



How We Talk About Autism and Why it Matters

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THE UNIVERSITY OF NORTH CAROLINA

TEACCH[®]

Autism Program

Services Across the Lifespan



SCHOOL OF
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Speaker Introduction

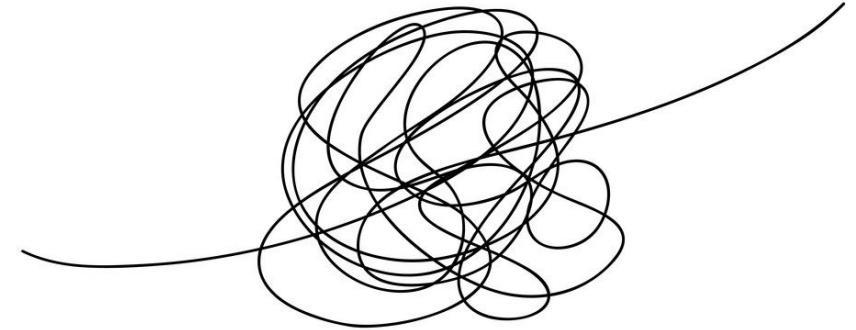
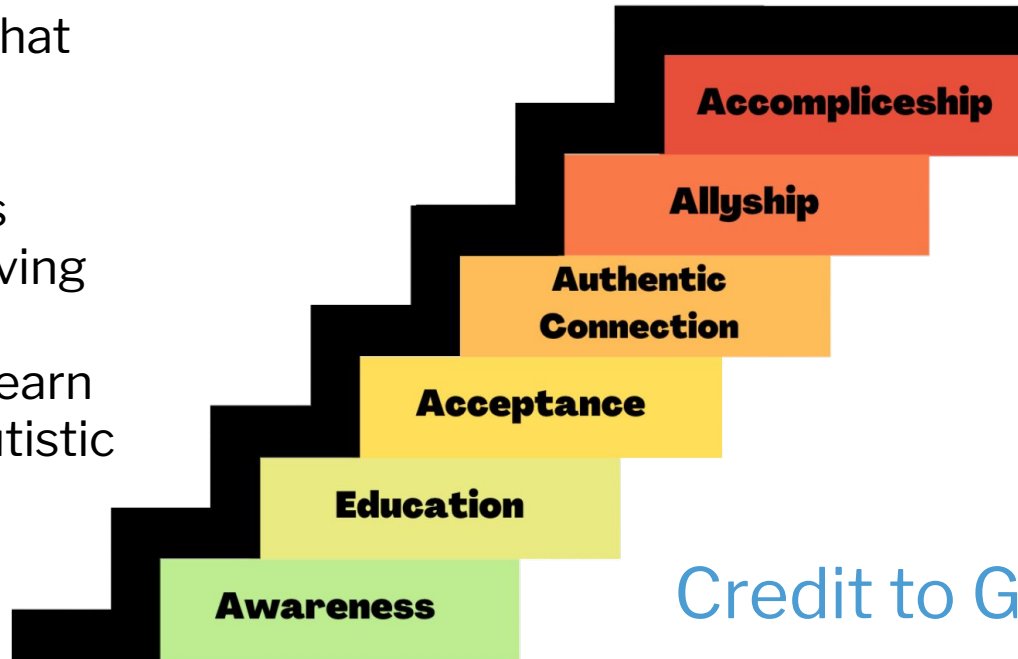


Jacklyn Boheler, MS, OTR/L

- Neurodivergent
- Occupational therapist by background
- Passionate about neurodiversity affirming approaches and principles of disability justice
- Co-founder of a local nonprofit, B3 Coffee
- UNC Class of '19 (undergrad) and '21 (graduate)

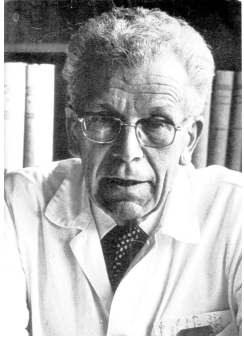
Disclaimers*

- Allyship is a process– mistakes are part of that process!
- Language is always evolving
- Listen and learn from the Autistic community!



