in their study of over 2500 children who all met diagnostic criteria for autism, found that Black children were consistently 4% less likely than White children to have a documented diagnosis of autism on their records. These disparities are further expanded upon in the following studies. It was additionally found that, upon a child's initial visit to a specialized mental health clinic setting, White children received the appropriate diagnoses of Autism 72% of the time, while Black children received the appropriate diagnoses of autism only 58% of the time, meaning Black children were 14% less likely to receive a proper diagnosis (Mandell et al., 2002). Moreover, Black children are additionally over 2.5 times more likely to receive no diagnosis at all, during their first visit to a mental health or psychiatric clinic in comparison to White children (Mandell et al., 2007). Even more, Black children are at higher jeopardy of receiving later diagnoses, with Black children on average receiving appropriate autism diagnoses over 2 years later than White children—which is often about 3 years after parents' first attempt to receive supports (Aylward et al., 2021; Mandell et al., 2002; Mandell et al., 2009). Similarly, Mandell et al. (2002) also recognized that Latino children were similarly at-risk of receiving later diagnoses and receive their appropriate Autism diagnosis 3 years later than White children. Mandell et al. (2002) assert that Black children (in comparison to White children) must access mental health and psychiatric settings 3 times as often, over a period 3 times as long, to finally receive their appropriate diagnosis. Even after receiving an autism diagnosis, some disparities in service access continue, as Black children are over 5 times less likely to receive out-patient autism related services (Bilaver et al., 2020; Losen et al., 2014).

While it can be argued that these diagnostic differences could exist for a multitude of reasons, including sociocultural differences in help-seeking, socioeconomic barriers, and/or systemic racial injustices, it should still be noted that these inequities exist and persist. Moreover, even further complicating these disparities, Black Autistic and neurodivergent children face even more troublesome statistics. More specifically demonstrating the link of these diagnostic discrepancies to race, Black children are not only more likely to receive no diagnoses and later diagnoses, but Black children are also more likely than White children to receive an incorrect diagnosis.

Mandell et al. (2007) further examined rates of misdiagnosis for children who met the diagnostic criteria for autism. Their study, including over 400 children, found that children were most commonly misdiagnosed with ADHD, with approximately 21% of children getting an incorrect ADHD diagnosis prior to receiving the appropriate autism diagnosis. This statistic remained consistent across races (Mandell et al., 2007). However, it was further identified that Black children were more likely to receive incorrect diagnoses of adjustment disorder and conduct disorder, when compared to White children. Specifically, Mandell et al. (2007) found that Black children were approximately 2 times more likely than White children to receive a diagnosis of conduct disorder, with approximately 15% of Black children receiving an incorrect conduct disorder diagnosis, and about 6% of White children receiving an incorrect conduct disorder diagnosis. Even further, Black children were about 5 times more likely to receive an incorrect diagnosis of adjustment disorder when compared to White children, with over 12% of Black children being misdiagnosed with adjustment disorder, compared to just over 2% of White children being misdiagnosed with adjustment disorder (Mandell et al., 2007).

These research findings were echoed in other studies which showcased similar racial disparities existing for other racialized children and youth. When investigating the implications of conduct disorder diagnoses on children and youth, a study by Cameron & Guterman (2007) found that Hispanic children were most likely to be assigned with a conduct disorder diagnosis, with Black children second most likely to receive the diagnosis, and White children least likely to be assigned the diagnosis (43.3%, 34.4%, and 24.4%, respectively). Importantly, it was recognized that all these children, irrespective of race, displayed similar levels of behavioural aggressiveness. This indicates that Black and Hispanic children's behaviours may overall be viewed as more 'clinically aggressive' than White children's behaviours—even when those behaviours externally present similarly (Cameron & Guterman, 2007). Interestingly, Fadus et al. (2020) highlight that Black and Hispanic children who display these so-called 'aggressive' behaviours are often diagnosed with conduct disorder or oppositional defiant disorder, while White children who display similar behaviours are often diagnosed with anxiety or mood disorders.

Racialized children—in this case namely Black, Latino, and Hispanic children—who are Autistic and/or neurodivergent are being misdiagnosed. Importantly, these disorders are categorized as behavioural disorders, which interestingly enough can present similarly to developmental disabilities, but carry different, more problematic societal connotations. To understand the implications of these incorrect diagnoses more fully, we need to more closely examine how these diagnoses are conceptualized in the medical model, through the Diagnostic and Statistical Manual of Mental Disorders (alternatively known as the 'DSM'). Adjustment disorder is classified in the DSM as an emotional and/or behavioural disorder, given to individuals who display unhealthy or extreme reactions to changes in one's life

(American Psychiatric Association, 2013). Conduct disorder is classified in the DSM as a behavioural disorder, given to individuals who display anti-social behaviours, who violate others, and/or who do not follow social norms, laws, or behaviours (American Psychiatric Association, 2013). Oppositional defiant disorder is classified in the DSM as a behavioural disorder, given specifically to children who display patterns of behaviour that are considered hostile, defiant, combative or disruptive (American Psychiatric Association, 2013). It is critical to recognize the implications of these incorrect diagnoses. In all instances of aforementioned misdiagnosis, it is evident that Black, Hispanic, and Latino Autistic and neurodivergent children are problematized, pathologized, and understood within a context of deviance, disruptiveness, and/or defiance.

Moreover, and notably consequential, it was shown that Black children are particularly vulnerable to receiving lower diagnosis rates of ‘mild-moderate’ autism, and are more likely to be diagnosed with ‘severe’ (otherwise harmfully known as “low-functioning”) autism. It can be argued that this indicates a racial bias, as Black children are seemingly over-represented and over-labelled as intellectually disabled, yet under-diagnosed as non-intellectually, neurologically disabled (Coles & Powell, 2020; Dumas, 2014; Gibson et al., 2014; Losen & Orfield, 2002; Ratto et al., 2016).

Literature further indicates that Black youth are not only under-represented and misdiagnosed with autism and neurodevelopmental disabilities, but they are additionally excluded from equitable education through an over-representation in special education classes (Coles & Powell, 2020; Dumas, 2014; Dyches et al., 2004; Gibson et al., 2014; Fadus et al., 2020; Losen & Orfield, 2002; Parrish, 2002; Reschly, 1997; Skiba et al., 2002; Wilt, 2021). In the 1970s, Black students constituted only 16% of children enrolled in school, yet made up 38% of students placed in special education/classes for the intellectually disabled (Losen & Orfield, 2002). In comparison, White children constituted 63% of students enrolled (47% more enrollment than Black students) yet made up 54% of students in special education classes (only a 16% higher rate of placement than Black students), and even further, were 76% of those considered intellectually gifted or talented (Losen & Orfield, 2002). Only 8% of all Black children were seen as intellectually gifted or talented (Coles & Powell, 2020; Dumas, 2014; Gibson et al., 2014; Losen & Orfield, 2002). Similar trends of Black student over-representation continue to appear today, as Black children are primarily most over-represented in the classification of emotional and behavioural disorders, and intellectual disability, as exemplified above (Parrish, 2002; Wilt, 2021).

Implications and Calls to Action

While the exact reasons behind these misdiagnoses and inequitable diagnoses are yet to be determined, and while the literature on Black Autistic and neurodivergent people is still limited, it remains clear that these discrepancies exist. Even more, the implications of these discrepancies are clear as well. Black youth, as well as Hispanic and Latino youth, are being incorrectly over-categorized as “bad” or “the problem kids” while simultaneously being over-represented within special education classrooms, leading to these youth not getting the appropriate care and supports they need. These rates of incorrect diagnoses further make invisible (i.e., ‘less common’) the existence of Black Autistic and neurodivergent people, further exacerbating the problem at its source.

As indicated by Goff et al. (2014), Black children are left vulnerable in today’s society, and Black youth, specifically Black boys, are seen as “less innocent…than their

White same-age peers” (p. 526) resulting in a dangerous dehumanization process. This dehumanization process is a key factor in the misidentification of Black youth behaviours as misconduct or deviance, rather than as indicators of needs or developmental disability. It is evident that Black children and youth are being unjustly mischaracterized, resulting in a lack of appropriate mental health, and developmental disability, diagnoses. The dehumanization of Black Autistic and neurodivergent youth results in the experience of harsher realities. Black children are 18 times more likely than White children to be sentenced as adults and represent 58% of children sentenced to adult facilities (Goff et al., 2014). Black children, and specifically boys, are seen as less childlike and less innocent than White children and White boys. Consequently, Black children are dehumanized, not given the privilege of innocence, are less likely to have the characteristics of childhood applied to them and are more likely to be held responsible for their actions. In the context of autism and neurodivergence, if Black children are less likely to be afforded the privileges associated with childhood, their behaviours are more likely to be pathologized and dehumanized, rather than supported—leading to lower rates of accurate diagnoses.

This dehumanization process fundamentally strips Black children and youth from the necessary and just considerations afforded to non-Black (primarily White) children and youth—the safe and supportive learning environments needed for children to thrive—and consequently violates the rights and needs of children to be understood, nurtured and protected (Gibson et al., 2014; Goff et al., 2014). These issues, in my view, start and stem from the diagnosis process. More research is needed to fully understand and contextualize the racial disparities evident in autism and neurodivergent disability diagnoses. It is pivotal to critically analyze how racialized children, youth, and families experience the diagnosis process. Further, we need to reimagine how we recognize ‘difference’, and how we conceptualize what autism and neurodivergence ‘look like’—particularly when existing in a non-marginalized young body.

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

What's in a Name? A story of two diagnoses, and why the words we use matter when it comes to mental health

De l'importance d'un nom : l'histoire de deux diagnostics, et pourquoi les mots importent lorsqu'on parle de santé mentale

McKenna Hart[1]

Abstract

This essay reflects on my mental health journey that began when I first received a diagnosis of bipolar II disorder at age 18. After countless ineffective treatments and conflicting diagnoses over the course of my young adult years, by the time I was 23, I feared that my condition would never improve. However, a family members' autism diagnosis prompted me to pursue an assessment myself. After two years on a waitlist, I received a diagnosis of Level 1 Autism Spectrum Disorder, which changed my perception of myself and led to a massively improved quality of life. This transformative experience showed me the importance of informed and compassionate care, and the need for a more nuanced understanding of mental health conditions and the language used to describe them.

