

# **Neurodiversity, Autism Politics, and Language: A Brief Introduction**

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# Disclaimer

- The views represented in this presentation are not necessarily the views of the presenter or the University of Kentucky, except when the experiences and views of the presenter and the University are specifically discussed.

# Agenda

- Neurodiversity Paradigm
- Framework of Self Advocacy
- Language Use
- Community Politics and Struggles
- Avoiding Discrimination Case Studies
- Questions and End Discussion

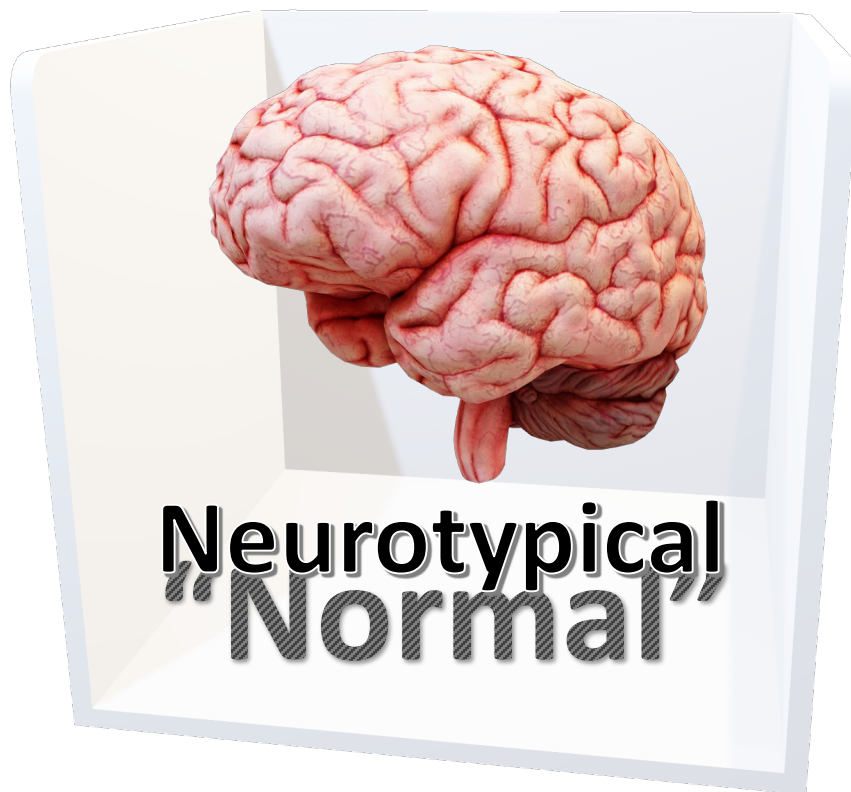
# Neurodiversity Paradigm

# The Pathology Paradigm

- Autism is a **neurodevelopmental disorder** that manifests as impairments in three primary areas of functioning:
  - communication and play
  - social relatedness
  - restricted interests and activities



## Neurodivergent



## The Neurodiversity Box



# Defining Neurodiversity

- Nick Walker, an Autistic Self-Advocate has developed an expanded definition of Neurodiversity
- Neurodiversity holds that, “there is no ‘normal’ style of human brain or human mind, any more than there is one ‘normal’ race, ethnicity, gender or culture” (Walker, 2012, p.228).
- Walker (2012), goes on to explain that the, “...dynamics of power, privilege, and marginalization... that manifest in society in relation to other forms of human diversity...also manifest in relation to neurodiversity” (p. 228).
- According to Walker, the concept of neurodiversity was developed as part of an effort to move away from a pathology paradigm for autism and toward the consideration of autism as an identity.

