

Neurodiversity and FASD

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KEY MESSAGES

The concept of neurodiversity is a relatively new phenomenon that represents the wide variety of differences among humanity. Although neurodiversity has been discussed in relation to other disabilities, increased attention is needed to better understand and consider how FASD can be part of neurodiversity. This issue paper describes the concept of neurodiversity, identifies some of the ways neurodiversity is discussed in the literature, and presents recommendations for considering FASD and neurodiversity.

Issue:

The term *neurodiversity* first emerged in the late 1990's. The term was coined by sociologist Judy Singer [1-3] and was first used in print by journalist Harvey Blume [4] with the goal of promoting the equity and inclusion of *neurological minorities*. Neurodiversity began with individuals labelled with autism spectrum disorders who wanted to be seen as *different*, not disabled [5]. This wider view focusing on brain differences instead of deficits offered an alternative view of disability in which strengths and needs are recognized as being present for everyone [5]. Since its introduction, the concept of neurodiversity has continued to grow. While many self-advocates and scholars have joined the calls to embrace neurodiversity, there is no shared understanding of neurodiversity, neurodivergence, or neurotypicality [6], and as such it is not clear what it means to be neurodivergent, and who can (and cannot) be considered neurodivergent.

The purpose of this issue paper is to introduce the concept of neurodiversity, identify some of the ways neurodiversity is discussed and framed in the literature, and present recommendations for considering FASD and neurodiversity.

Background:

Neurodiversity (sometimes also referred to as neurodivergent or neurodiverse conditions) represents the wide variety of differences among humanity [6] and means different things to different people [7]. Consequently, people study neurodiversity in a number of different ways, which

complicates the issue. For some, neurodiversity is considered a *social justice movement*. Practically, this movement impacts research, practice, and policy as it influences the way in which we view and address certain neurological differences. For example, neurodiversity advocates encourage inclusive, nonjudgmental language. For others, the neurodiversity view is an *individual* consideration, and may also be personal. Being neurodivergent can help shape identity and how people see themselves and their value in the world.

Neurodivergent people experience, interact with, and interpret the world in unique ways. These differences in experience can sometimes create challenges but may also lead to positive outcomes, such as creative problem-solving and new ideas.

In this issue paper, we highlight some of the *individual*- and *societal*-level considerations for neurodiversity and FASD. Although we recognize that these considerations are intersectional and complex in nature, we present them separately here to help emphasize the different ways that neurodiversity has been viewed and positioned.

1. Neurodiversity from an Individual-Level Perspective

When it was first introduced, the concept of neurodiversity was presented as being similar to ecology and the concept of biodiversity, wherein diversity among brains is viewed as being as enriching as biodiverse life on earth or diversity among different cultures [1, 4, 5]. This early conceptualization focused on the idea that neurodiversity reflects *naturally occurring* cognitive variations [5, 8] and is part of humanity's "genetic legacy" [8]. Scholars who operate from this view describe conditions such as autism, dyslexia, and attention deficit hyperactivity disorder (ADHD) as naturally occurring variations with distinctive strengths that have contributed to the evolution of our technology and culture [8]. From this standpoint, neurodivergent minds are valued for their contribution to, and helped by, their niches (i.e., their environments) [7]. In this way, neurodiversity is positioned as something that is *intrinsic* to the individual.

Unsurprisingly, depending on how one views and defines neurodiversity, there is a risk of contributing to further othering (i.e., viewing individuals as fundamentally different from a dominant group) for different forms of neurodiversity. Although many individuals have adopted a broader way of thinking about neurodiversity, including those who include individuals with (some) mental health labels [5], these conceptualizations are based around natural genetic variation and often gatekeep who can (and cannot) be considered neurodivergent.

More recent work has sought to broaden the boundaries around neurodiversity. For instance, some have suggested that neurodiversity refers to perceived variations in cognitive, affectual, and sensory functioning that differ from the majority of the population (or the 'predominant neurotype') regardless of origin [6]. These newer, and wider, theorizations broaden the scope of neurodiversity to consider many conditions that have an impact on an individual's sense of identity, as well as differences from standard ways of seeing, responding to, and interacting with, the world [6]. For example, Chapman has referred to neurodiversity as a 'moving target', and one that is inclusive as opposed to exclusive [7]:

"And if the neurodiversity framing is as helpful for those labelled as having disordered personalities as it has been for so many autistic people, wouldn't it be better to develop a more inclusive concept of neurodiversity rather than exclude them? And why should it matter

if any given set of traits is ‘natural’ or not anyway? I rather think the focus on whether things are natural or not often detracts from more important goals.”

