DOI: 10.1111/jocn.16902

### EDITORIAL



### Journal of Clinical Nursing WILEY

# Enhancing the nursing profession's awareness of neurodiversity

Neurodiversity is an umbrella term for a range of neurodevelopmental conditions such as autism, attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia, dyscalculia and Tourette's syndrome (Doyle, 2020). Other terms used to describe neurodevelopmental conditions include neurodivergent, neurodistinct or neuroatypical. Why is this discussion important? Because between 15% and 20% of the general population may identify as being neurodivergent (Doyle, 2020) and, by extension, similar figures are anticipated to reflect healthcare practitioners. The topic of neurodiversity is not new. In fact, the Journal of Clinical Nursing has published papers exploring topics such as the experiences of having tics (Lee et al., 2019) or autism (Brown et al., 2021). Consequently, nurses will either interact clinically with persons who are neurodivergent, conduct research with or about them or work professionally with them. Thus, the need for nurses to be well informed about neurodiversity is becoming increasingly important. Terminology matters and nurses will be well served by engaging with an evolving lexicon. We offer three areas where nurses can obtain a more comprehensive perspective of the challenges people who are neurodivergent may experience: appreciating the societal context by moving from a non-normative to normative perspective; clarifying the relevance of neurodiversity to nursing; and furthering equality and diversity in the profession.

# 1 | APPRECIATING THE SOCIETAL CONTEXT

The experience of being neurodivergent differs from person to person; however, people who are neurodivergent can encounter challenges when accessing and engaging with healthcare services, availing of employment opportunities or during more general interactions across society (Milton, 2012). The societal context can confer disadvantage considering that much of society's expectations are based on the neurotypical person. The neurodiversity movement seeks equality and acceptance.

Increasingly, representative organisations such as the United Kingdom-based Institute of Neurodiversity seek to challenge narratives which pathologise those who are neurodivergent. The neurodiversity paradigm is built on the social model of disability which changes the narrative around neurodivergence as well as broader disabilities (Doyle, 2020). This paradigm challenges healthcare professionals who are more accustomed to models of care that emphasise diagnosis and treatment as responses to presenting needs. Neurodiversity then embraces a strength-based model focusing on the need for societal adaptation. However, it is far more common for the experiences of persons who are neurodivergent such as for autism (as an example of neurodivergence) to be defined in terms of deficits relative to non-autistic people, for example, deficits in social cognition and communication. Moreover, it is possible that non-autistic and autistic persons may have difficulty interacting and empathising with each other, a situation Milton (2012) calls the 'double empathy problem'. Consequently, any perceived deficit can work both ways. Deficit models usually focus primarily on perceived deficiencies and/or limitations of individuals and groups, generally advocate for 'correcting' differences and are the antithesis of strength-based models.

An example of the strength-based model is reflected through self-advocacy actions. Self-advocates have played an important role, as seen in journalism (*The Washington Post* being a good example) acknowledging the expertise of autistic adults and in educating the general public about the neurodiversity movement. Such visible advocacy has enabled autistic people to see themselves as having their own culture akin to deaf culture and different to the majority culture (Friedner & Block, 2017). The work of advocates such as Jim Sinclair, one of the first advocates to articulate an anti-cure perspective, is highly relevant in this context wherein they ask parents to love their children for who they are. Self-advocacy has helped neurodivergent people to connect and create a sense of community based on shared struggles. The rise of the internet and social media has played an important role in this.

Society, and by extension, healthcare providers are being asked to re-imagine autism and other neurodivergence as an acceptable form of difference. Sienna Castellon, advocate and founder of Neurodiversity Celebration Week, makes clear that neurodivergent people should not be viewed through a deficits lens (Summers, 2020). In fact, differences in thinking and being in the world can be significant strengths in particular contexts. Changing the societal context means neurodivergent people should also not be viewed as those to 'fix' or 'cure' but rather they are a naturally occurring variance of the human experience.

## 2 | RELEVANCE TO NURSING

Nursing as a profession has often positioned itself as an advocate for seldom heard voices therefore it seems important that we engage with and are cognisant of the impact of the neurodiversity movement. There are compelling reasons to enhance neurodiversity awareness within nursing. From a clinical perspective, Benson (2023) asserts that the hegemony of neuro-normativity (neuro-normativity

# 

that focuses on the neurotypical experience to the exclusion of neurodivergence) can perpetuate the marginalisation of those who are neurodivergent.

Neurodivergent people may engage with healthcare differently. How they interact, talk, experience senses and interpret information can differ from those who are not neurodivergent. These differences can be emphasised in interactions with healthcare professionals. For example, there is the risk of either missed physical health diagnoses or misdiagnosis of neurodivergence. Missing a diagnosis in a person who is neurodivergent has the potential for a significant impact on physical health outcomes generally and more especially on outcomes of mental health illness (where there is an increased co-occurrence with neurodivergence). A missed physical diagnosis due to insufficient communication, or diagnostic overshadowing, may contribute to increased morbidity and early mortality.