Keywords

Misdiagnosis, bipolar disorder, autism, identity, inclusive nomenclature

Resumé

Cet essai est une réflexion sur mon parcours de santé mentale qui a commencé lorsque j'ai d'abord reçu un diagnostic de trouble bipolaire II à 18 ans. Après d'innombrables traitements inefficaces et des diagnostics contradictoires au cours de mes années de jeune adulte, je craignais, à 23 ans, que mon état ne s'améliore jamais. Cependant, le diagnostic d'autisme d'un membre de ma famille m'a incité à procéder moi-même à une évaluation. Après deux ans sur une liste

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d’attente, j’ai reçu un diagnostic de trouble du spectre de l’autisme de niveau 1, ce qui a changé ma perception de moi-même et m’a permis d’améliorer considérablement ma qualité de vie. Cette expérience transformatrice m’a montré l’importance d’une prise en charge informée et compatissante, ainsi que la nécessité d’une compréhension plus nuancée des troubles mentaux et du langage utilisé pour les décrire.

Mots-clés
Erreur de diagnostic, trouble bipolaire, autisme, identité, nomenclature inclusive

What do you call an 18-year-old girl who shows up to the Emergency Room covered in her own blood?

Bipolar II with mixed features. At least that’s what doctors started calling me after I’d spent less than 24 hours in the in-patient mental health unit at my local hospital. The diagnosis came from a psychiatrist I had never met before and never saw again, who sat behind a desk in the small, white, uncomfortably lit room. Before I could begin to unpack what that meant, I was escorted out of the one-way doors of the psych ward with a pamphlet, a prescription, and a loaded new label.

When it comes to medicine, a proper diagnosis can be the difference between life and death. But mine didn't help me much. Even while taking a handful of medications, I couldn't go more than a few months without having an ‘episode’. Sometimes that meant I couldn't get out of bed for a week or was plagued by anxiety attacks that left me feeling disconnected from my body. Other times I would go days without sleeping and become hypersensitive to even the smallest of noises. But no matter what kind of episode it was, they all ended the same: in an uncomfortable room, answering uncomfortable questions.

To make things more confusing, every mental health professional I met had a different opinion as to why I wasn't getting better, and the diagnoses piled up, each one accompanied by a new prescription with new side effects. By the time I was 23, I was the most medicated and most miserable I had ever been in my life. I felt broken—the kind of broken that couldn't be fixed.

Around the same time, a close family member of mine was struggling with his mental health as well. His diagnosis? Autism. One day, I accompanied him to a doctor's appointment, and as I listened to the psychiatrist explain his condition, I noticed how different the experience was from what I was accustomed to. While the two of us shared many of the same symptoms, like mood and energy fluctuations, here they were described much differently. According to this doctor, his instability was the result of a dysregulated nervous system. His brain was different, not disordered. Perhaps most notably, he needed care, not to be cured.

And so, I asked my family doctor to be reassessed, this time by a developmental disability specialist, and I was put on a two-year waitlist. As I waited, I became very curious about understanding the labels used in mental health and the system at large. The more I learned about the diagnostic criteria for different disorders, the more I found that they had in common. I also began to understand all the many ways the system can fall short, and who is most likely to be affected by that.

To start, accessing mental health care in Canada is not easy. “People have to wait a long time to get mental health support,” says Dr. Yona Lunsky, the director of a leading neurodevelopmental disability research and education center in Toronto, “and the more people who are waiting means that the people who finally do get services are worse off than they would have been had they received care earlier" (personal communication[2], April 26, 2024).

Even for those who are able to access care, the extent to which the system is overwhelmed can also impact the accuracy of assessment. "It's important for a psychiatrist or clinician to listen to their patient and not rush into a diagnosis," notes Dr. Pushpal Desarkar, a psychiatrist and scientist at the same clinic. "Because of the shortage of psychiatrists in Ontario and Canada, it's typically very busy, so one reason could be that they really may not have enough time to listen to all of this nuanced detail" (P Desarkar, personal communication[3], April 29, 2024).

This nuanced detail is critical when it comes to diagnosing mental health conditions. While the standard Diagnostic and Statistical Manual for Mental Disorders (the DSM-5-TR) (American Psychiatric Association, 2013) contains detailed descriptions and diagnostic criteria for hundreds of conditions, diagnoses are largely determined by the interpretation of the clinician. "We don't have any lab tests, so it really depends on the skill of the psychiatrist", explains Desarkar. However, because there is no clear-cut understanding of the brain mechanisms that cause these disorders, even the most experienced psychiatrists can make mistakes. Desarkar says that even in specialty clinics, psychiatric misdiagnosis rates can reach up to 70% (personal communication, April 29, 2024).

To further complicate things, mental health conditions are often co-occurring, and share overlapping symptoms, making them even more difficult to accurately diagnose and treat. "Sometimes people do go through a process of having different diagnoses given to

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[2] All quotes from Dr. Yona Lunsky are from a video interview conducted on April 26, 2024. Contributions were approved by Lunsky prior to publication.

[3] All quotes from Dr. Pushpal Desarkar are from a phone interview conducted on April 29, 2024. Contributions were approved by Desarkar prior to publication.

them," says Lunsky. "It takes some time to unpack and recognize what else is really going on, and it has to do with the expertise of the people and what they are familiar with." (personal communication, April 29, 2024).

While neurodevelopmental disorders are typically diagnosed in childhood (Zwaigenbaum et al., 2019), an increasing number of adults are seeking a diagnosis later in life (Levine 2024). At the clinic he works at, Desarkar remarks that approximately 8 out of 10 adult patients receive an autism diagnosis (personal communication, April 29, 2024). Many of these patients are women—a group that up until recently has been under-represented due to a historically male model of autism.

In fact, according to Desarkar, only about 20% of autistic women receive their diagnosis before age 18. Instead, they often first receive another diagnosis such as bipolar disorder or borderline personality disorder in their young adulthood. These assessments are often made by doctors who observe behaviors such as self-harming but fail to investigate the reasons why. "They don't get to the bottom of why autistic girls and women are cutting", he says. "They tend to miss the forest for the trees, going for the diagnosis they know." (P Desarkar, personal communication, April 29, 2024).

And so the question remained: could I be part of the 80% that was missed?

After waiting nearly two years, I finally had a date for my assessment. Before the assessment date, I had been asked to provide supplemental documents from my development in my early years, and as I read through old report cards, I found myself overwhelmed with emotion. For so long my identity had been wrapped up in words like ‘manic’ and ‘unstable’, but before I was any of those things I was ‘expressive’and ‘sensitive’. It was then that I realized just how much of myself I had learned to repress for the sake of fitting in.

Finally, the day of my assessment arrived. This time it took place virtually from the comfort of my own home, with two psychiatrists who specialized in autism. I braced myself for the typical uncomfortable prodding, but instead, I was surprised that they were most curious about things I had never talked about, like my encyclopedic knowledge of Transformers and my difficulty making friends as a teenager. By the time the assessment ended nearly four hours later, we had walked through my entire life. Two weeks later, I was told that I fit the criteria for Level 1 Autism Spectrum Disorder.

When I received my diagnosis I burst into tears. For so many years, I accepted the label ‘bipolar’ because it was the only word that came close to describing how different I felt, yet I often felt reduced to it, particularly by those who were meant to be providing care. For the first time, I wasn't being told that I was sick, or that I needed to be medicated to fit in with the rest of the world. Instead, I was being validated that my brain was wired differently, and that was okay. My formal diagnosis felt like permission to be myself, and that changed everything.

And so, under the supervision of my psychiatrist, I stopped taking mood stabilizers and instead started seeing a therapist who specialized in autism to develop strategies to manage my mood and triggers. Instead of relying on Benzodiazepines to soothe my anxiety, I prioritized creating a lifestyle that was comfortable from a sensory perspective. Perhaps the most meaningful change was in the attitude of my health care providers, who emphasized supporting my needs rather than suppressing my differences.

Now, having gone more than two years without a mood episode, it might be fair for me to say I was misdiagnosed the first time around, that my ‘depressive’ episodes could be explained by autistic burnout, and my ‘manic’ episodes the result of an overstimulated nervous system. But my symptoms did not change, only the attitude towards my care. The fact that I was given so many different diagnoses in the first place has made me wonder, could all these psychiatric conditions be more related than we realize?

Understanding these ‘neurophysiological underpinnings’ is a significant part of what Dr. Desarkar has dedicated his research to. “Unless we talk about certain dementias we do not have any 100% worked out biological model for any of our psychiatric conditions,” he notes (personal communication, April 29, 2024). Therefore, it is possible that the way we classify these conditions may change as we learn more about the underlying mechanisms that cause them. For example, Asperger’s Disorder was once a separate diagnosis given to describe an autistic person with low support needs, but was removed in the most recent version of the DSM in favour of the more inclusive label of ‘Autism Spectrum Disorder’.

“How we define a condition, how we measure a condition is always changing,” explains Lunsky. “We all try to follow the guide and then we realize that the guide isn't meeting our needs exactly, or is not quite right, so then we go through some efforts to change it”. When thinking about the future of mental health, Lunsky would like to see a ‘learning system’, which would adapt as we better understand these conditions (personal communication, April 26, 2024).

It may be a while before we truly understand the physiology of mental health conditions, but one thing we do get to decide is the way we describe them. Desarkar notes that while autism is technically described as a disorder, that term is rarely used in his practice. When it comes to the words we use, he emphasizes the importance of including the perspectives of those with lived experience. “This is the best way to learn from each other, and create a more inclusive nomenclature system,” he says (personal communication, April 29, 2024).

As someone who has been assigned many labels over the years, I believe this is a crucial first step. Perhaps the words we use right now are simply our best attempt at describing something that we can't fully grasp yet, but my experience has shown me that it's not necessary to fully understand these conditions to provide more effective care. Instead, it starts with compassion and acceptance that is reflected in the language we use. Through my autism diagnosis, I gained a new vocabulary to describe my experience. I went from being crazy to misunderstood, from disordered to different, from a problem to a person.

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CANADIAN JOURNAL OF AUTISM EQUITY
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It Begins with a Diagnosis: Our Journey and the Promise of Canada's Autism Strategy

Tout commence par un diagnostic : Notre parcours et la promesse de la Stratégie pour l'autisme au Canada

Emi Linds[1], Alastair Linds[2], Ella Shtaif[2], Sarah Cooper[2,3]

Abstract

This narrative shares the story of a family's journey into understanding and supporting their child, beginning with the transformative moment of an autism diagnosis. The diagnosis helped them step into his beautiful universe filled with things that spin. The essay explores the role that Canada's Autism Strategy plays in shaping a brighter future for families like theirs. Focusing on the Strategy's priorities—screening and diagnosis, public awareness and acceptance, and tools and resources—it reflects on how these initiatives promise a more equitable and inclusive future. This is a story of love, discovery, and advocacy, grounded in the belief that change begins with understanding, and that every journey begins with a diagnosis.