Credit to Greg Boheler, Autistic OT

Brief History of Neurodiversity Movement*



Hans Asperger, 1939 - Austrian Psychiatrist

- “Not everything that steps out of line and is thus ‘abnormal,’ must necessarily be inferior.
- Focused his research on autistic children with higher intelligence
- First to introduce the idea of a spectrum of autism



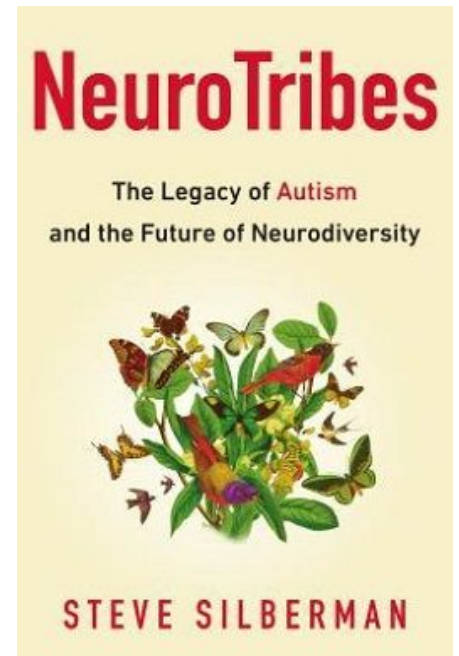
1998- Andrew Wakefield published a paper fraudulently linking autism to the MMR vaccine (later, the paper was revoked)

2009- ideas proliferated by organizations such as Autism Speaks about an “autism epidemic”



Leo Kanner, 1943 - Austrian American Psychiatrist/Physician

- “Refrigerator mothers”
- Cold parents (with autistic traits) created the disorder in their children by turning their backs on them
- Autism was a very rare child's disease and all autistics presented in the same way



1979- Lorna Wing (psychiatrist) and Judith Gould (psychologist) examined the prevalence of autism and re-introduced the idea of a spectrum ; discovered it was much more common than Kanner had previously described