# Neurotypical and Neurodivergent

- Neurotypical
  - Adjective
  - “Not affected with a developmental disorder and especially autism spectrum disorder; exhibiting or characteristic of typical neurological development”
  - First used in 1994 (Meriam Webster)
- Neurodivergent
  - Adjective
  - “having a mind that functions in ways which diverge significantly from the dominant societal standards of “normal.””  
(Walker)



# What's Considered Neurodivergent

- Autism
- The rest of the list is a matter of debate
  - Dyslexia
  - ADHD
  - Intellectual Disabilities
  - OCD
  - Language disorders
  - Tourette's Syndrome
  - Schizophrenia
  - Schizo-Affective Disorder
  - Antisocial Personality disorder
  - Dissociative Disorders

# To Summarize

- Neurodiversity = Everyone
- Neurodivergent  $\neq$  Autism
  - Instead Neurodivergent = Autism + Other Disorders
- Neurodiverse  $\neq$  Neurodivergent

# Higher Ed- A Dual Responsibility

- Higher Education is in a unique position in that we need to exist simultaneously in the pathology and identity paradigm of neurodiversity
  - Our obligations to the pathology paradigm are defined in the Americans with Disabilities Act, and our obligations to a protected class for the purposes of identifying discrimination.
  - Our obligations to the identity paradigm rest in our mission to provide students with development and growth

# Framework of Self-Advocacy

“The object of autism advocacy should not be a world without autistic people- it should be a world in which autistic people can enjoy the same rights, opportunities and quality of life as any of our neurotypical peers.”

Loud Hands, Chapter 4

Ari Ne’eman- Founder Autistic Self Advocacy Network

# A Brief History of Self-Advocacy

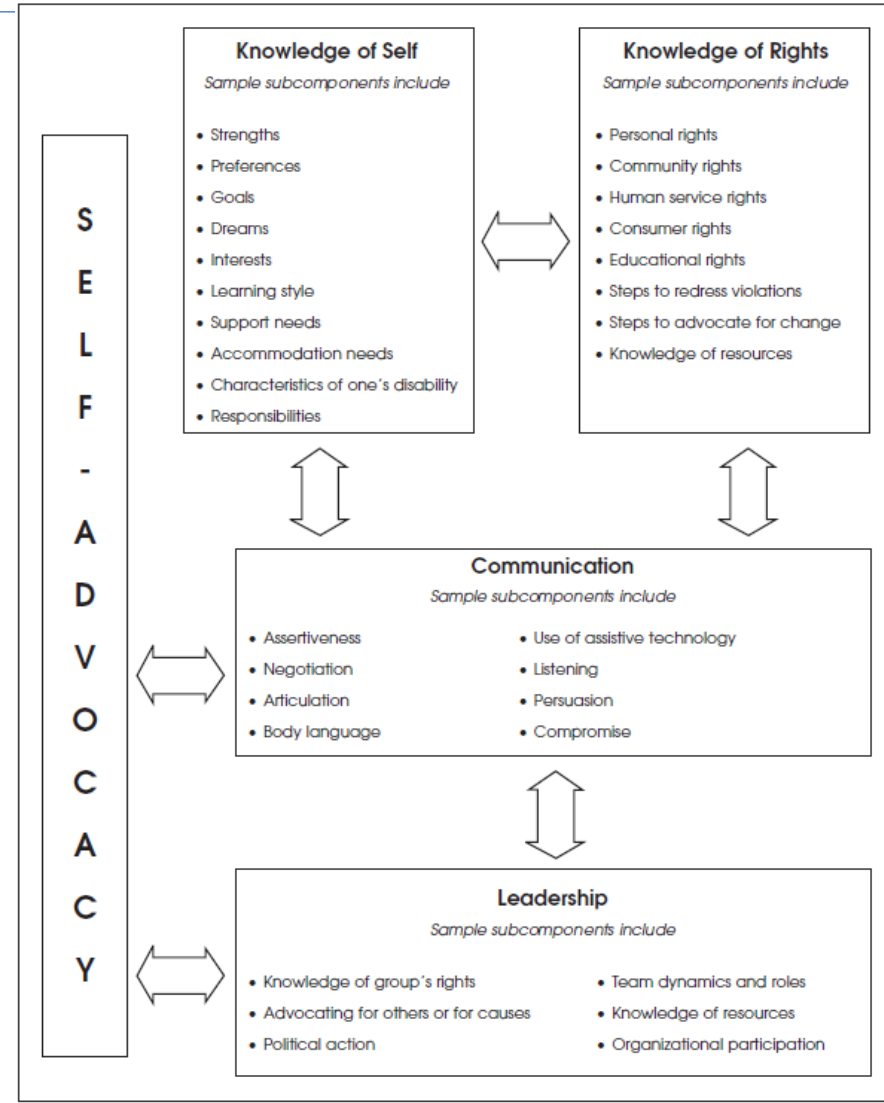
- Self-advocacy emerged out of the concepts of the civil rights movements from the 1950s-1960s, the end of mental institutionalization in the 1970s and the concept of self-help in the 1980s.
- The first organization devoted to self-advocacy was People First, an organization that developed into organizations of different names around the world, which was responsible for activism and the emergence of the idea that the voices of people with disabilities should be the primary voice for their disability (Test, et al, 2005).