Nurses understanding of neurodivergence can be reflected in care plans and treatment contexts—one size does not fit all. The individuality of each person is key. In our experience in Ireland, a majority of neurodivergent people prefer identity first as opposed to person first language. Such a preference is contrary to many diversity efforts being undertaken globally. A prudent practice is to ask a person their preference. Nurses must therefore take account of such individual difference and terminology preference in care-planning. Training is important with respect to improving understanding. A growing number of advocates and organisations are calling for mandatory repeated training in neurodiversity for all public facing professionals as part of continuing professional development. This training should be co-delivered by neurodivergent professionals to ensure better outcomes.

# 3 | FURTHERING EQUALITY AND DIVERSITY IN NURSING

Another equally important reason to engage with neurodiversity is to further equality and diversity in the nursing profession itself. Significant strides towards a more inclusive workplace have been made, including over the last decade, in areas such as gender, ethnicity and sexual expression. We assert that neurodiversity may well be a remaining bastion of exclusion. Sweetmore (2022), a mental health nurse, offers an insightful if sobering account of gaps and missed opportunities of her own experience as an autistic woman availing of and working within services. Her work, in particular, illustrates issues of underdiagnosis and masking in women, and the potentially serious attendant mental health implications. It is unlikely that her experience is isolated. Organisations such as Untapped, based in Australia, seek to increase the participation of neurodivergent people in the workforce, and there is more work to be done in this regard. In fact, the Institute of Neurodiversity estimates that the numbers of neurodivergent professionals in all industries are significantly higher than currently estimated. Many neurodivergent professionals are not disclosing for fear of discrimination. However, this does not mean they are not there and all workplaces have a duty of care to their

employees to create a psychologically safe environment where everyone can bring their whole self to work. When this is not present and neurodivergent people have to mask, a risk to the individual's emotional and psychological wellbeing may arise. Masking involves a neurodivergent person hiding their true self and acting as though they are neurotypical.

There is no reason to believe that healthcare is any different to other employment sectors. In fact, were it to be demonstrated that healthcare or nursing is an outlier and that neurodivergent people are significantly underrepresented or forced to mask, a worrying picture of exclusion would be painted. As the largest of all healthcare professions, nurses work in remarkably diverse contexts. Surely, we should seek to ensure that diversity is celebrated in the make-up of our profession itself. Addressing the three areas highlighted in this editorial is one step to increasing awareness within the profession of an important issue—the needs and presence of persons who are neurodivergent. However, much remains to be done. As a profession that embraces diversity, nurses can lead the way.

> Timmy Frawley DGov, MEd, BNS, RN Associate Professor<sup>1</sup> <sup>(i)</sup> Blánaid Gavin MB BCh BAO, MSc (CBT), PhD, MRCPsych Associate Professor<sup>1</sup> Charlotte Valeur BSc Chair<sup>2</sup> Karen Morin PhD, RN, ANEF, FAAN, FAWHONN Professor<sup>3</sup>

> <sup>1</sup>University College Dublin, Dublin, Ireland <sup>2</sup>Institute of Neurodiversity, Morpeth, UK <sup>3</sup>University of Wisconsin-Milwaukee, Milwaukee, Wisconsin, USA

#### Correspondence

Timmy Frawley, University College Dublin, Dublin, Ireland. Email: timothy.frawley@ucd.ie

### ORCID

Timmy Frawley D https://orcid.org/0000-0002-2108-005X

### REFERENCES

- Benson, K. (2023). Perplexing presentations: Compulsory neuronormativity and cognitive marginalisation in social work practice with autistic mothers of autistic children. *The British Journal of Social Work*, 53(3), 1445–1464.
- Brown, M., Marsh, L., & McCann, E. (2021). Experiences of fathers regarding the diagnosis of their child with autism spectrum disorder: A narrative review of the international research. *Journal of Clinical Nursing*, 30(19–20), 2758–2768.
- Doyle, N. (2020). Neurodiversity at work: A biopsychosocial model and the impact on working adults. *British Medical Bulletin*, 135(1), 108-125.
- Friedner, M., & Block, P. (2017). Deaf studies meets autistic studies. The Senses and Society, 12(3), 282–300.

3

- Lee, M., Wang, H., Chen, C., & Lei, M. (2019). Social adjustment experiences of adolescents with Tourette's syndrome. *Journal of Clinical Nursing*, 28(1–2), 279–288.
- Milton, D. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability and Society*, 27(6), 883–887.
- Summers, H. (2020). Sienna Castellon: 'Autistic people are really struggling with how uncertain things are'. The Guardian. https://www.thegu

ardian.com/society/2020/nov/11/siena-castellon-autistic-peopleare-really-struggling-with-how-uncertain-things-are

Sweetmore, V. (2022). I am a mental health nurse so why did it take me so long to realize I'm autistic? *Journal of Psychiatric and Mental Health Nursing*, 29(6), 770–773.