



A Strength-Based Approach to Understanding Neurodivergent Parents

Concepts from the Developmental-Ecological Framework and Critical Disability Theory can help guide how public health nurses understand the experiences of neurodivergent parents and caregivers of infants and children. This resource introduces frameworks to guide nurses' understanding of neurodivergent parents' experiences and guidance on the use of inclusive and strength-based language.

Frameworks to Guide Nursing Approaches to Working with Neurodivergent Families

Developmental-Ecological Framework¹

- Children and adults live and grow within dynamic contexts that shape their health and development and with which they interact.
- In tailoring our care for neurodivergent children and adults, it is important to ask about their most proximal (closest) environments – their daily interactions, relationships and routines that take place within their families and closest supports.
- It is important to ask about how being neurodivergent is experienced within their school or work or community or their access to health or social services.
- At the broader level this may also intersect with other identities such as ethnic, racial or gender identity and one's experience of inclusivity or discrimination, of socioeconomic security and social connectedness with others.

Critical Disability Theory²

- An interdisciplinary framework for understanding that rejects the notion of disability as an inevitable result of individual impairment.
- It defines disability as a social construct related to the complex interplay of people's lived experiences and their social environment.
- For example, the extent to which specific neurodivergent profiles are seen as disadvantages depends on society's concepts of what is "normal" and the extent to which social, political, and institutional environments support and accommodate people's differences.



Developmental Ecological Framework



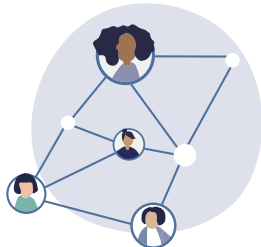
Neurodiversity =

Noun; represents the idea/movement



Neurodivergent =

Adjective; Descriptor for a person



Neurodiverse =

Adjective; Descriptor for a community composed of neurodivergent people



Neurotypical =

Noun or Adjective; Representing a person who is not neurodivergent

What is meant by the term NEURODIVERSITY?

Refers to the idea that certain developmental disorders are normal variations in the brain.

- They are not problems to be fixed, but more akin to differences to be accepted
- Just because neurodivergent people think differently, does not mean that they do not face barriers in many aspects of society or otherwise need accommodation.

Some specific *diagnostic profiles* related to neurodiversity include autism (or 'autism spectrum disorder'), attention-deficit/hyperactivity disorder (ADHD), intellectual disability (and related genetic or other profiles such as Fragile X or fetal alcohol spectrum disorder), but also learning disorders, communication disorders. Sometimes profiles or diagnoses such as obsessive-compulsive disorder (OCD) or schizophrenia are also included.



Identity-first versus Person-first language³⁻⁸

Person-first language

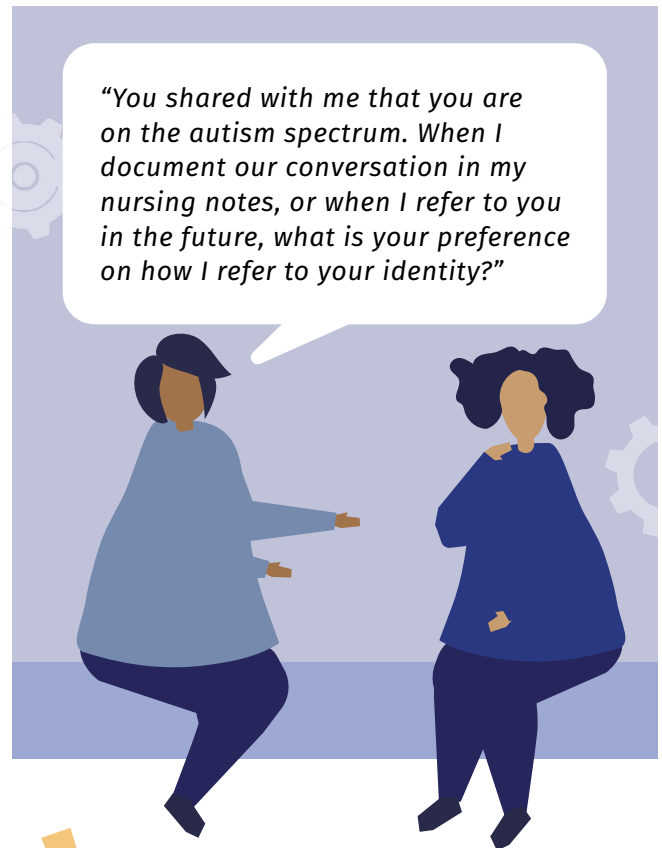
- Refers to someone as a person first, followed by their condition or situation.
- In applying trauma- and violence-informed care principles, to give hope when there are opportunities for situations to change, person-first language is often used such as:
 - A father experiencing social & economic disadvantage
 - A person experiencing homelessness
 - A woman who has experienced abuse

Identity-first language

- The use of person-first language (e.g. Person with autism) is more controversial in the Autistic community.
- This construction separates the person from their condition, but many Autistic people feel that they are inseparable from their autism.
- To separate one from their autism, they would have to become a completely different person.
- In the Autistic community, identity-first language e.g. **“Autistic person”** has been reported as the preferred construction by a majority of those surveyed across cultures and languages.



Use Inclusive and Strength-Based Language!



It is always preferable to ask people how they prefer you refer to their identity.



High support needs NOT Low functioning



Use language that reflects the level of support a neurodivergent parent or client requires, such as “high support needs” or “low support needs.”



Historically, people with significant challenges with completing day-to-day tasks were often referred to as “low functioning.”



Describing someone who has a high level of support needs with respect to specific skills (e.g. spoken language, social communication) is more helpful and respectful.



Functioning labels denote deficiency and lack specificity.



This language reflects that they need more support to do things, leaving their autonomy intact (in contrast to using language that would infer a person is lacking or deficient).



Use of term “low functioning” is disrespectful and not recommended.

Disorders, deficits, conditions, and differences

Terms such as “neurodevelopmental disorder” or “deficits” are clinical diagnostic terms that can be important for sharing clinical information or for accessing formal services.

However, the extent to which someone is “disabled” or “disordered” often depends on their environment – how accessible, supportive, and accommodating it is, or not.

The terms “conditions” and “differences” are more broad, less stigmatizing, and less negatively judgmental.

References:

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⁴Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). *Avoiding ableist language: Suggestions for Autism researchers. Autism in Adulthood*, 3(1), 18-29.

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⁸Sinclair, J. (2013). Why I dislike “person first” Language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2). <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1>

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