Shaping the Future of Autistic Student Engagement

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Programming Note: The Other Session

• This session provides a comprehensive overview of the Autism Spectrum, including prevalence, symptoms, accommodation and intervention strategies as well as a brief overview of the Neurodiversity Paradigm

• For more information on Neurodiversity, Autism Politics and Discrimination, please see the slide deck from my previous presentation

• 6:9 “Neurodiversity, Autism Politics, and Language, a Brief Introduction”
Agenda

• A Brief Survey
• Prevalence in Higher Education
• Recent History of the Autism Community
• Neurodiversity Paradigm
• Adapting and Responding to Neurodivergent Issues
• Autism Support Programs- A Larger Intervention
• Discussion and Questions
Survey of Room Experience

• Please signal if you feel the following statements apply to you
  • I am a member of the autism spectrum and I’m okay with disclosing that.
  • I have worked with autistic students on a regular basis in my role
  • I have occasionally worked with autistic students
  • I do not believe I have ever worked with an autistic student
Prevalence
Why are we talking about this?

• The current prevalence rate of Autism in the US is 1 in 44 (CDC)

• 75% percent of youth with Individual Education Plans (IEPs) who have been diagnosed with autism or other emotional disabilities expect to obtain post-secondary education (Lipscomb, Haimson, Liu, Burghard, Johnson & Thurlow, 2017)
  • Contrast with approximately 55% of parents who have the same expectation

• A 2011 Virginia Tech study of a large sample (n=667) of students at one institution revealed that Autism prevalence in college students stood between .7 and 1.9 percent (White, Ollendick, & Bray).
Prevalence vs Registration for Disability Services

• In Fall 2021, the University of Kentucky had an enrollment of 31,776

• Based on the 2011 VT study, the autistic population of UK should be between 223-604

• However, registrations with the DRC for autism that same semester hovered around 68

• Why?
Recent History of the Autism Community
Before the Internet

• The building of Autistic community happened at the fringes of conferences for parents and professionals regarding autism.

• A newsletter was started in 1992 by Autism Network International.

• This created opposition among parents and professional groups for reasons that were unclear, but surprisingly common in early self-advocacy and self-determination movements for all disabilities.

• In response the first online forum for Autistic people was created.

• Eventually, the first Autistic-led Autism Conference, Autreat, started in 1996
What the Internet meant to the Autism Spectrum

• Autistic people regularly possess systematic spatial reasoning, a key concept in understanding and using computers.

• The Internet allows members of the spectrum to focus on the substance of a conversation more than in the nuanced world of vocal and face-to-face conversations.

• Through text-based conversations on the internet, members of the autism spectrum can demonstrate intelligence, eloquence, and empathy, often by allowing members of the spectrum to consider phrasing, in essence, thinking before they speak (Jordan, 2010).
The Internet in Autism Community Building

• The Internet provides options for advocacy and communication not available to such a diffuse group, providing support that Autistics, especially those in isolated areas, may not be able to find locally. This, therefore, can help with feelings of isolation.

• Further it can provide a connection for members on the spectrum to help them make sense of autism and the wider world. Autistic members like communicating on autism message boards not only about the spectrum, but about their interests and how autism affects their lives (Jordan, 2010).

• Further, organizations such as the Autistic Self-Advocacy Network (ASAN) hold their volunteer meetings through a text-based online system so Autistic volunteers feel comfortable communicating.
2013 Changes to the DSM

• Four separate disorders, including Asperger’s Syndrome were combined into “Autism Spectrum Disorder” (ASD)

• Most studies seem to indicate that between 50-75% of individuals who were diagnosed under the DSM-IV would also be diagnosed under the DSM-5
  • The greatest decreases were in the following groups: IQ over 70, previously diagnosed with PDD-NOS, or Asperger’s Syndrome. (Smith, Reichow, and Volkmar, 2015)
  • At the same time, some individuals who were not eligible for an Autism diagnosis were now eligible for a diagnosis of Social Communication Disorder (Kulage et al, 2020) (315.39 (F80.82))
Impact of 2013 Changes

• This change provoked substantial confusion within the Autistic Community regarding
  • Diagnostic criteria and the trustworthiness of diagnosticians
  • The impact of being able to ‘pass’ as neurotypical
  • The value of self-knowledge of diagnosis and group affiliation
  • The impact of Official vs. Self-Diagnosis (Parsloe and Babrow, 2016)
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

Neurotypical “Normal”

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 ≠ Autism
  • Instead Neurodivergent = Autism + Other Disorders
• Neurodiverse ≠ 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
Adapting and Responding to Issues of Autism
Signs of Neurodivergence

• Unusual social communication
  • Different approach to communication
  • Increased or decreased interaction
  • Non-verbal communication disconnect
  • Decreased or increased eye contact
  • Issues in developing, maintaining, understanding relationships, friendships
  • Issues in understanding social and conversational norms
Different Approach to Communication

• Members of the Autism Spectrum may communicate verbally or through Augmentative and Alternative Communication (AAC)
  • This could include a word board or an AAC device
  • It may also include communication through text or a smart device during a meeting
  • Member’s communication style may change from day to day or over time

• What strategies can you adapt to assist students?
A Word on Eye Contact

• Eye Contact may be uncomfortable for members of the autism spectrum.