The Neurodiversity Movement*

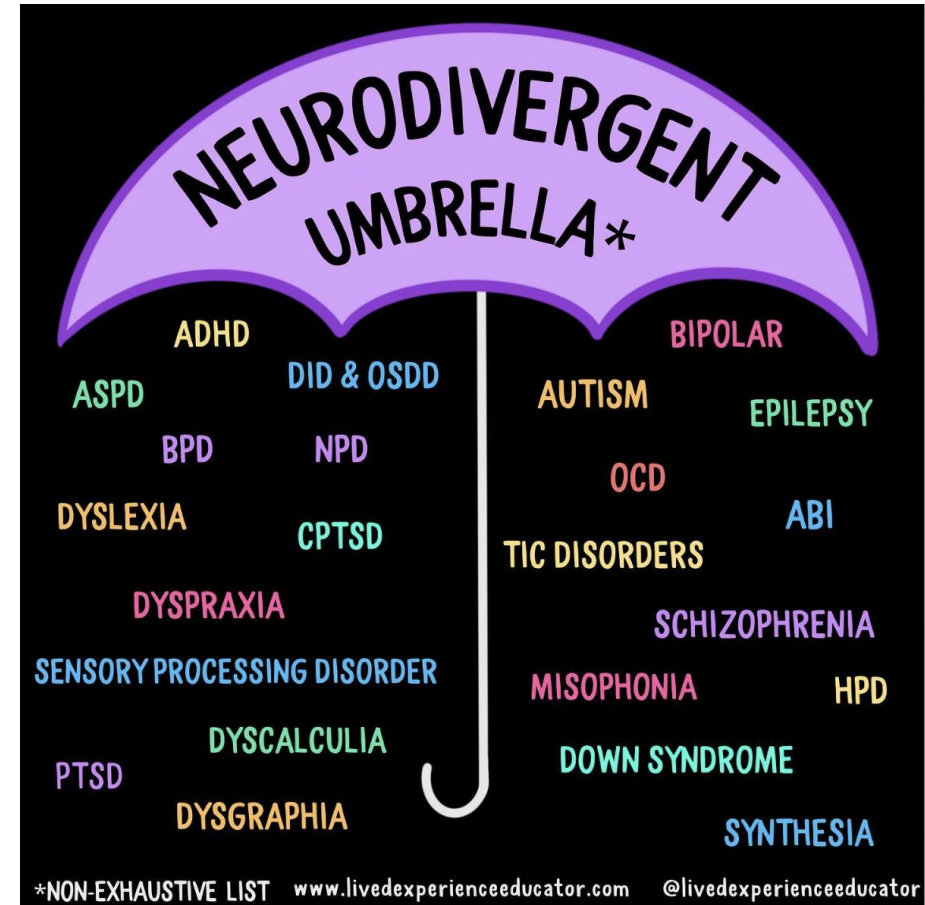


The term “neurodiversity” was coined by Australian sociologist Judy Singer, in her honors thesis, 1998

- “Neurodiversity is:
 - a state of nature to be respected
 - an analytical tool for examining social issues
 - an argument for the conservation and facilitation of human diversity”
 - — **JUDY SINGER 2020**

Neurodivergent refers to an INDIVIDUAL

Neurodiverse refers to a GROUP or POPULATION



Person First or Identity First?



Person First Language:

- “Person with autism, person with a disability”
- Aims to center the individual’s humanity, not their disability
- Based on a medical model of disability
- Preferred by 24% of people with autism (Keating et al., 2022)

Best practices:

- **Defer to individual preference**
- **Educate clients on language & its meaning**
- **Use person first & identity first interchangeably if preference is unknown**
- **“On the spectrum” is a pretty neutral term**

Identity First Language:

- “Autistic, disabled”
- Aims to acknowledge a person’s disability as central to their lived experience & not shameful
- Based on a social model of disability
- Preferred by 80% of autistic people (Keating et al., 2022)

Person
with
autism



Autistic
person



Neurology is not an accessory
www.identityfirstautistic.org

What about functioning labels?*



- Functioning labels are not recommended
 - “High functioning” → overlooks support needs
 - “Low functioning” → overlooks strengths
 - Doesn’t capture the complexity of humans!
- Levels should only be used when speaking clinically

Alternatives

- **Best practice:** describe specific support needs.
 - “Sam is a non-speaking AAC user and a prolific poet. He requires support with personal care such as toileting.”
 - “Jamie has a PhD in physics and holds a full time research job; however, life skills can be challenging for her. She relies on her partner for things like like pumping gas and grocery shopping.”
 - Kinley is an autistic child with an intellectual disability who benefits from visual structure and transitional supports.
- If the above is too tedious: say “higher support needs” or “lower support needs.” Or, state whether or not the person has an intellectual disability or co-occurring medical diagnoses (of course, consider HIPAA here!).

What about the new term “profound autism”? (Lord et al., 2022)



• Pros

- Supports advocacy on a legislative/policy level for funding of 24/7 care & robust support services for those who need it
- Provides a succinct term for research purposes
- For example, intermediate care facilities in NC are currently at risk of losing funding. Every person should be able to choose where they live, but given the DSP crisis and lack of community infrastructure, these settings are still necessary for people with higher support needs & aging parents

• Cons

- Doesn't capture the “spiky” skill profile that many Autistic people display, which could lead to underestimating their strengths
- Maintains a divide/hierarchy within the Autistic community
- Feels degrading / pathologizing, especially when used in reference to an individual
- The term lacks participatory research, consideration of Autistic research priorities, & lacks support of Autistic-led orgs (i.e., ASAN, Neuroclastic)

Do the best you can until
you know better.
Then when you know better,
do better.