Moving forward, scholars have called for neurodiversity studies to consider *all* neurodivergent differences and not to exclude types of neurodivergence that may be seen as “less culturally palatable” [9]. Therefore, it seems likely that the concept of neurodiversity will continue to change and move based on the complex interactions between those who are categorized by it, and the systems and institutions that challenge and respond to it [7].

2. Neurodiversity from a Systems-Level Perspective

From the individual-level and ecological lens, neurodiversity is about the value of variety. Our differences create space for interdependency in which everyone contributes to, and is helped by, the environment. However, others have adopted a more sociopolitical framework for thinking about neurodiversity, where it is viewed as a response to current systems, practices, policies, and structures, and is part of a larger effort to de-pathologize difference [7, 10]. When considering neurodiversity, it is also important to consider the systems-level intersections and their relevance for disability advocacy and social justice. In many instances, systems are not conducive to valuing people differently for different reasons. Often times, these distinctions are artificial, fully intersectional, and operate in fluid and dynamic ways that further elevate complexity for individuals with lived experience.

At its core, the neurodiversity social movement challenges the idea of normalcy. Singer referred to the “hegemony of normalcy” (i.e., the dominance of one social group – “neurotypicals” – over another) in her early work, identifying the taken-for-grantedness, invisibility, and naturalness of the concept of *normal* [1]. Disability theorists have stressed that what we call the norm is a rarely achieved, white supremacist ideal and the ongoing myth of a universal ideal person or norm upholds oppressive systems against those who are not European, white, male, middle class, Christian, able-bodied, thin, or heterosexual [6, 11].

These systematic biases also extend to the construction of disability. For example, popular and professional conceptualizations of disability, particularly autism, have associated disability with whiteness, high socioeconomic status, and masculinity [12, 13]. The emphasis on these “unmarked” categories (i.e., white, straight, able-bodied, and male) [14] provide reminders that caution us to be aware of culturally white frameworks that often leave other cultures and racialized people out of the discussion. Although autism is generally associated with these privileged unmarked categories [12, 13], FASD is often constructed as a diagnosis for the marginalized, with emphasis on the prevalence of FASD among special populations such as children in care, justice-involved individuals, or Indigenous communities [14, 15].

Researchers have called for attention and care within the neurodiversity movement to ensure that it does not become another tool for disability and identity that reproduces “white supremacy, cis-heteronormativity, classism, cisgenderism, or sexism” [16]. Neurodiversity, therefore, is a push-back to the ideal that ‘neurotypical’ is the only way, or even the best way, to be [1]. For these reasons, and perhaps problematically, neurodiversity has often been counterposed with “neurotypicals” (or NTs), a term that was coined by autistics to sideline the term *normal* and its associated meanings [1].

These tensions also bring to light competing ways of thinking about neurodiversity, mainly the medical model of disability and the social model of disability [17-19]. For example, among autistic individuals, many described that the challenges they face daily are not “symptoms” of their autism, but rather are hardships experienced because of a society that refuses to make basic accommodations for people with disabilities and problems with the way society responds to people who do not meet the standard expectation of “normal” [8].

In line with the individual-level lens described above, when using a medical model framing of disability, autism and other forms of neurological difference are viewed as residing exclusively *in* the individual and as conditions that need to be treated and managed. The aims of the medical model are to prevent individuals from living a life that deviates from the supposed ideal normal state, and to ease difficulties that arise from living in a society that is constructed according to these assumptions of an ideal state [6].

In contrast, the social model of disability is concerned with structures and systems that pose restrictions on disabled people. According to the social model of disability, society should ensure that all individuals with neurological or physical differences can be independent and equal in society, with choice and control over their own lives [6].

These tensions are not easily reconciled. However, it is clear that there is a need to both recognize neurodivergent lives and experiences of the world *and* to challenge entrenched cognitive norms [9]. At the heart of the issue, despite existing challenges and contradictions, neurodiversity means redefining the way we think about disability and evolving our societal assumptions to elevate the valuing of difference wherein the lives of individuals who are neurodivergent are valued for their inherent contributions, purpose, and meaning as human beings.

