What is Neurodiversity?

DNEA Resource Guide

There are a lot of different terms related to neurodiversity. This resource guide defines some key terms and provides some useful tips and resources about autistic culture.

Key Terms to Know

Neurodiversity refers to natural differences in the brain that can lead people to experience and interact with the world in a variety of ways. These differences are not considered “right” or “wrong.”

Example use: “Our workplace values neurodiversity and works to accommodate and support all employees.”

Neurotypical people generally behave and process information in ways that are considered standard or typical.

Example use: “John’s communication skills and social interactions are typical for his age; these qualities are often associated with neurotypical people.”

Neurodivergent people see and understand the world around them differently than neurotypical people. Autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) are two examples of diagnoses that are considered to be nuerodivergent.

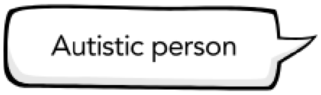
Example use: “ Neurodivergent students often have unique views and strengths that can help create classrooms that are diverse and open to everyone.”

Self-identification may occur when people identify themselves as being neurodivergent without having a formal diagnosis. This may occur when a person has difficulty getting an appropriate assessment, or if a person does not want a formal assessment.

Example use: “Molly, who self-identifies as having autism, joined an online group for people who identify as neurodivergent.”

Language Preferences

For a long time, people were encouraged to use **person first** language when discussing people with disabilities. This movement focused on person’s disability being just one part of their identity.



Many people with disabilities prefer **identity-first** language because they feel their disability is an important part of their identity.

Each person and family may have a different preference about the language they use to describe their disability. Identity-first and person first language are often both used in order to respect both preferences. The best way to determine a person’s language preference is to ask them! It is also acceptable to ask a caregiver if a person is unable to communicate their preference due to complex communication needs.

Additional resource guides and a full list of references at https://www.delawareautismnetwork.org/.

Vertucci, K., Slavin, L., Mallory, S., Fletcher, A., & DNEA CDS Team. (2023). *DNEA resource guide: What is neurodiversity?* Delaware Network for Excellence in Autism.

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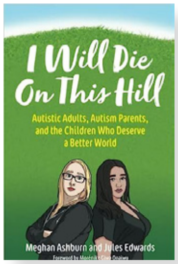
NEMOURS CHILDREN'S HEALTH

What is Neurodiversity?

Resources

Books

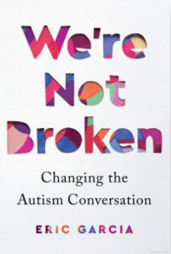


I Will Die on This Hill by Meghan Ashburn and Jules Edwards

Loud Hands: Autistic People, Speaking by Julia Bascom

Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance, and Identity by Autistic Women and Nonbinary Network

Uniquely Human: Updated and Expanded: A Different Way of Seeing Autism by Barry Prizant



We're Not Broken: Changing the Autism Conversation by Eric Garcia

What I Mean When I Say I'm Autistic: Unpuzzling a Life on the Autism Spectrum by Annie Kotowicz

Online

Autistic Self Advocacy Network at autisticadvocacy.org

Autism Intervention Research Network on Physical Health (AIR-P) at airpnetwork.ucla.edu/

Autism Intervention Research Network on Behavioral Health (AIR-B) at www.airbnetwork.org

Research

den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, *23*(2), 271–273. https://doi.org/10.1177/1362361318820762

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology*, *12*, 1-7. https://doi.org/10.3389/fpsyg.2021.635690

Stenning, A., & Rosqvist, H. B. (2021). Neurodiversity studies: Mapping out possibilities of a new critical paradigm. *Disability & Society*, *36*(9), 1532–1537. 10.1080/09687599.2021.1919503

Tips

- **Partner with autistic people!** When working on a project that involves autism, get input from autistic people – ask them what they think about your ideas.
- **Respect language differences!** Ask someone if they prefer person or identity-first language and do your best and use their preference of *a person with autism* and/or *an autistic person*.
- **Learn more about autistic culture!** Read articles, books, or personal stories written by autistic people. Engage with autistic communities through online forums and social media. Attend workshops and training that feature autistic speakers.
- **Use a person-centered approach!** Focus on improving quality of life rather than trying to make a person look "less autistic" or forcing them to behave in a standard or typical way.