• They will still be paying attention to conversations even if they do not make eye contact.
Signs of Neurodivergence

• Unusual Behavior
  • Repetitive movements or speech
  • Avoidance of change, use of rigid routines and communication patterns
  • Unusual living habits
  • Intense interest in special interests
  • Hyper or hypo reaction to sensory inputs, (pain, sound, texture, lights, smell, etc).
Repetitive Movements- Stimming

• Helps to regulate emotional and sensory input
• Could be rocking, clapping, dancing, making noises (laughter, humming etc).
• Could involve an object (Fidget spinner, fidget necklace)
• Chances are you do it too.
• Unless it is self-injurious or destructive, leave it alone!
The Natural Rhythm of Stimming
Sensory Issues

• In meetings and in life members of the Autism spectrum may be hypersensitive or hyposensitive to sensory issues (light, smell, sound, etc).

• It can be helpful to have a desk lamp or low light option
  • Keep in mind that certain types of light produce more issues

• Also students may use a stim toy
Special Interests

• Can be anything
• Can change over time
• Could have career applications
Accommodation Considerations

• Many accommodations are the same as other students with disabilities.

• Housing Accommodation
  • May need private ‘space’

• Classroom and Testing
  • Fidget Devices
  • Moving around classroom and testing area
  • Breaks
  • Private testing spaces
  • Sensory accommodations

• Developing a plan for responding to emergencies
Difficult Conversations with Neurodivergent Students
Tips for having difficult conversations

• Context and Background are CRITICAL!
  • If this conversation is the result of a university policy or procedure, show that procedure
  • Assume that you may need to explain the social context behind the case
  • Do not deal in absolutes, unless it is an absolute
  • Be specific
  • Use examples in lieu of smile or metaphor

• Understand that emotional reactions may look different
  • Emotions may be under or overstated
  • Reactions may look scary (but probably isn’t dangerous)

• If possible, you may need to take a break.
• Reduce sensory inputs (if you have a floor lamp, this is a great time to use it)
Social Context

• Social context and understanding that comes naturally to Neurotypical people may look different in Neurodiverse people

• Examples include
  • Eye contact
    • Do not assume a lack of eye contact is a lack of engagement.
  • Courtesies (please, thank you, holding doors, etc).
    • Neurodivergent people may need to be taught the social context and reason behind courtesies

• Romantic Behavior
  • Neurodivergent people may misinterpret friendly gestures as flirting, or not understand flirting if it occurs
  • Neurodivergent individuals may not understand the difference between flirting and stalking.
So, that bit about reactions

• An extreme emotional or sensory event may result in some form of physical expression, if severe enough this may be what is commonly referred to as a “meltdown”

• In most cases, meltdowns, while appearing to be violent, are not. In the few cases that are, this violence is usually expressed as mild-self injurious behavior (hitting the head, hitting an object, etc).

• The best thing you can do is give the student physical and mental space; this may involve leaving the room if you can do so while keeping an eye on the situation.

• Also, reducing sensory inputs (lights, speaking in a soft tone, etc) can help.
  • Do NOT touch the student

• If you feel concerned for your safety, leave the area, and follow appropriate emergency procedures.

• Ensure your campus police/safety are trained in deescalating these incidents.
What a Meltdown Looks Like
Conflict Resolution with Neurodivergent Students
Proactively Handling Roommate Conflicts

• Be Proactive!
  • Take time to sit with the roommates during roommate agreement development to make sure that clear expectations are set that students will hold themselves accountable to.

• Keep in mind sensory concerns
  • Dealing with smells (perfume, body spray), sound, and light as part of your standard roommate agreement makes this equitable for all

• Keep things reasonable
  • It is unfair to expect ‘absolute’ quiet or absolutely no smell, or absolute cleanliness (or no cleanliness). Explain why, using examples

• Be specific
  • What sound making devices are included in quiet time, what is the definition of clean?
Mediation

- In addition to applying the standard rules and philosophies of mediation with neurodivergent populations, here are some additional points to emphasize:
  - Make sure to lay out the rules of a mediation and hold parties to them
  - Help students to recognize the impact of their behavior on not only the other party, but on themselves
  - Work to develop SMART solutions
  - Recognize that incremental changes over time may be more effective than trying to solve everything in one meeting.
  - Understand that neurodivergent people may be resistant to change
    - Try to work changes into current routines
  - Do NOT out the student as neurodivergent
Common Career Issues for Neurodivergent People
Strengths and Goals