3. FASD *and* Neurodiversity

Neurodiversity is critical to consider in the context of FASD when addressing the *individual* outcomes of identity, autonomy, and the pursuit of healthy outcomes [20]. Additionally, neurodiversity is important as it provides a *social* framework to enhance human- and person-centred philosophies that value all individuals in society and their inherent strengths and challenges, including individuals with FASD. Specifically, this framework includes creating the social mechanisms to facilitate growth and well-suited supports for *all* members of society.

Finding a balance between autonomy and support for individuals with FASD aligns well with a neurodiversity framework as it asserts the value and the purpose that may be realized when societal structures are modified to be well-suited for the success of, and respect for, the individual. Philosophically and practically, this framework aligns with humanistic and strengths-based conceptualizations of FASD. Conversely, alignment with such a framework need not subsume or encompass all aspects of an individual, or require de-identification of uniqueness. Individuals with FASD are unique in many ways [21]; aligning this understanding and recognition *with* a neurodiversity framework may optimize growth opportunities. This positioning asserts that these unique elements do not have to define or devalue a person, but rather that each person has the right to supports that facilitate their success and inclusion in society.

Conversations about neurodiversity are only just beginning to emerge within the field of FASD. Thus, although tensions regarding neurodiversity (and neurodiversity as applied to FASD) clearly exist, it is

critical to consider how individuals with FASD interact with these labels, and how they interact within these communities. There is much we do not know yet; however, we **do** know that individuals with FASD want to have a voice in these spaces and want to be recognized [22, 23].

Moving forward, in this evolving, murky space, there is a need for professionals, individuals with FASD, caregivers, policy makers, frontline service providers, and other key stakeholders to give space for reflection and consideration of neurodiversity and FASD. It is important to recognize both neurodiversity *and* FASD. These terms are not interchangeable, but each term is valuable.

Recommendations for FASD and Neurodiversity:

In this section we offer both theoretical and pragmatic recommendations for considering FASD and neurodiversity. Some of these recommendations centre on the individual with FASD while some focus more broadly on the society around them. We present these recommendations with recognition of the fact that FASD and neurodiversity, when considered both independently and together, are *complicated*.

- **Genuinely humanize the FASD narrative.** In its history and at its heart, the idea of neurodiversity stems from equitability in the human condition and acknowledges that *all* human beings have areas of strengths and challenges. The extent to which we choose to define ourselves, and where we choose to situate ourselves, is perhaps secondary. We do not need to focus exclusively on one aspect of a person, such as their disability. Rather, we can recognize that all human beings, including individuals with FASD, are complex and multifaceted. In the context of FASD, further advancement of strengths-based and anti-stigma approaches are greatly needed to continue challenging the entrenched deficit-focused narrative of FASD. Positive, affirming language to talk about the brain and its many variations is warranted. It is also important to bear in mind that acknowledging neurological differences does not imply that all difference is good or that human traits associated with neurodivergence are always desirable. However, it accepts that there are “good” and “not so good” traits in *all* human beings [6]. Therefore, we can be encouraged to continuing to balance the story of FASD [24, 25], and recognize that all human minds come with particular challenges at different stages of life, including those that are considered impairments by the individual themselves, as well as strengths and values that support success and highlight purposeful contributions to society.
- **Include individuals with FASD.** Individuals with FASD should not be excluded from conceptualizations of neurodiversity. Building on the expanding and evolving conceptualizations of what it means to be neurodivergent, FASD should be considered and discussed within this framing. By adopting an *inclusive* rather than exclusive definition of neurodiversity, we can continue to accommodate *all* variations, rather than dismiss them.
- **Recognize that individuals with FASD have rights and action those rights.** In line with calls from scholars for people with neurodiverse brains to be liberated from prejudice and to achieve dignity, integrity, and wholeness in their lives [5], continued work is needed to advance the human rights of individuals with FASD to ensure their full and equal participation in society. Individuals with FASD deserve recognition, civil rights, an end to discrimination, and FASD- and neurodiversity-informed services that are appropriate to their level of need. Individuals with FASD also deserve mutual understanding and appreciation of their strengths based on what they can do (and not what they cannot) [8].