Keywords

Diagnosis, Canada's autism strategy, early intervention, families, advocacy, policy reform, autism acceptance

Resumé

Ce récit raconte l'histoire d'une famille qui s'est efforcée de comprendre et de soutenir son enfant, en commençant par le moment transformateur qu'a été son diagnostic d'autisme. En effet, le diagnostic les a aidés à pénétrer dans l'univers magnifique et tournoyant de leur enfant.

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L’essai explore le rôle que joue la Stratégie pour l’autisme au Canada dans la construction d’un avenir meilleur pour des familles comme la leur. En se concentrant sur les priorités de la stratégie (dépistage et diagnostic, sensibilisation et acceptation du public, outils et ressources), l’autrice réfléchit à la façon dont ces initiatives promettent un avenir plus équitable et plus inclusif. Il s’agit d’une histoire d’amour, de découverte et de plaidoyer, fondée sur la conviction que le changement commence par la compréhension et que tout voyage commence par un diagnostic.

Mots-clés

Diagnostic, stratégie pour l’autisme au Canada, intervention précoce, familles, défense des droits, réforme des politiques, acceptation de l’autisme

“There is love, so much love, and also a longing - a feeling of standing on the edge of his universe, arms outstretched, hoping one day he’ll reach back.”

I remember watching my child, G, mesmerized as he spun toy plates on the kitchen floor for hours. His eyes locked onto their motion, following each revolution with a focus so intense it felt like he was disappearing into another universe. His small hands, so confident and precise, moved like he was tracing the lines of a world only he could see. I saw both the beauty and the isolation that autism can bring. The way he connected with spinning was magical. But then, when we would call his name, it was as if we were echoes, distant calls he couldn’t reach. There is love, so much love, and also a longing - a feeling of standing on the edge of his universe, arms outstretched, hoping one day he’ll reach back.

Love brought us to the edge of his universe, and we needed to learn how to take the first step, to chart a course into his orbit, and to find supports that would help his star shine.

Diagnosis: Relief, Dreams, and Action

When our pediatrician initially suggested a “wait-and-see” approach, we felt a fierce urgency to act, to fight for early intervention so that he could find his voice. This intervention wasn’t about 'fixing' him but about supporting his unique way of communicating. We wanted to understand him better and help the world see and appreciate who he truly is.

After some persistent advocacy, we were escalated to a local neuro-developmental centre and then came the waiting. We were told that assessing autism before age three was challenging due to the spectrum of typical toddler behaviour. So, we waited. We managed his meltdowns in noisy spaces, trying to shield him from the chaos that overwhelmed him. We watched as his daycare turned him away, unable to handle his needs.

With the help of a known psychologist specializing in autism diagnosis, we scheduled a private, in-home assessment (which I acknowledge is a privilege that many cannot access). She administered the Autism Diagnostic Observation Schedule – Second Edition (ADOS-2) and the Autism Diagnostic Interview – Revised (ADI-R). We were sat down with a world of uncertainties, stuck in the doldrums unable to move, floating aimlessly. Finally, after what seemed like an eternity, we were given the validation we sought after. With the diagnosis in hand, we could finally access comprehensive support services—a step many individuals and families reach much later in the public system.

The diagnosis was the beginning of a remarkable journey. It was an invitation to truly understand him, to celebrate his strengths, and to immerse ourselves in his world. And what a world it is—a beautiful, spinning one.

Spinning was his passion, his joy, and his way of making sense of the world. At first, we simply observed as he spun toys, objects, and anything he could find. But soon, we joined him. We spun wood coins, plates, heavy objects, and light ones. It was the beginning of our shared language. As toys conducted their revolutions, so too there were revolutions in his development. His first word, ‘spin’, emerged from this connection. It opened the door to ‘round’, ‘start’, ‘stop’, and eventually a cascade of words tied to the joy of watching the world whirl.

We are in Alberta, and the diagnosis opened the door for us to access support services through our provincial health care system. A play therapist came to our home and met our child on his level. On our living room floor, they worked on social and emotional skills through play to develop tools to better navigate our world. Through play, they helped him build skills like turn-taking and following sequences, all while guiding him through the orbits of his own joy.

The diagnosis granted us weekly visits from an incredible youth worker at a local not-for-profit. She helped us learn about visual schedules, communication aids, and parenting strategies to create an environment at home where our child is fully supported.

The diagnosis also provided access to Program Unit Funding (PUF), an education focused funding grant, which allowed our child to attend a local school designed for children with disabilities with a great staff to student ratio. He accessed early intervention services like speech and occupational therapy which helped provide him the tools to communicate his needs to others.

Through this process, we became keenly aware of how precarious this journey could have been without timely diagnosis. For us, paying out-of-pocket for a private assessment meant bypassing years-long waitlists and gaining access to support. However, for many families, the cost of private assessments is prohibitive. This creates a devastating waterfall effect—delaying diagnosis, caregiver education, support services, and the opportunity to champion each child’s unique way of communicating and thriving. It’s a stark reminder that equitable access to timely diagnosis and services is a necessity that should provide the foundation of any system designed to support autistic individuals and their families.

For our child who views the world through a different lens, and focuses so intensely, it transforms the mundane into something magical. When he receives support, autism for him is not a deficit, but a way of seeing the world that reveals the extraordinary.

For many autistic individuals with complex support needs, autism is a continual challenge for dignity, safety, comfort, and access to fundamental communication. Families caring for autistic individuals with complex support needs also face the challenges of caregiving without sufficient support, navigating systems to secure housing, respite care, and other essential services. Their needs are urgent and deserve attention and respect. It's crucial that support systems address both their immediate as well as their long-term well-being and autonomy.

Canada's Autism Strategy: A Vision for Change

When Canada's Autism Strategy[4] was released on September 26, 2024, I couldn't sit still. I printed out the 46-page document, sat at my kitchen table, steam pouring out a cup of coffee at 11pm, and began reading line-by-line. My hands trembled impatiently as I held my highlighter, and not just because of the caffeine. I felt giddy, jittery with excitement, as if I'd just stumbled upon the ignition switch for a fire that had always burned inside me.

As I read through its pages, I thought about all the people on the spectrum who are a part of my life and how this document, this plan, has the potential to create real, lasting change for all of them.

Among its five priority areas, three spoke directly to us as a family:

Priority area 1: screening, diagnosis and services;
Priority area 4: public awareness and acceptance; and
Priority area 5: tools and resources.

They align with the hopes we hold and the dreams we envision for a more inclusive world.

Priority area 1: Screening, Diagnosis, and Services

For our family, the diagnosis was the turning point—it was the reason we could have play therapy sessions on our living room floor. Paying for a private assessment bypassed the waitlists of the public system and gave us the key to accessing support services. However, the stark reality remains: many families and individuals face significant delays and barriers.

There is also inconsistency across diagnostic systems. Families and individuals in one province may face dramatically different timelines and standards compared to others. Some may be told to wait years, while others are directed to long, fragmented processes with no

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[4] https://www.canada.ca/en/public-health/services/publications/diseases-conditions/canada-autism-strategy.html

clear path forward. The diagnosis, which should be a bridge to support, often becomes a barrier in itself.

We're glad to see that Canada's Autism Strategy recognizes these systemic failures and offers a vision for change. Its focus on creating consistent, equitable national standards for screening and diagnosis, reducing wait times, and increasing capacity in the healthcare system addresses the very challenges we witnessed. For families like ours, this priority represents hope: hope that every autistic individual will be supported as early as possible to thrive as their authentic selves.

Priority area 4: Public Awareness and Acceptance

There is a unique kind of heartbreak that comes with seeing your child repeatedly misunderstood by the world. But for every moment like that, there are a hundred moments of wonder and joy seen through their eyes. My child's love of spinning is a gift, and it has recently grown into a focused interest for circuits and systems, for understanding how the world moves and works.

The Strategy's commitment to public awareness campaigns gives us hope for a future where our society goes beyond tolerating differences to cherishing and celebrating them. I believe in creating a culture of belonging, where every autistic individual feels seen, respected, and loved for who they are.

Priority area 5: Tools and Resources

When we started this journey, it felt like piloting a rocket-ship through uncharted space. We had no map, no clear destination, and no guide to help us navigate the complexities of his unique universe. Each discovery, whether it be a resource or a strategy for managing sensory overload, felt like finding a star in the vast expanse of the unknown, illuminating just enough to move forward. Every step required trial, error, and relentless determination.

The Tools and Resources priority of Canada's Autism Strategy promises to change this for families like ours. It aims to build a shared map for every parent, caregiver, and autistic individual, equipping them with evidence-based, accessible, and culturally relevant tools. With this, families and autistic individuals can chart their course with purpose and know they are not alone in their mission.

Our journey is only a small part of a vast and diverse spectrum of experiences, and every story in this community is unique and equally valuable. Listening to autistic individuals and self-advocates has shown me the importance of removing barriers to uplift and support the autistic community.

The release of Canada's Autism Strategy offers hope. It's a promise—a fragile yet powerful one. For my family, it is a promise that the love we have—the fierce, unyielding love that pushes us to advocate, to learn, and to fight—can create real, lasting change.

The stakes are too high, the love too deep, and the future of every autistic Canadian too important for anything less.

And I believe it begins with a diagnosis.

If you'd like to read the Canada Autism Strategy, please visit:
https://www.canada.ca/en/public-health/services/publications/diseases-conditions/canada-autism-strategy.html

Poem and Art by Emi Linds

extraordinary

dream on, little one
the world is loud
but your dreams are louder
let them hold on
to what they know
as you
forge the extraordinary

CANADIAN JOURNAL OF AUTISM EQUITY
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The Curious Intersectionality of Being an Autistic Chinese Canadian

La curieuse intersectionnalité d'une Sino-Canadienne autiste

Joy Lu[1]

Abstract

In this piece, I aim to explore the complex intersectionality of being both autistic and Chinese Canadian, a topic that is rarely discussed. As someone who is multiply marginalized, my cultural background and traditional Chinese upbringing played a significant role in delaying my autism diagnosis until adulthood. I want to shed light on the unique challenges East Asians face in relation to autism, especially since, despite Canada's rich diversity and large Asian population, autistic Asians remain significantly underrepresented and underdiagnosed. By sharing my personal journey, I hope to bridge that gap. The narrative begins with a personal reflection on my past misunderstandings about autism and how those misconceptions were shaped by my cultural context. It then delves into a broader analysis of why autism awareness is generally lacking in Chinese communities. Finally, I will demonstrate how I've taken on the role of advocating for greater autism awareness, particularly within these communities, while striving to educate others. Through my story, I aim not only to raise awareness but also to foster a deeper understanding and acceptance of autism, helping to create a more inclusive and supportive environment for people of all cultural backgrounds.