Additional resource guides and a full list of references at https://www.delawareautismnetwork.org/.

Vertucci, K., Slavin, L., Mallory, S., Fletcher, A., & DNEA CDS Team. (2023). *DNEA resource guide: What is neurodiversity?* Delaware Network for Excellence in Autism.

Research Recap: Avoiding Ableist Language

Article Reference: Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3(1), 18–29. https://doi.org/10.1089/aut.2020.0014

Ableism is discrimination and social prejudice against people with disabilities and people perceived as disabled. Ableism characterizes people as defined by their disabilities as inferior to people without an identified disability. It's important that professionals understand what ableism is, reflect on the language they use in their communication, and use non-ableist language alternatives to describe autism and autistic people.

Language and meanings are constantly evolving, what appears in the table below as recommendations may be inappropriate in some current or future contexts. Ableist discourses are not always reducible to terminology, so it would be possible to avoid using any of the terms in the table that are recommended against and still be perpetuating ableism through language choices.

> “I am proud of my identity and of my community. I don't “have” something that makes me who I am. I simply am.”
>
> *- Amy Sequenzia**

** https://awnnetwork.org/from-ableist-to-self-advocate/*

Potentially Ableist Terms/ Discourses and Suggested Alternatives

Current Ableist Terms	Suggested Alternatives
Special interests	Focused or passionate interest, areas of interest or expertise
Special needs	Describe the specific needs of the individual
Challenging behavior, disruptive behavior, problem behavior, abnormal behavior	Specific description of their behavior (flapping, bumping, stimming, meltdowns, self-injurious)
High/Low functioning	Describe the individual's strengths and needs, acknowledge the level of support needed
At risk for autism	Increase likelihood, chance of autism
Suffers from autism	Has autism, is autistic
Comorbid (unless used in a medical or diagnostic setting)	Co-occurring
Autism symptoms	Describe their characteristics, features, traits
Treatment	Support, services, educational strategies
Normal, typical kids, healthy	Neurotypical, nonautistic, individuals without disabilities
Cure, recovery, optimal outcome	Describe goals of the individual

Table reproduced with permission, from Bottema-Beutel et al., 2022

Trauma and Youth with Autism

DNEA Resource Guide *for Professionals*

Adverse Childhood Experiences (ACEs) are traumatic experiences in childhood, such as witnessing violence in the home, experiencing neglect, or having a family member with a mental illness. ACEs can have lasting effects on future physical and mental health but are often an overlooked health disparity in the autism population (Rigles, 2016).

Youth with autism may have difficulty coping with such experiences. Individuals with autism have a higher rate of internalizing disorders, such as anxiety and depression, and often struggle with emotional regulation skills, which help facilitate coping with these stressors (Kerns et al., 2015).

Assessment of Trauma in Youth with Autism

It can be challenging to identify trauma in autistic youth. For example, the emotions created by trauma may lead to challenging behaviors, which may be incorrectly attributed to the youth's autism. It is important to recognize and treat trauma because it can negatively impact development, behavior, mental and physical wellbeing, and a youth's sense of safety.

Identifying trauma can also be difficult if a person has complex communication needs. Consider an autistic person's communication needs by adapting assessment materials and practices to include visual supports. Ensure a person has access to alternative or augmentative communication devices they may use to communicate.

Observations and assessment data, including input from those who know the youth well, can help identify signs of trauma. Knowing how a youth typically behaves and recognizing the onset of new behaviors may help determine events that influenced a change.

TF-CBT for Youth with Autism

Treating trauma increases the quality of life of youth with autism and may reduce their need for additional supports and services. Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) is an evidence-based treatment used to help children and adolescents recover after trauma. An autism-sensitive application of TF-CBT can be an effective treatment for youth with autism who have experienced trauma (Earl et al., 2017).

It's important to adapt TF-CBT to meet the youth's individual needs and learning styles. For example, this may include using visual supports, such as session schedules or social narratives, and increasing caregiver involvement in helping to reinforce skills outside of therapy. It is also important to allow additional time when teaching emotional stages. Be mindful of sensory differences and ways to incorporate sensory experiences into treatment.

Additional resource guides at https://www.delawareautismnetwork.org/

Suggested citation: Fletcher, A., Mallory, S., Mitchell, E., & DNEA CDS &TMD Teams. (2022). *DNEA resource guide for professionals: Trauma and youth with autism*. Delaware Network for Excellence in Autism.