# Self-Advocate and the Institution

- It is the objective of a self-advocate to demonstrate that they are capable of making decisions about themselves while challenging those that do not agree.
- A self-advocate will also challenge the overprotection of professionals.
- This is to gain autonomy and is seen as a critical skill in the adult development of a person with disability, especially students.
- Self-advocacy is seen as a sub-skill of self-determination.
- The role of the educational structure is seen as providing education in self-advocacy to students with disabilities, therefore giving them the ability to move beyond the structured support offered in education in the United States.
- This can be done through modeling and practicing skills as well as including students in the development of their accommodations, preferably at an early age (Test, et al, 2005).



# Test et al's Conceptual Framework of Self- Advocacy for Students with Disabilities (2005)



Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special education*, 26(1), 43-54.

# An example: The Autistic Self Advocacy Network

- Founded in 2006
- Works in several areas to advance the rights and care of Autistic people
  - Produces policy briefings and policy change tool kits for advocates
  - Hosts a Summer Leadership Academy for autistic undergrads
  - Developing state level organizations
  - Developing practical guides for autistic people on navigating college, receiving services,
  - Offers scholarships to autistic students
  - Developed Autism Acceptance month and the Disability Day of Mourning.

# A Matter of Language

Which of these sounds right to you?  
“Man with Autism” or “Autistic Man”

"As AHEAD moves to promote concepts of disability informed by social justice, we are adopting identity-first language across all communication, information and materials. This is not a directive or a recommendation about how others should identify; it is one way to model new thinking on disability that we see reflected in disability studies and in the disability rights community."

## AHEAD Statement on Language

<https://www.ahead.org/professional-resources/accommodations/statement-on-language>

# Identity-First versus Person-First Language

- The question is whether or not Autism is part of an identity.
- Many self-advocates consider it an inherent part of their identity, something inseparable
  - Similar to race, gender, or sexual orientation
- Conversely, most parents and professionals prefer to emphasize the humanity of their children and clients by putting the person first.
- It is seen as reclaiming a previously offensive term.
- It goes to whether Autism is a disease or a condition.
- Authors writing journal articles on issues surrounding autism identity use either one term or the other.



When we say “person with autism,” we say that it is unfortunate and an accident that a person is Autistic. We affirm that the person has value and worth, and that autism is entirely separate from what gives him or her value and worth...Yet, when we say “Autistic person,” we recognize, affirm, and validate an individual’s identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something.

## Lydia Brown, Autistic Self-Advocate

Autism Self-Advocacy Network, 2011

# Functioning Labels

- “High Functioning” vs. “Low Functioning”
- Generally defined based on speech and support needed
- Practically, it might help determine accommodations and therapies.
- But, it doesn’t quite work, functioning labels also present problems on multiple levels because the division between groups is unclear



# Additional Language Issues

- “Mental Disorder” vs. “Cognitive Difference”
- “Differently abled”
- “Intellectual Disability” vs. “Cognitive Disability”
- “Battling” a “stolen” “wall”.