Keywords

Chinese Canadian, Chinese autistic, late diagnosis, autistic self-advocate, intersectionality

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Resumé

Dans cet article, je souhaite explorer l'intersectionnalité complexe entre le fait d'être à la fois autiste et Canadienne d'origine chinoise, un sujet qui est rarement abordé. En tant que personne marginalisée de plusieurs façons, j'ai vu le rôle important que mes origines culturelles et mon éducation chinoise traditionnelle ont joué dans le retardement de mon diagnostic d'autisme jusqu'à l'âge adulte. Je souhaite faire la lumière sur les défis uniques auxquels sont confrontés les Asiatiques de l'Est en matière d'autisme, d'autant plus qu'en dépit de la riche diversité du Canada et de son importante population asiatique, les Asiatiques autistes restent largement sous-représenté·es et sous-diagnostiqué·es. En partageant mon parcours personnel, j'espère combler cette lacune. Mon récit commence par une réflexion personnelle sur les malentendus que j'ai vécus par le passé au sujet de l'autisme et sur la manière dont ces malentendus ont été façonnés par mon contexte culturel. Je propose ensuite une analyse plus large des raisons pour lesquelles la sensibilisation à l'autisme est généralement insuffisante dans les communautés chinoises. Enfin, je montre comment j'ai assumé le rôle de militante pour une plus grande sensibilisation à l'autisme, en particulier au sein de ces communautés, tout en m'efforçant d'éduquer les autres. À travers mon histoire, je vise non seulement à sensibiliser, mais aussi à favoriser une meilleure compréhension et acceptation de l'autisme, en aidant à créer un environnement plus inclusif et plus favorable pour les personnes de toutes origines culturelles.

Mots-clés

Canadien d'origine chinoise, autiste d'origine chinoise, diagnostic tardif, militant pour l'autisme, intersectionnalité

A recent study shows that nearly 80% of autistic females are undiagnosed as of age 18 (McCrossin, 2022). And I am included in that 80%. I do not want to talk about late diagnosis per se, because there are already so many amazing self-advocates out there talking about their experiences of being late diagnosed, and the consequences of growing up with unrecognised autistic traits. Rather, I want to talk about being an autistic Chinese Canadian, and its impact on getting diagnosed late, how Chinese autistic people are often unrepresented within autistic communities, and the lack of autism awareness within Chinese communities.

I stand at an interesting (but rarely talked about) intersection of being an autistic person who is active in the online autism community, and being a Chinese person whose racial and cultural community is very often ignorant about autism.

As a Chinese Canadian, I was ignorant about autism, and so were my parents

I first heard the word ‘autism’ when I was 18 years old. I didn’t know anything about what being autistic meant (even though, unbeknownst to me, I had an entire 18 years of lived experience of being autistic) because I had never encountered the word or concept before. Interestingly, the person who introduced me to autism was an autistic classmate with Chinese heritage, someone who was talkative, very extroverted, and a very talented artist.

We were working on a group art project together during the winter session at Rhode Island School of Design (located in Providence, Rhode Island, USA), and he said, “I have autism”. I asked him what that was because I had never heard of that word before. He said 自闭症, which is the Chinese word for autism. I remember being surprised, not believing what he had just said. And then I replied, “Oh so you’ve gotten better now”. He told me, patiently, that there is no “getting better” with being autistic. Rather he had learned skills to manage it better. For a while, I simply could not believe him, even though I was undeniably very interested in the topic. This disbelief stemmed from the fact that, based on my initial understanding of autism, I felt like *I* was the one who fit the “autism” description better. Let me explain.

I was born in Canada, but moved to China with my parents when I was around five. I usually tell people that I was raised bilingual, and even though that is true, that is not the whole picture. During my middle and high school years, I went to a school with a British educational system where everything was taught in English, and everyone communicated in English. So naturally my English would be at the ‘native speaking’ level. But there is a caveat: the school was in China, and within and without the school, culturally speaking, I was mostly Chinese. My way of thinking, my scope of knowledge, my values and worldview, my ignorance and biases, were all shaped by the Chinese culture around me. In Chinese culture, people didn’t talk about autism, neurodivergence, or mental health-related topics at all. So, in my first 18 years of life, I had never heard of the word ‘autism’.

I was, however, sure that I knew what the Chinese term for autism meant, even when I really did not. Chinese is different from English as a language system. In Chinese language, each character has an apparent meaning already, and a word or phrase is deciphered by connecting the meanings of the single characters together. This means that while many Chinese people (and the 18-year-old me) might not know what autism is, when they hear or read the Chinese term for autism, they would understand the literal meaning of the characters, and thus infer or assume that the condition is exactly as it is described.

The Chinese name for autism has two versions, and one of them is 自闭症, meaning ‘self-enclosure disease’. The other name is 孤独症, meaning ‘the lonely disease’. So naturally, people would often think that autism equals being shy or very quiet, and the autistic person is either doing it on purpose or it is a disease that can be cured, since it is ‘self-enclosure disease’. People might otherwise think that the autistic person was neglected or was not exposed to enough friendship or parental care, since it is ‘the lonely disease’.

Now you might understand why, the 18-year-old me would think that the autistic classmate was not autistic at all: he was loud, passionate, and had a big personality. He was everything that autism was not – or so I thought. That is also why I thought that even *I* appeared more ‘autistic’ than he did: I have always been very quiet, introverted, and reserved, and I was aware that I came across as quite ‘closed off’ and ‘strange’.

I was lucky enough to have the resources and opportunities to learn about what autism actually was, and how it can exhibit in different individuals. I was also (somewhat by chance) diagnosed as autistic as a young adult, a few years after hearing the word “autism” for the first time.

It was not my fault that I was ignorant about autism

Even though objectively speaking, my autism diagnosis would be considered a ‘late’ by many, I think that taking cultural factors into account, my diagnosis is actually quite early. Because I would imagine that it is quite hard to be diagnosed with something that you do not know anything about, including the symptoms and traits. Chinese people not only do not talk about neurodiversity and mental health issues, they also do not tend to go to hospitals for those issues, even when they are in fact suffering greatly from something. This is due to the deep-rooted sense of shame related to going to hospitals and admitting that you have an illness or abnormality. This is not only true for Chinese people living in China, but also for Chinese Canadians (and Chinese people who live in other countries, especially newer immigrants). This is a cultural phenomenon, rather than a geographical issue.

The ethnically Chinese autistic people who I know, were all diagnosed when they had moved to English-speaking countries, or their parents were earlier immigrants to English-speaking countries. Their values are more aligned with Western culture than Chinese culture. They have somewhat successfully assimilated into the local communities instead of staying within the Chinese communities, so they could be exposed to information and resources about autism.

However, I think Chinese people, including Chinese Canadians, are severely underdiagnosed when it comes to autism. I am not solely blaming the Chinese communities for this. I also believe the medical field and self-advocacy groups should do better to address this issue as well.

As a Chinese Canadian, I do not see myself being represented in the autism community—whether it's social media, mass media, films, discussions, or autism groups. In fact, I do not see a whole lot of conversations around Chinese autistic people at all. Partly, it is because Chinese autistic voices are indeed rarer, and also because Chinese people, in general, are less likely to actively speak up given their cultural habits (especially about "shameful" topics such as autism). Also, it is possible that most people within the autistic community do not really think about Chinese autistics, because we get very little representation overall. People say that we need to uplift and listen to racially diverse autistic voices, but they tend to forget that Chinese, or even East Asian autistics exist. People say that we need to listen to Black and Brown voices, but what about Chinese voices?

Autistic people complain that a lot of media portrayals of autistic individuals often fit the stereotype of a lower support needs white male, who often speaks in a robotic tone and lacks empathy. Some well-known characters who fit this stereotype include Shaun Murphy from *The Good Doctor (2017)*, Sam Gardner from *Atypical (2017)*, and Sheldon Cooper from *The Big Bang Theory (2007)*. I have come across a lot of commentary online, especially from medium-to high support needs autistic individuals and BIPOC autistics, pointing out that these characters reinforce a somewhat one-dimensional and biased portrayal of autism. I am sure autistic people who fit the stereotype exist, and I can also understand the excitement when films and TV shows finally feature female and non-binary autistic characters who are more talkative, extroverted, and empathetic. There are also occasional portrayals of autistic people of colour, such as in the Pixar short film *Loop (Burke et al. & Milsom, 2020)*, although most autistic representations in mass media are white. This is still great, because we are seeing a real transition and progress happening regarding autistic representations. But what about Chinese autistic people? Or even East Asian autistic people in general? We are also autistic—late-diagnosed, early-diagnosed, or undiagnosed—we are still part of the autistic community. Yet we do not exist in films or discussions about autism. We are even quite invisible at in-person autism events.

This racial bias and lack of racial representation within the autistic community run so deep, that I sometimes feel a disconnect between my cultural/ethnic identity and my autistic identity. Sometimes when I look at myself in the mirror, and see a Chinese girl in her 20s, with bespectacled deep brown eyes and shoulder-length deep brown hair, I would think to myself: “Huh. How can someone who looks like this be autistic? An average-looking

Chinese girl with average height and average body weight, with a not-so-average brain. Is that even possible? No wonder I got diagnosed so late."

It is just a vicious cycle: Chinese people have a very limited understanding of autism. There are no Chinese autistic representations in the media, medical field and advocacy groups do not include Chinese autistic voices. Thus, it becomes even more unlikely for Chinese people to be educated about autism. This leads to severe underdiagnosis, misdiagnosis, and late diagnosis for Chinese autistics.

Now I'm no longer ignorant, I want to help educate ignorant people

I wanted to break the cycle, even just a tiny bit (because how much can a single person accomplish by themselves anyway?). So, I created an Instagram account, under the name *"The Auti Anthology,"* that talks solely about the intersectionality of being a Chinese Canadian autistic person. My account, to my knowledge, is the first and currently only account ever on Instagram that posts entirely about experiences and insights of being autistic and being Chinese at the same time. I talk in-depth about my lived experiences, as well as first-hand and second-hand research I do in my daily life.

I also write about how Chinese people around me, including family friends and neighbours, react to my autism diagnosis. Some reactions were more positive than others, but all the Chinese people were very ignorant about this topic prior to my explanation, which is not really their fault. Some of them did say some very shockingly harmful and perhaps hurtful things about autism, autistic people, and autism diagnosis. Which again says a lot about the general lack of awareness of autism within Chinese communities. My Chinese neighbour in Canada said that "Western doctors are all crazy! They randomly give out diagnoses to people. Autism is not a real thing!” Well, okay, I guess she had just discredited the entire Western medical field, as well as an entire autistic community.

Apart from Instagram, I am also active on a Chinese social media platform called 小红书 (which is basically the Chinese equivalent of Instagram). Autistic self-advocates on this platform are rare, and often divided, with rampant Aspie Supremacy and outdated information and sometimes questionable intentions. Almost all of them are late-diagnosed, and many of them are filled with resentment and anger from being undiagnosed and unsupported for years or even decades.