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Trauma and Youth with Autism

DNEA Resource Guide *for Professionals*

Trauma Informed Approaches

Education

As youth spend much of their time in schools, trauma-informed approaches are crucial to supporting social, emotional, and physical well-being. Trauma-informed approaches in education help create safe, trusting, and healing environments. For more information on Delaware-specific trauma-informed approaches in education, please visit: https://www.doe.k12.de.us/Page/4349

Organizations

Becoming a trauma-informed agency or organization means committing to changing an entire organization's practices, policies, and culture. This ongoing type of change necessitates that all staff in all roles modify their behavior and provide an awareness of trauma's impact on the needs of trauma survivors.

The publication *Delaware Developmental Framework for Trauma-Informed Care*, describes the purpose of trauma-informed care as well as a framework for a trauma-informed care continuum of implementation. For more information on implementing trauma-informed approaches in organizations, please see the publication linked above.

If you suspect that a youth with autism has experienced trauma, you can support their recovery by:

- *Building on natural supports by identifying strengths in the youth and their caregivers;*
- *Creating a safe environment and fostering trusting relationships; and*
- *Seeking trauma-informed care training to obtain specialized knowledge and skills.*

If you suspect a youth has been abused or neglected, you must report your concerns to the Delaware Division of Family Services electronically at https://dscyfkids.force.com/ReporterPortal/s/ or by phone at 1-800-292-9582.

References

Earl, R. K., Peterson, J. L., Wallace, A. S., Fox, E., Ma, R., Pepper, M., & Haidar, C. (2017). *Trauma and autism spectrum disorder: A reference guide.* Bernier Lab, Center for Human Development and Disability, University of Washington.

Family Services Cabinet Council. (n.d.). (publication). Delaware developmental framework for trauma-informed care. Retrieved from: https://governor.delaware.gov/wp-content/uploads/sites/24/2019/02/Delaware-Developmental-Framework-FSCC.pdf

Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(11), 3475–3486. https://doi.org/10.1007/s10803-015-2392-y

Rigles, B. (2016). The relationship between adverse childhood events, resiliency and health among children with autism. *Journal of Autism and Developmental Disorders*, 47(1), 187–202. https://doi.org/10.1007/s10803-016-2905-3

Additional resource guides at: https://www.delawareautismnetwork.org/

Suggested citation: Fletcher, A., Mallory, S., Mitchell, E., & DNEA CDS & TMD Teams. (2022). *DNEA resource guide for professionals: Trauma and youth with autism*. Delaware Network for Excellence in Autism.

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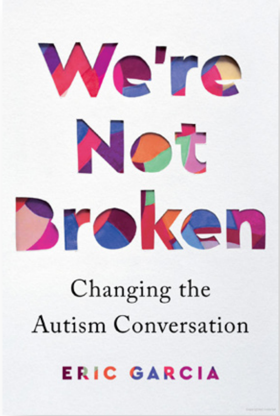
Book Club Conversations:

We're Not Broken: Changing the Autism Conversation

DNEA Resource Guide

Book reference

Garcia, E. (2021). *We're not broken: Changing the autism conversation*. Houghton Mifflin Harcourt.



We're Not Broken: Changing the Autism Conversation by Eric Garcia is about the author's journey with autism and how society views individuals with autism. Garcia challenges the prevailing narrative of autism and advocates for a neurodiversity movement that accepts and celebrates the unique experiences and abilities of autistic individuals.