# Old Wounds Run Deep- Autism Politics

# The Autism Speaks Issue

- Autism Speaks presents major issues for neurodivergent individuals
- While Autism Speaks has worked to improve its image, the autistic community is still distrustful of the organization
- Some of these issues include
  - Lack of Autistic Representation at the executive board level
    - Currently, only one openly autistic person is on the board
  - Lack of funding for actually autistic people
    - Only 1% of Autism Speaks budget goes toward funding services though the family services grant program, while executive members are highly compensated
  - Autism Speaks historically uses language portraying autism in a negative light.

# Diagnosis Issues

- Students seeking a diagnosis, particularly after K-12 education, may face barriers to access including
  - Cost
  - Access to Specialists
  - Fear and mistrust of specialists
  - Issues describing symptoms
  - Complexity of healthcare system

# Content Warning

- The next seven slides discuss content that may be disturbing to some attendees including
  - Discussions of treatment practices that can be considered abusive or torturous
  - Discussion and video of a negative police interaction resulting in an autism meltdown

# The Applied Behavioral Analysis Issue

- Usually, the only type of behavioral therapy funded by government grants/programs
- Autistic adults, have issues with types of ABA. These include:
  - Similarities to animal behaviorism and conditioning
  - Instructing children in a compliance-based program, making them a possible target for abuse.
  - Lack of consent
  - Risks of future burnout from the stress of working to “pass” as neurotypical
- In lieu of ABA, Autistic adults suggest a child-led approach and treatment such as DIR/ Floortime.
- Members of the Autism Spectrum protested the 2022 ABAI conference in Boston specifically regarding ABAI’s relationship with the Judge Rotenberg Center

# The Judge Rotenberg Center

- Residential facility in Canton, MA
- The facility is the last in the US to use graduated electronic decelerators (skin shock devices) to control clients
- The center has been consistently criticized by various organizations including the United Nations Special Rapporteur on Torture and the Department of Justice.





# JRC Current Situation

- After years of advocacy, the FDA passed a final rule banning the use of the devices in 2020
  - This decision was overturned by federal courts in 2021 saying the FDA did not have statutory authority to ban a device for a particular use
- In June 2022, the US House included provisions banning GEDs in the Food and Drug Amendment Act of 2022 which then passed.
- An amendment in the December 2022 omnibus bill affirmed the FDA's right to ban contingent shocks used for behavior modification
- The FDA must now reauthorize the rule passed in 2020

# Discrimination Case Studies

# Buckeye, AZ Autism/Police Interaction

- In January 2018, police believed a 14-year-old autistic and intellectually disabled teen was under the influence of an inhaled substance, when he was engaging in self-stimulating behavior
  - Notably the teen's caretaker would not let the teen stim in the lobby of the building they were at.
- The police officer grabbed the teen and attempted to restrain him, creating a meltdown situation.
  - Further the caretaker immediately assumed that the teen had 'hurt someone' before explaining to the officer what stimming was.
- The family is suing for \$5 million, wants a personal apology from the officer, for the officer to do community service with the autistic community and for the department to receive training. The lawsuit went to trial on February 21, 2023
- The officer was cleared of misconduct by an internal investigation and eventually retired under a disability claim.

# Arizona Journal Video of Officer's Body Cam



# Questions to consider

- Is my Campus Safety or Police trained to work with neurodivergent individuals?
  - What is “Stimming”?
  - Why do you think he started shouting, “I’m okay”?
- If this happened on my college campus, how would I respond?

# Iris Allen

- Allen was an autistic trans first-year student of color at Hampshire College in MA, studying Music Theory in Fall 2017
- Allen was removed from campus for “a threat [that] was made to members of our campus community,” according to the college.
- News reports indicate that the student threatened to, “shoot up the campus with a Glock.”
- Allen was found responsible in a student conduct process for, “violations related to civil behavior and disruption, failure to comply and threatening and intimidating behavior. The nature of the violations was not specified. He was not found responsible for bullying.”

