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Foreword

Stephen Gentles, *Wilfrid Laurier University, Canada*

Janet McLaughlin, *Wilfrid Laurier University, Canada*

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Dr. Stephen Gentles



Dr. Janet McLaughlin

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

Stephen Gentles¹  and Janet McLaughlin¹

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

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

¹ Wilfrid Laurier University, Canada

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

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

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

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


We were invited to share our perspective as academics whose research has been caregiver-focused (one of us is also a parent of an Autistic child). At younger (particularly pre-teenage) ages, it is primarily parents who must advocate for their child's needs, navigating and accessing

care and services across sectors to address the ultimate parental concern of their child's current and future happiness. Sometimes, such as when independent communication and living is never established, this advocacy and support role can continue throughout the lifespan. Therefore, as we do more to amplify the voices of Autistic people, we believe that parents' perspectives can also be a relevant part of equity-related conversations.

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

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

ORCID iD

Stephen J Gentles  <https://orcid.org/0000-0003-2004-1451>