I am not an angry person, in-person or online. I am just a quiet Chinese Canadian autistic girl, who is bilingual and wants to spread true autism awareness from the perspective of an actually autistic individual. So, I make posts that differ from the ones I post on Instagram: I introduce the more up-to-date information about autism, recommend books for the newly diagnosed, and explain what the autism community and general awareness are like in the English-speaking world.

Even though self-advocates are rare, there are so many parents of autistic children (living in China, Canada, the US, the UK, and around the world) active on Chinese social media, desperately trying to find cures for their newly diagnosed autistic children. Many of them have never heard of the word “autism”, and do not know a single autistic person, and unfortunately many assume that autistic people are not even capable of forming thoughts or ideas. And yes, this includes parents who have already immigrated to Western countries including Canada. The parents think that they have a demon as a child. They are lost, angry, and very much hopeless. In a society/community in which autism is seen as a terminal illness, the parents cannot see a single speck of hope for their children, and the diagnosis came heavier than a death sentence. The parents cannot see any representation of happy autistic people, let alone autistic people who can go to universities, live independently, have jobs, have families, and have a life. (This is a testament to the lack of autism awareness in some communities, so yes, autism awareness is still very much needed. Autism acceptance is a pure luxury in some cultures) Their anxiety and desperation build up, hurting both them and their autistic children. This is another vicious cycle. Another thing that I wanted to do something about.

I leave comments under online posts made by parents of autistic children (often complaining about having an autistic child or expressing extreme desperation after receiving a new diagnosis), and I tell them my story. I tell them about how I was a withdrawn child who did not interact with other children, that I went undiagnosed for many years, and that with support I could go to the best design school in the US and the world's premiere art university for my masters, that I can now make friends on my terms, that I can handle some freelance design jobs, that I grew up and learnt new skills and have accomplished things that no one dared to imagine that I could. I tell them nothing is impossible, that a diagnosis is just a diagnosis, that this is the start of a unique but nonetheless hopeful journey, and that they should learn from their children and not punish autistic people for being autistic. I tell them that I, just like anyone in this world, have limitations, but I, also just like anyone in this world, can mature and change.

Whether the parents listen or not, whether they thank me or attack me, it’s none of my business. I have done my part, and I leave the rest to them. There is only so much a person can do, and I am not, nor should I be, omnipotent.

I also leave comments under online posts made by people who are questioning if they are autistic, and wondering if they should be assessed. I also tell them my story, but from a different angle. I tell them in detail about my autistic traits through the years, I tell them how gratifying it was to find an autistic community, and I tell them the accommodations I could access after receiving a diagnosis. I tell them that they are not faulty, they do not have an illness, that there is an entire community made of people just like us. I tell them that I understand that it's extra hard in China, that I recognise the difficulty of not having supportive parents, and that I still encourage learning more about yourself regardless.

I tell all of them that, being autistic and being Chinese at the same time, is a truly odd experience, no matter where you live. I also tell all of them that, even though Chinese communities are currently quite ignorant about autism and autistic people, things will change, for the better. Things will be better for autistic Chinese people, no matter where they live, because the world learns, gradually and slowly, that an autism diagnosis is in fact not a death sentence, but an opportunity to embrace differences. Even though Chinese autistic voices are rare right now, we are still speaking, still writing, still contributing, still actively fighting for a future in which we can all be heard, be accepted, and be truly included.

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

The Bastard

Le bâtard

W. Roberts[1]

Abstract

This poem reflects on my journey as an undiagnosed Autism Spectrum Disorder (ASD)/Attention Deficit Hyperactivity Disorder (ADHD) foster child growing up in rural Newfoundland. It highlights the abusive and neglectful developmental years and how that lack of guidance drove me to a directionless life, regardless of the paths I tried to walk.

It attempts to highlight the paths I have taken, the frustrations felt, the mistakes made, and the meeting of my wife. I am still "licking old wounds" in her shade.

Life has been incredibly complex due to the multitude of masks I was forced to wear in order to survive, alone, without any evidence as to who, or what I am. I still do not fit, but at least I now know why. That's a great starting point.

Keywords

Autism, identity, abandonment, neglect, self-discovery

Résumé

Ce poème reflète mon parcours d'enfant non diagnostiqué ayant un trouble du spectre de l'autisme (TSA) et un trouble déficitaire de l'attention avec hyperactivité (TDAH) et placé en famille d'accueil dans la campagne de Terre-Neuve. Il met en lumière les années de développement marquées par les abus et la négligence et montre comment ce manque d'orientation m'a conduit à une vie sans direction, quels que soient les chemins que j'essayais de prendre.

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Il tente de mettre en lumière les chemins que j’ai empruntés, les frustrations ressenties, les erreurs commises et la rencontre avec ma femme. Je suis encore en train de « panser de vieilles blessures » à son ombre.

La vie a été incroyablement complexe en raison de la multitude de masques que j’ai été forcé de porter pour survivre, seul, sans aucune preuve de qui, ou de ce que je suis. Je ne suis toujours pas à ma place, mais au moins je sais maintenant pourquoi. C’est un bon point de départ.

Mots-clés
Autisme, identité, abandon, négligence, découverte de soi

Mandated facades we are compelled to portray;
Cloaking of self to stumble through each trying day.
Crafted personas hastily met with decay,
Our crossed wires and blown fuses on spotlit display.

A young woman gave birth in a cold, tattered bed;
With no golden rings, she was unloved and unwed.
Frantic to rid her womb of its black, murky dread,
Afforded no comforts—a boy-bastard instead.

Judged unworthy without a hint of a trial,
The now-mother proclaims she was “Never with child!”
The bastard is reduced to a neglected file
And remanded to beasts with tastes hellishly vile.

The guardian beasts danced a macabre ballet:
Crooked teeth and greased faces, clothes stained and frayed.
Histories of barbarities openly displayed,
Eyes creased with hatred with an innocence to flay.

At the ripe age of four, the bastard started school,
An unspoken promise of solace from the cruel.
But reprieve was a lie, again proven a fool;
Kids banned him from the bus, no adult to overrule.

The events of the times the young bastard endured:
The stripping and tearing, being hunted and lured.
On full display, yet not a concerned head was turned;
All deaf and mute with line of sight oddly obscured.

The bastard chameleon begins its foray
From verminous nest to critical light of day.
Incessant confusion by the games others played,
Dimpled cheeks his first mask peacocked in display.

Those meant to befriend him, to mentor and inform,
Instead offered their mockery, insults, and scorn.
Gazing down flawless noses, his presence they mourned,
Oft echoing the question of why he was born.

The bastard’s stunted mind now a mottled driftwood,
Twisted, gnarled, wormed, of little use and no good.
Each word he uttered was harshly misunderstood;
His scant rules came from books, not adults as they should.

The seeded storm yet caged on its predestined path,
A swelling northern sea oft threatening its wrath.
His potential moot: criminal or polymath,
Sticks and stones for his bones and names just for a laugh.

Anarchy and the bastard became steadfast friends;
He became the bastard they saw, wanted, and penned.
Curtains thrown open from staged pretenses descend,
The prophesied delinquent with lives to upend.

Nineteen years alive yet still twenty years behind,
The Crown’s door slammed shut, the bastard run out of time.
No money for the beasts, and as if by design,
Discarded again and given nothing in kind.

The now seething, writhing, and cascading rage
Finds a place to call home guarding a dive bar stage.
His fury and despair in a silk-ribbon cage
Is unfocused, untamed, unwanted, and unsage.

Elaborate masks are created and displayed,
A tickle-trunk of self; the roles clumsily played.
To an empty house, the bastard foolishly brayed
Everything to no one; such was the life he'd made.

Four times a student and a thousand times an ass,
He had three graduations, twice top of the class.
Awards bearing his name, plaques of shiny faux brass,
Nothing learned, nothing gained, yet another impasse.

His jobs and relationships were treated as one,
Elaborate riddles in some uncommon tongue.
His failures a sitcom in a looping rerun,
A trail of burnt bridges left on a map undone.

All of the bastard's past deeds a compacting truth,
His shame, guilt, and remorse rapidly taking root.
Cheek held to splintered floorboards by time's heavy boot,
All of value outcast, withdrawal absolute.

Yet pressure and time are curious in effect;
Seismic shifts will divide but will also connect.
With oft-leaded burdens and some time to reflect,
The bastard has a choice: be crushed or resurrect.

Foundational cracks creep up the bastard's deceit;
Unmortared walls collapse, sloughing off in defeat.
Shielded eyes squinting in the powdered concrete,
Ozymandias woken from his wretched sleep.

A figure steps forward, a face he somehow knew;
Eyes of bright sapphire, smile-crinkled corners subdue.
A soft hand on a hard shoulder offers renew
With three enigmatic words: “I. Accept. You.”

The old bastard looked up with a skeptical eye
To the refuge promised; his skeletons scream “Lie!”
Pushing aside the fallacious, stale battle cry,
He accepts the hand up with a smile brazenly wry.

The bastard's protector, standing firm by his side,
An essence yet tainted, having no darkness to hide.
Promised sanctuary real; without trick or lie,
Old wounds licked in her shade; lifelong bindings untied.

The long-sought answers to questions asked by no one,
Forty years in a desert yet soaked to the bone.
Five hundred dollars to make a bastard undone:
ADHD – Severe, ASD Level One.

The ever-seething, writhing, and cascading rage,
All the fury and despair from a long-passed age,
Is cast out; the bastard no longer bearing its cage.
He is now focused, now tamed, now wanted, now sage.

Refuse the facades we are compelled to portray;
Lose the personas affording endless dismay.
Our wiring is sound, though we trip breakers some days;
You only have one self; put it on proud display.

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

April 2025 Volume 5 Issue 1

The Vestiges of Disability

Les vestiges du handicap

Jan A. Wozniak[1,2]

Abstract

This collection of poetry consists of two parts, marking a chronological transition from disability to empowerment. The first, 'Big Yellow Buses' and 'The Dead of Winter', address the consequences of growing up without an autism diagnosis, including themes of bullying, isolation, and despair. The second, 'Autistic Bunker' and 'Atlas Unbound', focus on life after receiving a diagnosis, including its effect on authenticity, purpose, and change. The temporal progression from the confusion and hardship of undiagnosed childhood and adolescence to the self-awareness and community integration of adulthood indicates a profound transformation in personal identity. By evoking the visceral and cognitive dimensions of autistic experiences across lifespan development, these poems reiterate the importance of awareness, acceptance, and community connectedness, which remain tantamount to supporting the health and wellbeing of autistic individuals currently and in the years to come.