## Iris Allen (Contd)

- Additionally, the finding said, "'As you know, you were presented most recently with a behavior contract in which you specifically agreed that you would refrain from any further inappropriate conduct, including threatening behavior and/or using words, actions or implied threats that may generate reasonable fear in another person,"
- Allen was then suspended through the spring semester for, "for outbursts and panic attacks that were related to his autism," according to supporters. Allen was also suspended from two other area colleges since they share a police department.
- Allen is also homeless. Following the suspension, Allen reported he was left by local police at a McDonald's and then lived in a hotel.
- Allen appealed the decision, but the appeal was denied. A third appeal was also denied.
- The college says, "We have not been able to publicly correct or address the accuracy gaps in the narrative due to privacy laws related to a student's academic record,"
- It is unclear if Allen ever returned to Hampshire College



# Allen- Questions to Consider

- Does your school have a Behavioral intervention team?
  - Does your DRC have representation on that team?
- Do you have a clear separation between behavioral intervention and student conduct?
- When doing threat assessment, how much weight should be given to current mental status (i.e. a meltdown)?
- How would you react if this happened at your school?



# Niko Boskovic

- In April 2017, he won a trip to the United Nations in New York through the Independent Order of Odd Fellows.
- Niko is non-verbal and communicates with a letter board. Once the national organization found out that he was autistic, they rescinded his prize.
- The organization would only give their reasoning as ‘we are not equipped to accept people with disabilities’ to local lodge members.
- The local lodge of the organization filed a complaint. Eventually, Niko was allowed to go on the trip, after intervention by local disability rights groups.

# Boskovic- Questions to Consider

- How do you collaborate with study abroad, alternate break, or other traveling groups at your institution?
- Would having an aide or alternate communication on a trip be considered a reasonable accommodation?



# Oxford University

- In April 2017, The Equality and Diversity Unit published a list of racial micro-aggressions
- The list included “Not making eye contact or speaking directly to people.”
- After an outcry on Twitter, the university apologized saying, ““We made a mistake. Our newsletter was too brief to deal adequately and sensibly with the issue. We are sorry that we took no account of other reasons for difference in eye contact and social interaction, including disability. Oxford deeply values and works hard to support students and staff with disabilities, including those with autism or social anxiety disorder.”
- <http://www.bbc.com/news/uk-england-oxfordshire-39742670>

# Oxford- Question to Consider

- Are you training your campus departments, including your DEI departments on working with neurodivergent individuals?

# Resources and Questions



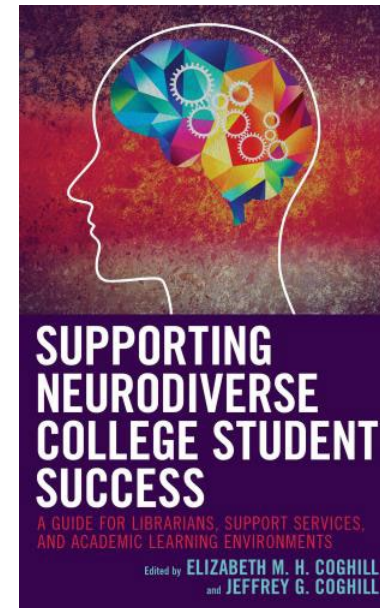
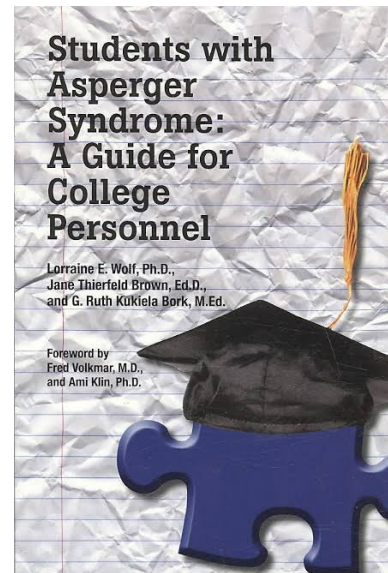
# Stairway to STEM

