

## COMMENTARY

## Tourette syndrome and Tourettic persons: Internationalizing neurodiversity across diagnostic borders

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Autistic activists have long worked to influence autism service provision and research through the lens of neurodiversity. A movement whose origins come from autistic individuals unhappy with parent and professional associations' emphasis on causation and cure,<sup>1</sup> neurodiversity argues that the objectives of society should be oriented towards autistic individuals' flourishing, rather than non-autistic appearance.<sup>2</sup>

Bervoets et al. argue for adopting this approach to Tourette syndrome.<sup>3</sup> This idea has much to recommend it. Neurodiversity has been applied to other disability diagnoses, though disagreements still exist as to its scope.<sup>4, 5</sup> The authors make a compelling case that autistic and – to use the terminology of the authors – Tourettic individuals can make common cause under the neurodiversity umbrella.

In favor of this proposition, the authors describe the challenges faced by those seeking to suppress tics. In the words of one individual quoted, '... if you'd ask what hinders me most about it: well, that I need to spend so much energy in not ticcing, because ... it is energy I cannot spend in doing those things I want to do well.'<sup>3</sup> These words capture the opportunities lost when such demands to pass are imposed on people with disabilities. The same sentiment has frequently been expressed by autistic individuals with respect to efforts to suppress stimming.<sup>2</sup> A powerful commonality exists across diagnoses.

Somewhat less compelling is the authors' criticism of those who assert 'categorical difference between Tourettic and non-Tourettic brains', arguing that such an assertion 'unduly creates hierarchies of people.'<sup>3</sup> The belief that rooting disability in the brain necessarily implies hierarchy is one that is more associated with the mental health recovery movement than with neurodiversity. Unlike neurodiversity, mental health recovery proponents generally frame their conditions as distinct from their self-identity. In contrast, neurodiversity proponents think of their disabilities as inseparable parts of themselves (hence the use of identity-first

language like 'autistic' or 'Tourettic') and thus reject service provision models that push them to suppress non-harmful disability-related traits in the name of typical appearance. Because neurodiversity does not see the neurological disabilities it encompasses as inherent deficits, there is no conflict with empirical findings emerging from a difference of the brain, even as the difficulties that disabled people face are in part constructed by society.

As this contrast implies, neurodiversity is not the only existing critique of mainstream psychiatric practice. Neurodiversity activists have a strong interest in internationalizing the movement's ideas to new diagnoses.<sup>5</sup> By popularizing the rejection of the demand to pass as neurotypical beyond their own diagnostic borders, each disability group will have greater capacity to challenge harmful approaches at home. But principles of self-determination demand that adoption of neurodiversity principles come from each group of disabled individuals themselves.<sup>4</sup> Not every disability community will find this approach resonant – and meaningful buy-in can only be accomplished through domestic organizing and political activism. In short, neurodiversity cannot be adopted by a disability community through theory alone; it must be the result of a true grassroots desire from people with that condition. Ditto choices about language preference. One could easily imagine a circumstance where the word Tourettic becomes the new preferred term 10 years from now – but to get there will require broad adoption from persons with the condition, a process that is only now beginning. Until then, both identity- and person-first language should be accepted.

From this perspective, the authors' article and similar recent work should be seen as an opening gambit to a broader conversation on language and service-provision preferences with respect to Tourette syndrome. If this community decides to count themselves as part of neurodiversity, they will be welcome. But ultimately, that decision must come from those most directly impacted: Tourettic individuals themselves.

This commentary is on the invited review by Bervoets et al. on pages 1422–1428 of this issue.

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**DATA AVAILABILITY STATEMENT**

Not required

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## Leaving no one behind: Cerebral palsy in indigenous populations

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Indigenous people, whilst making up approximately 5% of the world's population, account for 15% of the poorest with a life expectancy up to 20 years lower than non-indigenous populations.<sup>1</sup> For example, the Irish Traveller population have one of the worst health statistics within the European Union with a life expectancy of approximately 50 years (<https://lenus.ie/handle/10147/42776>; <https://assets.gov.ie/18860/acc3cfe37d1e4b67a53f7da58eacc725.pdf>). Tackling health inequality remains a challenge for health care professionals working with these populations. Positive health promotions may struggle to reach indigenous populations who may not engage with traditional communication styles. This can result in some disorders, linked to poor socioeconomic status, remaining stubbornly prevalent.

Cerebral palsy (CP) is more common in those families with a poorer socioeconomic status.<sup>2</sup> Contributing factors to the aetiology of CP include adolescent pregnancy, preterm birth, low birthweight, and postnatal traumas. This increased risk has been established in indigenous populations in Ireland, Canada,<sup>2</sup> and Australia.<sup>3</sup>

Reduction in the incidence of CP throughout the world is due to many factors, including better nutrition, improvement in antenatal and neonatal care, and reduction in environmental factors that are a risk for intrauterine growth restriction (e.g. smoking). Antenatal health initiatives may exclude marginalized groups within society due to language difficulties, poor literacy, and other cultural barriers.

Whilst the incidence of CP has dropped in general over the last two decades, it had remained much higher in Australians of Aboriginal descent. Martin et al. have revisited the incidence of CP in Aboriginal and Torres Strait Islander children to document trends in prevalence over time.<sup>4</sup> They noted that the prevalence declined after the mid-2000s to 2013–2014, most notably in adolescent mothers and term births. Martin et al. found that a relatively high attendance of up to 65% of Aboriginal and Torres Strait Islander mothers attended antenatal clinics and also that there was a reduction in the number of females smoking, most notably amongst the 18- to 24-year-olds. They also found that 50% of CP was associated with preterm birth and this rate had not declined over the same time period. Indigenous people are often isolated and live in remote regions. Internationally, centralization of obstetric services is promoted; bearing in mind the isolated nature of these communities, the authors felt attention must be given to whether outcomes in these populations are adversely affected by over-centralization of services.

Internationally, health services aiming to engage with indigenous populations have developed a 'two-way' bicultural working model, with both indigenous community workers and non-indigenous professionals employed to deliver services. Culturally sensitive health promotion programs focussed on healthy pregnancies (known as 'Mums and Bubs') possibly explain some of the decline in CP prevalence, as a result of the decrease in smoking and the reduction in adolescent pregnancy rates.

This commentary is on the original article by Martin et al. on pages 1475–1485 of this issue.

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