-Maya Angelou



Unresolved: The Problem of Partial Representation

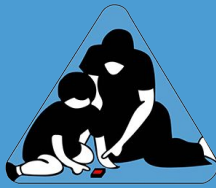


As of now, the research has not included “autistic people with high support needs, nonspeaking autistic people, and autistic people of the global majority.” (Bernand et al., 2023)

Should the perspectives of parents, caregivers, and family members be included? (Singer et al., 2022)

There is likely no “consensus” answer. As always, we will need to individualize to honor autonomy and choice.

Other Language Considerations*



Ableist

- Euphemisms, i.e. “Special Needs,” “Differently Abled”
- Handicapped
- Mentally retarded
- Referring to adults as kids, or speaking to adults using “baby talk”
- Non-verbal
- Normal / regular people
- “Suffers from, a victim of, overcomes”
- Asperger’s

Affirming

- Person with a disability or disabled
- Neurodivergent or neurodiverse
- Intellectual disability
- Non speaking or minimally speaking
- Neurotypical or non-disabled



Affirming Language Guidelines

The ASD SIG aims to be a safe space for all members to communicate and collaborate, inclusive of neurotype. The guidelines below center autistic perspectives regarding strengths-based language that is accepting of differences.

Instead of This...	Try This!
Autism Spectrum Disorder, ASD ³	Autism, autistic (the term "disorder" is unnecessarily medicalized and reinforces negative discourses that autism is wrong or needs to be cured)
Person-first language (e.g., "person with autism" or "person with ASD") ^{2,4}	Identity-first language (e.g., "autistic person"), on the autism spectrum, formally identified as autistic
High/low functioning; high/low severity or support needs ²	Describe specific strengths and needs, acknowledge support needs likely vary across domains (e.g., requires substantial support to participate in unstructured recreation activities, but minimal support to complete academic work)
"At risk" for autism or ASD ²	Increased likelihood/chance of autism/being autistic
Autism symptoms ² and impairments ³	Specific autistic characteristics, features, traits, or experiences
Treatment ²	Support, services, educational strategies (when applicable)
Cure/recovery/optimal outcome ²	Focus on quality-of-life outcomes that prioritize what autistic people want for themselves
Mild/moderate/severe language difficulties ¹ ; social communication difficulties ⁴	Specify the language difficulties or differences; describe characteristics of autistic communication
Poor reciprocity, monologues, goes off on tangents ⁴	Uses longer conversational turns and info-dumps, characteristic of autistic communication style for sharing information and connecting with others
Blunt, abrupt, rude ⁴	A direct communicator, uses language efficiently
High-/low-functioning autism, severe autism or severity of autism ¹ , Level 1/2/3	Descriptions of individual characteristics (e.g., with/without intellectual disability or language impairment) or specific support needs (see above)
Deficit/Weakness ¹	Area of challenge, difficulty, difference
Flat affect ^{1,4}	Uses neutral facial expressions
Poor/unusual eye-contact ^{1,4}	Prefers to use reduced levels of eye-contact; eyes move around the room when speaking

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Poor/unusual eye-contact ^{1,4}	Prefers to use reduced levels of eye-contact; eyes move around the room when speaking
Restricted/Special interests ^{1,2}	Focused, intense, or passionate interests; Areas of interest/expertise
Meaningless/aimless/purposeless play ⁴	Preference for parallel play and interaction
Rigid, Inflexible ¹	Preference for sameness and routine; Consider whether is it the autistic individual, the environment around them, or both that is or are inflexible
Stereotyped behaviors ⁴	Repetitive body movements or stimming as a form of self-regulation and communication
Aloof and disinterested, on their own agenda, in their own world ⁴	Demonstrates a monotropic thinking style characteristic of neurodivergent children; hyperfocused on interests and difficulties shifting attention to less interesting activities; differences in preference for body language and proximity
Challenging behavior/disruptive behavior/problem behavior ^{1,2}	Meltdown (when uncontrollable behavior), stimming (when relevant), more specific description of the behavior (e.g., self-injurious or aggressive behavior)
Discussions about economic impacts of autism/autistic people or compare costs to those of potentially fatal diseases, conditions ² or natural disasters	Discussions about economic impacts that situate costs in society's systemic failure to accommodate autistic people and recognize the people most affected by oppression due to this failure are autistic people (not "taxpayers"). Avoid suggesting autism is uniformly detrimental and will lead to poor outcomes.