Keywords

Mental health, sensory differences, autistic needs, autism awareness, progress

Resumé

Cette œuvre poétique se compose de quatre poèmes en deux parties, marquant une transition chronologique entre le handicap et l'autonomisation. La première partie, comprenant « Big Yellow Buses » et « The Dead of Winter », aborde les conséquences d'une enfance sans diagnostic

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d'autisme, notamment les thèmes de l'intimidation, de l'isolement et du désespoir. La deuxième, constituée des poèmes « Autistic Bunker » et « Atlas Unbound », se concentre sur la vie après avoir reçu un diagnostic, y compris son effet sur l'authenticité, la raison d'être et le changement. La progression temporelle entre la confusion et les difficultés de l'enfance et de l'adolescence non diagnostiquées et la prise de conscience de soi et l'intégration dans la communauté à l'âge adulte indique une transformation profonde de l'identité personnelle. En évoquant les dimensions viscérales et cognitives des expériences autistiques tout au long de la vie, ces poèmes réitèrent l'importance de la prise de conscience, de l'acceptation et des liens avec la communauté, qui restent essentiels pour soutenir la santé et le bien-être des personnes autistes aujourd'hui et dans les années à venir.

Mots-clés
Santé mentale, différences sensorielles, besoins des autistes, sensibilisation à l'autisme, progrès

Big Yellow Buses

Freezing up, catatonic like a scarecrow–
feeling not quite human today (being a
verbal punching bag for bullies & all).
In the rural Southwest, I take my beatings
politely; the bus ride, my 5-year stretch
in a yellow prison on wheels. Momentarily
free, I'd walk my driveway in silence, then
open the front door of my home & begin
to scream (my lovely after school routine).

The Dead of Winter

Dear Son, your mother worries when she sees that melancholic dog

come running. Seasonal rotation, the dead of winter hits hard,

fingers flick the I.V. drip as the hemlock sets in. Your apartment

in the upper Northwest, a barren tundra – sparse, frozen, unforgiving;

shades drawn, mail stacking by the door, empties stand like monuments

to one's enduring lament. The bottles clink by noon, ambient sounds

emanating from within, but regrettably, still no signs of the boy I once

knew. He's buried deep in the permafrost and we can't seem to get through.

Autistic Bunker

My space is a fortress of special interests—

science books and exercise equipment fortify the perimeter,

while blackout curtains repel the intrusive glare of daylight's assault.

A symphony of white noise emanates from the machine next to me,

as the city explodes in a crescendo of screams, trumpeting horns,

and round-the-clock emergency sirens just outside my window.

Hey-ho! Light and sound, the yin and yang of my sensory issues

keep me hypervigilant from oh-six hundred to twenty-two hundred

each day, holding my position as a hermit, a recluse, an agoraphobic

soul, with a vitamin D deficiency that would panic most physicians.

My partner (sardonically) refers to it as "a cave," never fully appreciating

this soldier's militaristic discipline, having to wade through the social tripwires

and sensory ambushes of the neurotypical jungle. Amidst the fray,

I hunker down behind the walls of my carefully constructed bunker,

finding momentary peace amidst all the world's calamity.

Atlas Unbound

My journey, an odyssey, circumnavigating a world not designed for inclusivity, where
Inaccessibility manifests as towering mountains, discrimination, a cunning predator, always lurking in the tall grass, calls for Herculean effort and Sisyphean persistence to endure.
I have borne the weight, unknowingly, disability configured into perceived burdensomeness, so many years spent trudging alone through the muddy foothills of indifference, carrying internalized shame and guilt like a colossal stone on my shoulders.
In a culture that measures individual worth by stride and speed, my journey, like Hephaestus',[3] unfolds like an intricate dance of invisible barriers as the rhythm of expectations clashes against the melody of my inherent neurodiversity.
I look upon the Scylla and Charybdis[4] of disabilities: on one side, the long tentacles of ableism bear down with dehumanizing stereotypes, making disclosure a negative experience; on the other, marginalization, a relentless, vacuous force, prevents escape from the gravitational pull of socioeconomic stressors.
However, with strength in numbers, my community found, I refuse the Siren call luring disabled minds and bodies to shipwreck amidst broken systems, institutions, and policies while families tiptoe the poverty line from here till eternity, their faith diminishing into dust each day.
For I am Atlas unbound, not burdened by negative conceptions of disability, but empowered by resilience to strive for something more, knowing the path to an inclusive and equitable world is always within reach, my eyes now fixate on the infinite horizon of progress.

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[3] Hephaestus is an Olympian God in Greek mythology known for having a disability.

[4] Two ancient sea monsters encountered by Odysseus in Homer's *Odyssey.* Being caught between the two means you're confronted with two unfavourable options or choices in a particular situation, leaving you to feel stuck or hopeless.

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Autism-Informed Mindfulness: Collaborative Practitioner Experiences

La pleine conscience au service de l'autisme : expériences collaboratives des praticiens

Jan A. Wozniak[1,2], Sue Hutton[1,3]

Abstract

Within Canada, there remains a continuing need for neurodiversity-affirming and community-informed programs and interventions for autistic adults. Over the past year, we—a late-diagnosed autistic adult practicing mindfulness and a mindfulness teacher interested in autism with extensive involvement in the autism community—have co-delivered mindfulness sessions to autistic adults, including self-diagnosed and formally diagnosed persons, using a synchronous virtual format. The manualized intervention outlined in this paper was initially designed and implemented by Lunsky and colleagues (2022). In this experiential commentary, we reflect on our experiences delivering this program and why collaborative partnerships like this are important for those intending to work with autistic individuals in clinical and therapeutic settings. Specifically, we highlight the tools and strategies we implemented within our formal and informal mindfulness practices to ensure that participants had their social and sensory needs met throughout the duration of our six-week program. Additionally, we discuss what we learned while co-facilitating autism-informed mindfulness and our recommendations for fellow practitioners moving forward.

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Keywords
Autism-informed mindfulness, virtual programming, co-facilitation, collaboration, neurodiversity-affirming spaces

Resumé

Au Canada, il existe un besoin constant de programmes et d'interventions pour les adultes autistes qui tiennent compte de la neurodiversité et de la communauté. Au cours de l'année écoulée, nous — un adulte autiste diagnostiqué tardivement qui pratique la pleine conscience et une enseignante de la pleine conscience qui s'intéresse à l'autisme et qui est très impliqué dans la communauté des autistes — avons co-dirigé des séances de pleine conscience à des adultes autistes, y compris des personnes auto-diagnostiquées et des personnes ayant reçu un diagnostic formel, en utilisant un format virtuel synchrone. L'intervention guidée décrite dans cet article a été initialement conçue et mise en œuvre par Lunsky et ses collègues (2022). Dans ce commentaire expérimental, nous réfléchissons à notre expérience de la mise en œuvre de ce programme et aux raisons pour lesquelles des partenariats de collaboration comme celui-ci sont importants pour ceux qui ont l'intention de travailler avec des personnes autistes dans des contextes cliniques et thérapeutiques. Plus précisément, nous soulignons les outils et les stratégies que nous avons mis en œuvre dans le cadre de nos pratiques formelles et informelles de pleine conscience pour veiller à ce que les besoins sociaux et sensoriels des participant·es soient satisfaits pendant toute la durée de notre programme de six semaines. En outre, nous discutons de ce que nous avons appris en coanimant la pleine conscience adaptée à l'autisme et de nos recommandations à l'intention des autres praticien·nes pour l'avenir.

Mots-clés
Pleine conscience et autisme, programmation virtuelle, cofacilitation, collaboration, espaces respectueux de la neurodiversité

Autism Advisor Background

Mindfulness has been a core practice since my late teenage years. It provided me with the tools to navigate adversity, offering clarity and resilience in moments of uncertainty. Receiving my autism diagnosis was a profound turning point—an ‘a-ha moment’ that allowed me to piece together my past, reframe my experiences, and better understand myself. With that said, autistic individuals frequently navigate inhospitable environments, face challenging social encounters, experience sensory overload, and struggle with confusion and uncertainty as they move through a foreboding neurotypical world. Learning to get through life without acceptance and support felt insurmountable at times, with the common ablest attitudes (at least in my life) being ‘sink or swim’ and ‘grin and bear it.’ Reading Vedic, Buddhist, and Taoist texts provided a much-needed purview into mindfulness and acceptance, helping me to let go and work through many of the problematic thoughts, feelings, and emotions that followed me throughout my life.

When I eventually began to practice mindfulness consistently and ‘bring it off the cushion,’ I discovered a greater connection with others and the world around me. Mindfulness allowed me to welcome the unknown, step back from my thoughts, and experience life more meaningfully. Years later, I eventually had the opportunity to observe and participate in a manualized group-based virtual mindfulness program for autistic adults. A manualized program is a structured framework that provides clinicians with clear guidelines to ensure consistent and effective delivery of therapeutic interventions (Thompson-Hollands & Barlow, 2015). Cultivating self-compassion was a pivotal aspect of this journey, empowering me to embrace my autistic identity openly for the first time. Serving as a co-facilitator in this program was equally transformative, as it challenged the stigma I had previously internalized around self-disclosure in public forums. This collaborative process was iterative and dynamic, combining my lived insights as an autistic advisor and Sue's expertise as a mindfulness practitioner. By blending our perspectives, we reflected on how to utilize our strengths, share our insights, identify potential barriers, and adapt the program to meet the needs of neurodivergent meditators effectively.

Mindfulness Teacher and Clinical Social Worker Background

I co-lead mindfulness groups with and for autistic adults as a clinical social worker and mindfulness teacher. A core value in my work is challenging the ableism traditionally found in mindfulness programs. I have studied and practiced mindfulness in traditional settings since 1985, having completed professional training with Jon Kabat-Zinn, founder of Mindfulness-Based Stress Reduction (MBSR). I have also worked in various roles supporting people with developmental disabilities in community settings and advocacy and rights work for over thirty years. Since my initiation into mindfulness practices, I have taught in diverse settings, including community programs, educational institutions, hospitals, cancer centres, and prisons. Throughout the past 40 years, encompassing innumerable experiences, interactions, and contexts, I believe my work with autistic adults and advisors in developing and delivering neurodiversity-affirming mindfulness groups has afforded the deepest insight into these practices.