- **Elevate the voice of individuals with FASD.** Individuals with FASD need to be at the forefront of telling their own stories and advocating for their own advancement [8]. Further interdisciplinary, strengths-based, and participatory work is needed that includes examples of positive peer role models of individuals who have succeeded on their own terms. If the voices of neurodivergent individuals, including those with FASD, are heard more loudly, an ecological view of society can emerge that is more accommodating for different styles of being and that is content to let each individual person find their own niche [2].
- **Ask individuals with FASD how they want to be identified.** FASD and neurodiversity is complicated. Given that neurodiversity can look different for different people, and can be experienced differently by different people, we suggest asking individuals with FASD how they identify and to inquire about what neurodiversity looks like for each individual with FASD. Individuals may wish to identify as a person with FASD, as a neurodivergent person, as differently abled, as a person with a disability, as disabled, or any/all of the above. It is acceptable for individuals to be any or all of these identities. Regardless of their identity, individuals with FASD should be best supported by individualized, tailored, and person-centred supports and services that are informed by a multidisciplinary team assessment (e.g., FASD assessment and diagnosis) that best understands the person and their unique strengths and challenges.
- **Promote goodness of fit.** Accepting equitability tenets of neurodiversity, as well as calls for a balanced understanding of FASD, places responsibility on all members of society to adapt systems of support and expectations for contribution to create space for a broader range of individuals. Specifically, this response can include increased efforts to co-creating housing, work, educational, and other environments to attain suitability for individuals with FASD. Actively exploring options for inclusion in life that is not narrowly defined and allows for flexibility is critical. Just as individuals with FASD must have choice in how they identify, choice in approach to inclusion is also warranted.
- **Reflect on our biases.** Collectively, we need to challenge our own understandings and implicit biases of what it means to be ‘normal’ and work to accommodate all types of neurodivergent brains, including those with FASD. In this “neurodiversity debate” there has been a tendency to divide the world into two groups – neurodiverse and neurotypical [5]. If we work towards a shared vision of a more neurodiversity-tolerant society, one that understands that *each person is unique*, disorders can be reframed as differences and varying dimensions of these neurodiverse conditions can be fully acknowledged, moving away from longstanding attitudes of fear, pity, and condescension towards those society perceives as being “less able” than their “more able” peers [5]. We need to give thought to what our culture could look like where differences are accepted as diverse ways of being, rather than as different from norms that align with perfect ideals of being.
- **Increase support and challenge inequity at the systems level.** Supports and services should be tailored to meet the needs of neurodivergent people, including individuals with FASD. In line with changes in the broader disability community, and in line with human rights advocacy, self-advocates and individuals with lived and living experience should be involved in the development of policies that directly influence their lives, and individuals with FASD should be provided with appropriate accommodations and opportunities for their full participation in society [26]. Increasing support and providing FASD-informed services requires system-level shifts in attitudes about disability, difference, and FASD. Individuals must continue to challenge and resist the systemic inequities and the ways in which people with FASD are disabled by environmental and attitudinal barriers that prevent their equal participation,

rather than their individual impairments. Challenging these entrenched attitudes and societal norms requires increased education and training on disability, FASD, and neurodiversity.

- **Embrace the complexity.** As we have described, there is no one size fits all approach to neurodiversity. We encourage readers to embrace the complexity of these concepts and to continue on with thoughtful consideration around all of these different concepts, ideas, and at times contradictory conceptualizations. This may mean there is not always an answer, or a solution, or even an explicit action – but rather to allow space for the discomfort and growth we may experience from this discomfort.

Conclusion:

Although neurodiversity may be a complex concept, with many different definitions and purposes, at its heart it is simple. Individuals should be appreciated for who they are, difference does not dictate value. As a civil society we have a responsibility to facilitate equitable access to opportunity. By the very act of genuine acceptance of difference, we are compelled towards action that promotes wellbeing and healthy outcomes for everyone.

Within the FASD community, this is an emerging storyline. Initial efforts to support those with FASD have evolved away from well-intentioned but paternalistic and patriarchal efforts to provide an “external brain” towards balanced and humanized perspectives, with increasing awareness of the lived expertise and unique – and necessary – contribution of individuals with FASD to our communities. We are better together, and embracing a neurodiversity perspective allows us to support *all* differences and ways of being, including those of individuals with FASD.

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