References and Further Reading

- ¹Dwyer, P., Ryan, J. G., Williams, Z. J., & Gassner, D. L. (2022). First do no harm: Suggestions regarding respectful autism language. *Pediatrics*, 149(Supplement 4). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9066426/pdf/nihms-1801134.pdf>
- ²Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adult Life*, 3(1), 18-29. <https://doi.org/10.1089/aut.2020.0014>
- ³Monk, R., Whitehouse, A. J., & Waddington, H. (2022). The use of language in autism research. *Trends in Neurosciences*, 45(11), 791-793. <https://doi.org/10.1016/j.tins.2022.08.009>
- ⁴Divergent Perspectives (2022). *Neurodivergent Report Writing*. <https://www.divergentperspectives.co.uk/post/neurodivergent-affirming-report-writing>
 Journal of Autism and Developmental Disorders (2022). *Suggestions for inclusive language in JADD submissions*. <https://www.springer.com/journal/10803/updates/23353702>
- American Psychological Association. (2021). *Inclusive language guidelines*. <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf>



Resources



- Autistic Self Advocacy Network College Handbook:
- Demystifying Disability– Emily Ladau
- Autism Grown Up: Toolkits on Disclosure, College Living, PSE Options



Work Together NC

Search available opportunities for people with intellectual and developmental disabilities in NC



Work Together NC

Possibility to Opportunity

Visit worktogethernc.com

Your one-stop resource hub for navigating the transition to adulthood

- Search resources by topic/audience/type
- Search services by type/county/MCO
- Make action plans for postsecondary goals

IDD Inclusive Employer Alliance



Employer Training Module



The online course will provide a brief introduction to IDD and guide you through several key topics related to IDD in the workplace, such as:

- Introduction to IDD Inclusion in the Workplace
- Language, Misconceptions, and Mindset Shifts
- Universal Design
- Tools for People with IDD in the Workplace
- Success Stories, Community Resources, and Next Steps

[View Employer Training Course](#)

Employer Training Benefits



Upon completing the no-cost training, you will have the opportunity to apply for recognition as an “IDD Inclusive Employer,” which comes with some perks!

- An “IDD Inclusive Employer” sticker to proudly display on your storefront
- Job candidate referrals (optional) and support from local agencies with training/coaching new hires
- Quarterly mentorship/networking calls with other IDD Inclusive Employers (optional)

Join our growing list of recognized IDD Inclusive Employers!

References



Bernard, S., Doherty, M., Porte, H., Al-Bustani, L., Murphy, L.E., Russell, M.C. and Shaw, S.C.K. (2023), Upholding autistic people's human rights: A neurodiversity toolbox for autism research. *Autism Research*. <https://doi-org.libproxy.lib.unc.edu/10.1002/aur.2907>

Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2022). Autism-related language preferences of English-speaking individuals across the globe: A mixed-methods investigation. *Autism Research*. <https://doi.org/10.1002/aur.2864>

Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., Carr, T., De Vries, P. J., Dissanayake, C., Divan, G., & Freitag, C. M. (2022). The lancet commission on the future of care and clinical research in autism. *The Lancet*, 399(10321), 271– 334. [https://doi.org/10.1016/S0140-6736\(21\)01541-5](https://doi.org/10.1016/S0140-6736(21)01541-5)

Singer, A., Lutz, A., Escher, J., & Halladay, A. (2022). A full semantic toolbox is essential for autism research and practice to thrive. *Autism Research*. <https://doi.org/10.1002/aur.2864>



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