Our Approach

Traditional mind-body practices, such as mindfulness, often pose challenges for autistic individuals due to their rigid structures and reliance on neurotypical norms (Hourston & Atchley, 2017; Hutton, 2020). For example, many mindfulness programs use abstract or metaphoric language that can be difficult for some autistic individuals to interpret, in turn reducing their ability to engage meaningfully with the practice (de Bruin et al., 2015; Lunsky et al., 2022). Furthermore, sensory and social preferences, such as intolerance of uncertainty or discomfort in unstructured settings (e.g., Jenkinson et al., 2020; Rodgers et al., 2017), can overwhelm autistic individuals when session lengths and formats remain rigid, especially if facilitators do not provide agendas in advance. Providing detailed descriptions of the program’s structure and each session in advance, along with offering flexible and shorter session options, can help reduce barriers and create a more accessible mindfulness experience. Similarly, differences in interoception, alexithymia, and aphantasia common among autistic individuals (King et al., 2024; Kinnaird et al., 2019; Trevisan et al., 2021) may require mindfulness instructors to move beyond conventional practices by offering diverse or multiple exercise options (Hutton, 2020).

By emphasizing adaptability and participant-centred approaches, mindfulness programs can create a more inclusive environment for neurodivergent meditators. For instance, providing reassurance that it is acceptable for specific techniques to be less effective for some individuals can alleviate pressure and encourage participants to engage with practices at their own pace and comfort level (Hutton, 2020; Lunsky et al., 2022). Additionally, virtual or hybrid learning options can help address sensory preferences and promote a sense of safety and acceptance toward neurodivergent needs (Loftus et al., 2023). Moreover, studies on virtual interventions underscore additional advantages, such as alleviating the burden of travel, reducing financial costs, and mitigating the mental and emotional strain often associated with attending in-person sessions (Westerberg et al., 2021). By addressing these barriers and emphasizing flexibility, programs can better accommodate neurodivergent meditators and support them through the initial challenges they might encounter when learning mindfulness (Hutton, 2020).

Given the scarcity of accessible resources for autistic adults, our synchronous virtual mindfulness program prioritized inclusivity and partnership (Lunsky et al., 2022). First, it was co-developed and co-facilitated with autistic advisors for autistic adults, ensuring that our practices addressed the needs and preferences of neurodivergent participants. Second, recognizing the structural and financial barriers to adult assessments, both self-diagnosed and formally diagnosed autistic adults were able to enroll in our program. Notably, we received a significant number of self-diagnosed individuals within our cohorts, reiterating the continuing need for accessible adult neurodevelopmental services across Canada. Third, by offering mindfulness in a synchronous format, we created a more communal setting where participants could connect with fellow autistic adults, unlike asynchronous practices done independently. Previous studies suggest that autistic adults find shared experiences valuable in mindfulness programs by enhancing reciprocity and social connection (e.g., Redquest et al., 2022). Fourth, with the virtual platform, participants could tune in from safe spaces (e.g., the comfort of their homes), select preferred modes of communication (e.g., speech, text-based chat, and emojis), and decide whether to be on camera during our sessions or specific practices (e.g., formal mindfulness exercises).

Co-facilitation between an autistic advisor and an experienced mindfulness practitioner created a supportive and enriching experience for all involved. The benefit of working with a mindfulness practitioner with an extensive background was the assurance it afforded when delivering the program, allowing the advisor to ease into the facilitation process while offering observational feedback and rapport-building with the participants. Tantamount to this process is *trust* in each other’s strengths and insight about mindfulness and neurodivergent perspectives. We would meet weekly outside of the group sessions to develop all materials and thoroughly plan how to make our delivery most effective. Additionally, we would debrief after our sessions, highlighting ways to improve the practices and identifying any barriers or challenges the group was experiencing.

Taking the time to discuss our delivery candidly provided an open and encouraging space for constructive feedback. Through the delivery of the groups, the voice of the autistic advisor was predominant in facilitating discussion and giving feedback to participants, while the mindfulness practitioner's role was more specifically related to teaching mindfulness skills. This division of duty effectively balanced participants during their practices and discussions. We also found that the tone of the groups was positive and supportive, thanks to the autistic voice offering warmth, encouragement, and mutual understanding throughout the sessions.

Co-delivering groups was a joyous and illuminating experience, especially the opportunity to foster a strong sense of community and connection between facilitators and participants. One of the common messages from participants was the growing need for safe, inclusive, and neurodiversity-affirming spaces. During our meetings, participants shared their lived experiences, challenges, and observations about individualizing the mindfulness tools for themselves and strategies for implementing mindfulness in daily life. Many participants referenced previous programs and services that neglected the autistic experience, which, in turn, discouraged them from attending and completing the practices. These included standardized eight-week programs offered in person or virtually, such as MBSR and mindfulness-based cognitive therapy (MBCT; Segal et al., 2002).

Some participants indicated that these programs failed to account for autism and co-occurring health and mental health challenges, such as trauma and anxiety, which could lead to overwhelming self-focused attention, sensory overload, and unpleasant thoughts, emotions, and memories from their past. Others found the length of these sessions, which typically range from 120 minutes to 150 minutes (Shapero et al., 2018), to be another significant accessibility barrier to sustainable participation and practice.

We discovered that having an autistic co-facilitator proved to be welcoming and neurodiversity-affirming for participants, validating their experiences and providing ample opportunities to listen and respond to shared experiences throughout the program. Moreover, having the autistic advisor's direct input into accessibility features in the group helped to reduce communication barriers that a non-autistic clinician may not be aware of. For example, to minimize uncertainty and potential anticipatory anxiety, we started each session with a thorough overview of the practices, reminding participants that they could stop or modify them to ensure safety and comfort. Additionally, at the beginning of the session, we provided ample opportunity for group members to discuss what worked and what did not, as well as ways to modify practices for greater effectiveness, thereby integrating principles of mutual aid within our program.

When considering an autism-informed, strength-based approach, we wanted participants to find activities and sources of pleasure that maximized authenticity and autistic joy in their mindfulness practices. We knew that with hectic schedules, the programming needed to be enjoyable and efficient during the initial weeks, especially with home practices. Prioritizing positive experiences, such as mindfully walking, swimming, cycling, being outdoors in nature, and spending time with their pets, may help participants remain motivated about incorporating mindfulness into daily life, especially as autistic individuals often find it difficult or stressful to change their routines (e.g., Gomot & Wicker, 2011). If and when participants encountered difficulties during the program, we provided opportunities to meet directly with the co-facilitators outside regular group sessions. Having both co-facilitators present during the sessions gave participants a greater recognition of autistic experiences and the support and assurance of clinical expertise.

Even though the co-facilitators guided these programs, we learned a great deal from the participants each week by engaging in constructive dialogues. In this process, we discovered that, for many, it was the first time they encountered mindfulness or psychological interventions that resonated with them and understood their unique needs. Some expressed not knowing what “calm” felt like, highlighting frequent exposure to stress, restlessness, and sympathetic dominant states, with many having to navigate the world with late and missed diagnoses. Those who received a more recent diagnosis sometimes underwent a process of personal growth by engaging with fellow autistic individuals within a group setting for the first time, which proved to be an enriching and empowering process. Specifically, many described feeling more self-compassionate about discovering they were neurodivergent and appreciative of the opportunity to learn from others with similar experiences.

Additionally, some individuals became increasingly comfortable when participating in group discussions, while others expressed a newfound desire to find connections with the autism community beyond our sessions. Between active listening and weekly reflective meetings, we continued to recognize how mindfulness can help autistic adults achieve greater self-awareness, acceptance, emotional regulation, equanimity, and social connection. Our modelling of acceptance and support of each other as co-facilitators reinforced the positive impact that meaningful collaborations can have on practices and programs involving autistic individuals.

What We Learned

The collaborative approach of autistic adults co-facilitating mindfulness groups with trained clinicians brings a richness that significantly enhances the effectiveness of the practices. The wisdom of autistic adults has transformed how we envision, practice, and teach mindfulness. Some of the most impactful ideas on making mindfulness accessible have come directly from autistic adults rather than clinicians and researchers, such as the inclusion of at-home mindfulness practices that prioritize passionate interests and interoception education to improve bodily and emotional awareness. Given that autistic adults experience various social and sensory challenges in daily life, we decided that rather than constantly trying to target these negative experiences, we would emphasize cultivating the positive parts of their day first, making mindfulness awareness easier to initiate and maintain.

For instance, when finding a daily routine to bring mindful awareness to during at-home practices, Jan suggested that participants start with something they commonly do that brings them joy, such as walking or moving outdoors and feeling the comforting sensations of the wind and sun on their faces. To make this process easier, we provided examples of joyous activities in daily life that offered simple sensory connections participants could focus on before progressing to multisensory awareness. During our sessions, we offered opportunities to discuss how participants could individualize their informal practices with these priorities in mind.

We understand that altering your mindful sensory awareness can be challenging when uncomfortable thoughts, feelings, and emotions tied to stress, anxiety, and burnout pull your focus. Mindfulness practitioners often use the phrase ‘Come to our Senses’ to encourage meditators to engage fully with their sensory experiences. We frequently incorporated this phrase into our teachings to help neurodivergent participants deepen their connection to their sensory world. For instance, some individuals who experienced anxiety or chronic pain benefitted by incorporating temperature (e.g., sitting in a warm shower) or sound (e.g., binaural beats) during mindfulness practices, helping them to overcome deterring factors such as excessive thought or negative sensations. Conversely, other participants needed to remove or adapt particular exercise components to minimize their uncomfortable sensations (e.g., drinking instead of eating during a mindfulness exercise). In doing so, they honoured their unique sensory processing needs by connecting with themselves and experimenting with sensory-seeking and sensory avoidance during their mindfulness practices.

For many neurodivergent people, sensory experiences can be overwhelming and potentially triggering (Crane et al., 2009; MacLennan et al., 2022; Scheerer et al., 2021), making it valuable for clinicians to work directly with autistic advisors to understand how to accommodate these experiential differences. If clinicians do not know what autistic meditators require, they may be unaware of the stress and disinterest that may arise during these practices. Research suggests that mindfulness programs can be more effective when they integrate sensory and social accommodations based on autistic participants’ input (Hartley et al., 2022; Lunsky et al., 2022), as rigid curricula may not always align with their diverse needs. In our experience, without careful consideration of adaptations, autistic participants can find mindfulness programs challenging to navigate and adhere to in the long term. Without consideration of neurodiversity, many clinicians who complete standard mindfulness-based training might neglect the needs of neurodivergent meditators. Therefore, it is our view that collaboration with autistic advisors and co-facilitators can play an invaluable role in developing curricula that increase the accessibility and effectiveness of mindfulness programs.