Book Club Discussion Questions

- People have differing thoughts about using person-first vs. disability-first language because of different beliefs and values. Some individuals and disability advocacy groups prefer person-first language because it emphasizes that the person comes before their disability and is not defined solely by it. Garcia describes himself as "autistic" using disability-first language. *What are your thoughts on the terminology differences? What terminology should be used when discussing the book?*
- Autism is a spectrum disorder and individuals with autism may have different strengths and needs. *Did anything come up that changed your perception of autism or the lived experiences of people with autism? What was it? How did your idea(s) change?*
- Garcia's book discussed the need for a shift towards a more inclusive and accessible society for all individuals, regardless of their disabilities. *What did you think about this message about disability acceptance and empowerment?*
- It is important to consider the impact of medical professionals' perspectives and societal attitudes about individuals with disabilities. These perspectives and attitudes can shape the way individuals with disabilities are treated in healthcare settings and society at large. Garcia discusses the importance of including and respecting people regardless of their neurobiology. He shares that autistic people's "fate" relies on finding a doctor who understands their autism. *Think about where you receive medical care. What suggestions might you make to make these services more inclusive of people with disabilities?*
- People with disabilities face discrimination and stigma in various domains of life. Negative attitudes about disability can lead to structural barriers, exclusion, and limited opportunities for social and economic advancement. *What systemic barriers addressed in the book were new to you? What surprised you about these barriers?*
- Disability activism and self-advocacy are important in shaping societal perceptions and creating change (e.g., raising awareness, empowering people with disabilities, influencing policy). *How might this book prompt conversations about disability rights, representation, and inclusion in your community?*
- Garcia's book discussed autism in relation to education, housing, healthcare, relationships, race and gender. *What passages or themes stood out as particularly memorable or insightful? Were there any moments in the book that particularly resonated with you?*

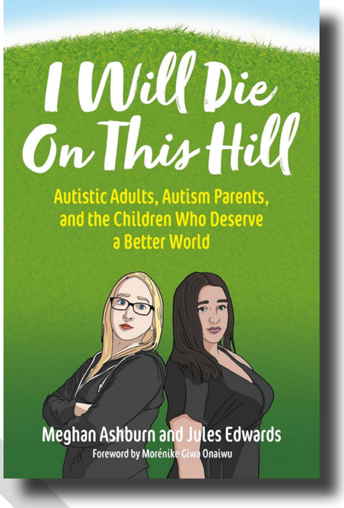
Additional resource guides at https://www.delawareautismnetwork.org/.

Book Club Conversations: Books about autism brought to you by the DNEA.

Book Club Conversations:

I Will Die On This Hill: Autistic Adults, Autism Parents, and the Children Who Deserve a Better World

DNEA Resource Guide



Book Reference

Ashburn, M., & Edwards, J. (2023). *I will die on this hill: Autistic adults, autism parents, and the children who deserve a better world.* Jessica Kingsley Publishers.

Book Club Discussion Questions

- Engaging in productive conflict can help us expand our perspectives, create connections, and effect change. *When and where have you engaged in productive conflict? What could you change about your style of engaging in conflict to make it more productive?*
- The book discusses the medical model of disability as focusing on “fixing and curing people,” the social model of disability as focusing on “accommodations and accessibility,” and the neurodiversity paradigm as focusing on “respect for all people regardless of neurotype.” *Which model(s) do you subscribe to and why?*
- Edwards connects a colonialist-capitalist worldview to the medical model of disability and to functioning labels. *How do you see hierarchy and capitalism impacting autistic people? Can you think of examples of autistic people being valued for their contributions outside of an exploitative system?*
- Edwards stresses the importance of intersectionality in the disability justice movement. *What are some identities within the disability justice movement that you would like to learn more about? How can you begin to learn more about these identities and their impact on disability?*
- Following her childrens’ autism diagnoses, Ashburn encountered several communities of parents of autistic children that held different values and served different purposes. *What are some of the ways that parent communities can help and harm parents of autistic children?*
- The authors take a strong stance against ABA (applied behavioral analysis). *Based on what you know, what is your stance on ABA therapy for autistic children? What more would you like to know about ABA or alternative strategies and supports for autistic children?*
- Ashburn writes about how the process of unlearning is difficult and uncomfortable, but necessary to improve the lives of autistic children. *What is something that you’ve changed your mind about as you’ve learned more about autism? What resources have been most helpful for you to expand your perspectives?*
- Ashburn and Edwards write that when autistic adults and parents of autistic children work together, they can achieve more for autistic children. *How could you work in an autistic-allistic partnership to create a better world for autistic children?*
- The authors stress the importance of listening to the autistic community when learning about topics related to autism. *Where do you receive information about autism? What are ways that you could engage with more autistic people and hear their perspectives?*
- The book closes with suggestions about how to become involved in autistic advocacy. *When it comes to issues that impact autistic people, what are the hills that you are willing to die on? What are ways you could advocate for causes that are important to you?*

Additional resource guides at https://www.delawareautismnetwork.org/.

Book Club Conversations brought to you by the DNEA.

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