- Stairway to STEM is a 501(c)(3) tax-exempt organization funded in part by a grant from the National Science Foundation
- “Stairway to STEM is a (free) online resource for autistic students, their parents, and post-secondary STEM instructors: our mission is to help students on the autism spectrum realize their capacity for success as they transition to collegiate environments and beyond, as well as to build their confidence, resilience, and self-efficacy.”
- [www.stairwaytostem.org](http://www.stairwaytostem.org)
- “Institutions of Higher Learning and their Resources- Your Mileage WILL Vary”
- “The Accommodations Process, a Primer for Faculty”
- “On Mentorship”, with Dr. Jen Heemstra, Emory University, Georgia
- “Steps to Autism Acceptance Podcast, Episode Three: Communication Within Interpersonal Relationships”
- Presenter is an Editorial Board Member for Stairway to Stem and was compensated for time spent working for the organization.



## The Bookshelf: General Autism Resources

*Students with Asperger Syndrome: A Guide for College Personnel*  
By Lorraine Wolf, Jane Thierfeld Brown, and G. Ruth Kukela Bork

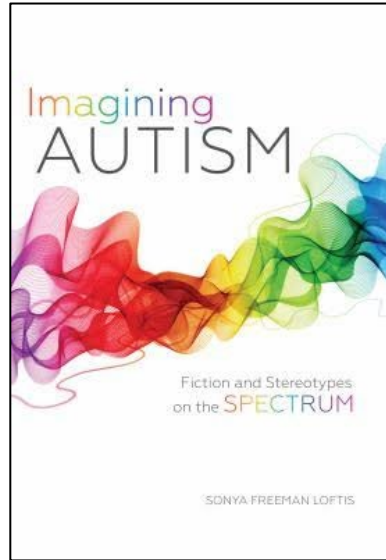


*Supporting Neurodiverse College Student Success: A Guide for Librarians, Student Support Services, and Academic Learning Environments*

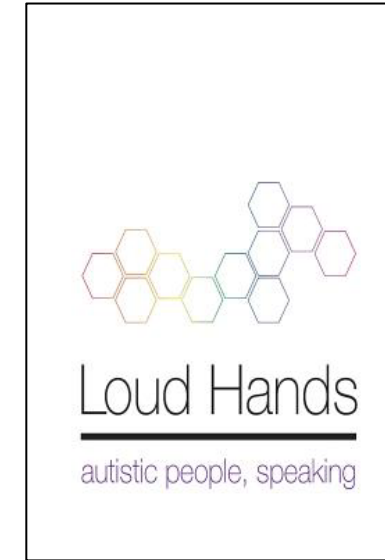
- “Chapter 2, Self-Advocacy”-with Elizabeth MH Coghill

## More on Autism Identity

*Imagining Autism:  
Fiction and  
Stereotypes on the  
Spectrum*  
by Sonya  
Freeman Loftis



*Loud Hands:  
Autistic People,  
Speaking*  
Edited by Julia  
Bascom



ASAN Sites:

[Autisticadvocacy.org](http://Autisticadvocacy.org)

[www.autismacceptancemonth.org](http://www.autismacceptancemonth.org)

[Disability-memorial.org](http://Disability-memorial.org)

# College Autism Network

- A joint-neurodivergent/neurotypical collective of educators, program directors, employers, and researchers dedicated to improving access, experience, and outcomes for autistic college students.
- Also hosts the annual College Autism Summit (October 12-14, Nashville, TN)
- <https://collegeautismnetwork.org/>

# *Student Affairs NOW* Episode

## Autistic & Neurodivergent College Students



John Caldora   Brett Ranon Nachman   Emily Raclaw   Lee Burdette Williams

HOSTED BY  
Heather Shea



<https://studentaffairsnow.com/neurodivergent/>

# Selected Works Cited

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- Walker, N. (2012). Throw away the master's tools: Liberating ourselves from the pathology paradigm. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 225-237). Washington, DC: The Autistic Press



# For More Information

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