Why This Matters

The benefits of sharing insights with a formally trained mindfulness practitioner and autistic advisor who understands the complexities and nuances of the autistic experience can help address the group's needs, including compassionate understanding, reassurance, and on-the-spot support. Mindfulness is perfect for this kind of partnership as it prioritizes curiosity and acceptance about different ways of being and practicing – taking time, noticing, not judging, and being present. On the one hand, Sue has acquired clinical knowledge about autism by working within the community and extensive experience with mindfulness, but she does not have direct experience as an autistic adult. On the other hand, Jan brought this lived experience to the program, but he possesses less formal mindfulness training and teaching. Therefore, to best serve autistic adults in our mindfulness program, we had to rely on each other's knowledge and experience, making collaboration an integral component of our success. Overall, this curriculum provided a valuable purview into the benefits of cross-neurotype mindfulness programming, which, in turn, helped ensure that we honoured neurodiversity and the lived experiences of autistic meditators.

Future Directions

Drawing from our experiences co-facilitating mindfulness, we recommend teaching mindfulness in accessible ways that effectively and compassionately provide sensory and social accommodations. One helpful strategy is to ensure that an autistic advisor and a trained mindfulness teacher co-lead all mindfulness programs to enhance the accessibility, sustainability, and impact on autistic meditators. Moving forward, we hope to continue facilitating mindfulness programs together. We intend to use the knowledge gained from our joint efforts to expand the number of available peer support opportunities, creating more welcoming and community-driven spaces for neurodivergent adults. Training more autistic adults to co-deliver mindfulness groups will benefit the future of neurodivergent mindfulness practices. Lastly, with the challenges associated with autism diagnoses, including late and missed diagnoses and high costs associated with adult assessments, we also believe that programs and practitioners need to be mindful of these additional barriers by fostering greater inclusivity for both self-diagnosed and formally diagnosed autistic individuals. These efforts can help to ensure that autistic individuals, irrespective of their lived experiences and socioeconomic backgrounds, have access to resources and programming that support their quality of life and overall wellbeing.

Closing Comments

In working together to deliver mindfulness groups, autistic adults and non-autistic clinicians can co-create warm, welcoming, and impactful programs for neurodivergent individuals. To make mindfulness and similar tools accessible to all, we encourage the broader adoption of the collaborative partnership approach outlined in this paper within autism and neurodevelopmental research and practice.

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Embracing Neurodivergence: A Personal Journey

Accepter la neurodivergence : un parcours personnel

MissNatasha Connects[1]

Keywords
Neurodivergence, autism, self-discovery, authenticity, empathy, societal expectations,

individuality, resilience, self-love, community

Mots-clés
Neurodivergence, autisme, découverte de soi, authenticité, empathie, attentes sociétales,

individualité, résilience, amour de soi, communauté

Introduction

Growing up, the awareness of my neurodivergent identity was a gradual revelation, marked by moments of confusion and confrontation with societal expectations. Initially blissful in my ignorance, I became aware of my differences when I overheard my parents discussing my behavior as peculiar.

The Impact of Secrecy

This discovery was compounded by the insistence of educators and mentors to maintain secrecy about my challenges, reinforcing a stigma that painted my uniqueness as a flaw. My interactions with family, particularly the tailored gifts from my aunties that reflected their expectations rather than my interests, further highlighted my divergence from the "typical" mould. As I grappled with feelings of inadequacy and defensiveness, I realized that societal pressures often pushed me to conform to an identity not of my choosing.

Recognition of Strengths

As an adult diagnosed with autism, I began to recognize my exceptional ability to discern patterns and understand unspoken intentions—traits often overlooked in conventional narratives about neurodiversity. This unique perspective cultivated a profound sense of empathy, challenging stereotypes surrounding autism.

Embracing Authenticity

Embracing authenticity became a pivotal part of my journey, allowing me to reject societal definitions of worth and value. A late diagnosis served as a catalyst for transformation,

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[1] Independent Artist

enabling me to appreciate the power of self-acceptance and the importance of surrounding myself with supportive individuals.

The Journey of Self-Love

Through this journey, I learned that self-love and understanding my intrinsic worth were crucial to my resilience. By releasing relationships that could not embrace my true self, I fortified my commitment to authenticity.

The Neurodivergent Experience

The neurodivergent experience encompasses a rich tapestry of reading, living, listening, playing, and prayer, emphasizing joy and self-discovery. Ultimately, this journey underscores that differences do not diminish one's worth; rather, they enrich the human experience.

Building Community

Building a community of acceptance and appreciation for individuality is essential, allowing us to navigate life with resilience and authenticity.

Introduction

En grandissant, la prise de conscience de mon identité neurodivergente a été une révélation progressive, marquée par des moments de confusion et de confrontation avec les attentes de la société. D’abord béate dans mon ignorance, j’ai pris conscience de mes différences lorsque j’ai entendu mes parents parler de mon comportement comme d’une bizarrerie.

L’impact du secret

Cette découverte a été aggravée par l’insistance des éducateurs et des mentors à garder le secret sur mes difficultés, renforçant ainsi une stigmatisation qui décrivait ma singularité comme un défaut. Mes interactions avec ma famille, en particulier les cadeaux personnalisés de mes tantes qui reflétaient leurs attentes plutôt que mes intérêts, ont encore souligné ma divergence par rapport au moule « typique ». Alors que je me débattais avec des sentiments d’inadéquation et de défiance, j’ai réalisé que les pressions sociétales me poussaient souvent à me conformer à une identité que je n’avais pas choisie.

Reconnaissance des points forts

En tant qu’adulte diagnostiquée autiste, j’ai commencé à reconnaître ma capacité exceptionnelle à discerner les schémas et à comprendre les intentions non exprimées — des traits souvent négligés dans les récits conventionnels sur la neurodiversité. Cette perspective unique m’a permis de cultiver un profond sens de l’empathie et de remettre en question les stéréotypes entourant l’autisme.

Accepter l’authenticité

L’authenticité est devenue un élément essentiel de mon parcours, me permettant de rejeter les définitions sociétales de la valeur et de l’utilité. Un diagnostic tardif a servi de catalyseur à ma transformation, me permettant d’apprécier le pouvoir de l’acceptation de soi et l’importance de s’entourer de personnes qui me soutiennent.

Le voyage de l’amour de soi

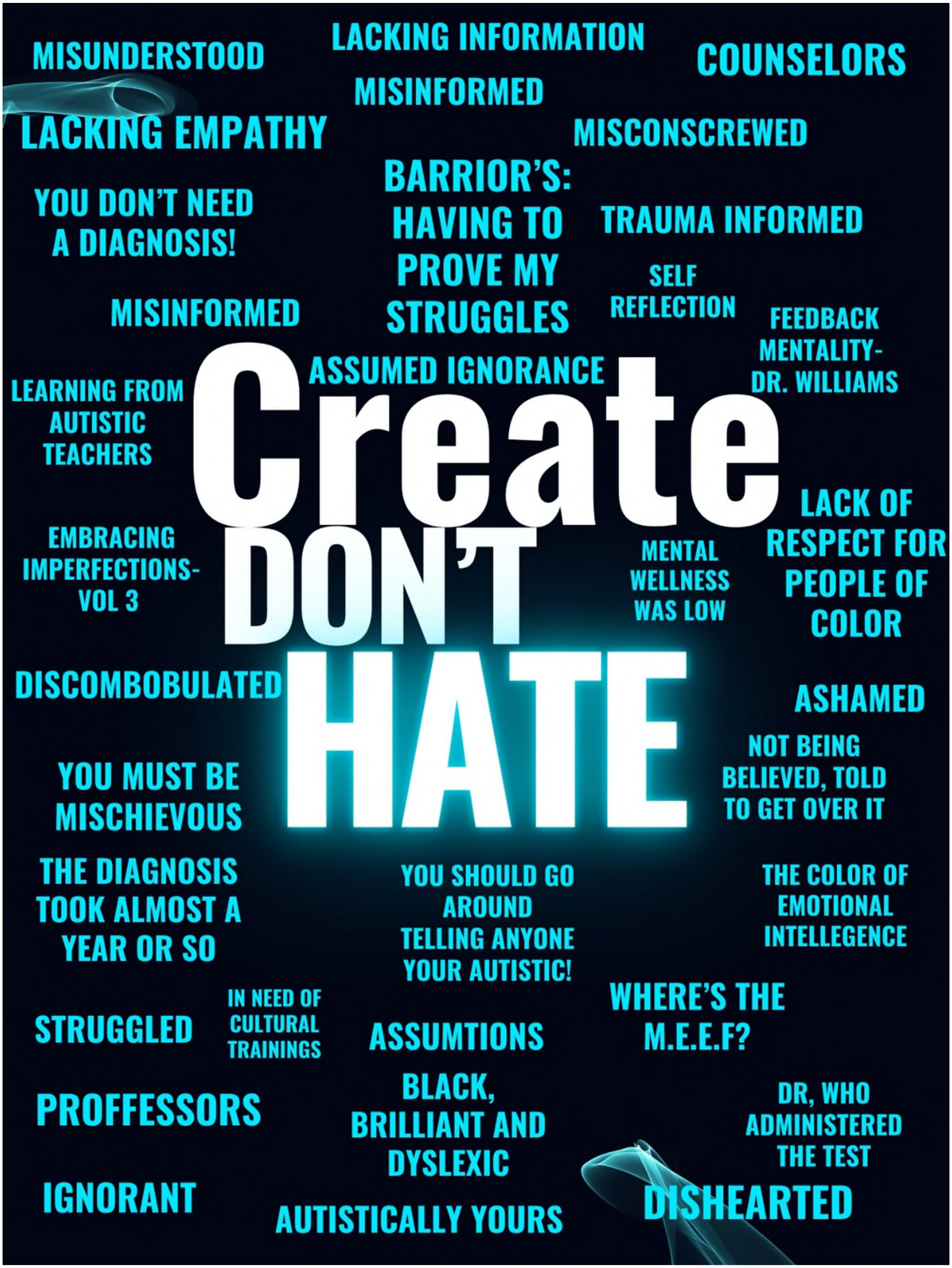
Tout au long de ce parcours, j’ai appris que l’amour de soi et la compréhension de ma valeur intrinsèque étaient essentiels à ma résilience. En mettant fin aux relations qui ne me permettaient pas de m’épanouir, j’ai renforcé mon engagement en faveur de l’authenticité.

L’expérience neurodivergente

L’expérience neurodivergente englobe une riche tapisserie de lectures, de vies, d’écoutes, de jeux et de prières, mettant l’accent sur la joie et la découverte de soi. En fin de compte, ce voyage souligne que les différences ne diminuent pas la valeur d’une personne ; au contraire, elles enrichissent l’expérience humaine.

Construire une communauté

Il est essentiel de construire une communauté d’acceptation et d’appréciation de l’individualité, qui nous permette de naviguer dans la vie avec résilience et authenticité.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THE DIAGNOSIS TOOK ALMOST A YEAR OR SO
YOU SHOULD GO AROUND TELLING ANYONE YOUR AUTISTIC!
THE COLOR OF EMOTIONAL INTELLEGENCE
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