• Mostly, this is just like any other student
  • Strong interest survey, StrengthsFinder, etc.
• Converting Neurodiversity into strengths
  • But don’t stereotype
• Reframing perceptions of self and weaknesses
• Converting a special interest into a career
• Reviewing what feedback and evaluations may look like
The Interview

• Considering Verbal and Non-Verbal Cues, how to read them and how your cues are read
• Scripting responses to common questions
  • And then making them sound not scripted
  • And dealing with trick questions like “what would you identify as your greatest weakness?”
• Dealing with “professional attire” and sensory issues surrounding it.
• Following up after the interview
Disability Disclosure

• Disclosing or not disclosing your disability, how, when, why, and if you should?
  • Realistically, disability discrimination in a hiring process is difficult to prove without an overt sign

• What sort of accommodations can an employee request?

• What is considered an essential function of a job?

• The function and audience of an average Human Resources department vs the function and audience of the UK Disability Resource Center.
Networking *(shudder)*

- Focus on types of networking beyond the cocktail hour or the job fair.
  - Effects of presentations, of demonstrating work, of creating natural connections in the workplace
- What sort of networking works for the student?
- Is the networking worth the energy?
- Can networking backfire?
- Developing a positive social media presence, networking through LinkedIn, Facebook, or another social media
Workplace Environment and Culture

• Choosing a work environment that works for them
  • Sensory implications
  • Accommodations and acceptance of disabilities
  • Supervisors with the right kind of previous experience
  • Considering the post-COVID era of remote work

• Workplace cultural issues
  • Professional Communication
  • Different types of office hierarchies and their implications
  • Collegiality and the unwritten rules of the watercooler.
Stress Management

• Job searching, interviews, and employment are stressful
• For neurodiverse individuals stress management may look different, or stress may have different causes.
• May need to work with students to explore coping strategies, especially related to interviews.
  • The extensive socialization required for an interview, especially an in person, or phone interview can be very draining.
  • Practice, teaching students how to take a break, subtle stim toys may help
  • Reminding students to take their time.
• Working to resolve and mitigate stress in the workplace
  • Could accommodations help?
  • Finding work that is appropriate to student’s stress tolerance
  • Making sure employment is a good ‘fit’
Examples of Neurodivergent Employment Programs

- Dell Autism Hiring Program: https://jobs.dell.com/neurodiversity
- Ernst & Young Neurodiversity Center of Excellence:
- auticon, US: https://auticon.us/
- SAP Autism at Work: https://www.sap.com/about/careers/your-career/autism-at-work-program.html
- Ultranauts: https://ultranauts.co/
Process and Service Issues for Neurodivergent Students
Steps to Make Processes and Services Neurodivergent-Friendly

• Is it logical?
  • Can you articulate why each step is present in a process? What is it meant to achieve?

• Provide information about the process through multiple means
  • Can it be demonstrated as a flowchart or other visual media?

• Be Specific
  • Make sure you are not assuming bases of knowledge that may not be present.

• Communicate deadlines well in advance, and close to the deadline

• Be Equitable
  • Especially in Hiring Practices

• Don’t reinvent the social skills wheel
  • Especially with ice breakers.
Case Studies for Different Staff Populations
Case Study for Residence Life Staff

• Andrew is a freshman student at living in a suite-style residence hall this semester. Andrew often locks himself out and has used the three free lockouts allowed within the first month of school. He has now racked up over $100 in lockout charges by the end of September. You are meeting with Andrew to try and resolve the situation. You know Andrew is neurodivergent due to his disclosure to an RA at the beginning of the year.

• What will you do to prepare your office for the meeting?
• What points will you address with Andrew and how would you address them?
• Why do you think Andrew keeps locking himself out of his room?
Case Study 2 for Residence Life Staff

- Alex is a diagnosed neurodivergent student living in a three person-suite on campus. Alex has recently been reported to the Behavioral Intervention Team due to their roommates, Angela and Blake reporting that Alex ‘flips out’ at night when they are trying to sleep. Alex will often bang their fists against their head and make groaning noises. BIT staff met with Alex who revealed the issue is a sensory sensitivity to the bathroom light/fan combination which Angela insists must be on at night, with the door open. They send the issue back to residence life staff for roommate mediation. During the preparation for the mediation, it comes out that Angela has PTSD and that light and sound in the bedroom is a coping mechanism.

- How would you approach this mediation?
- What are some possible solutions that would be equitable to all parties?
Case Study for Academic Advisors

• Christie is a business major. Christie has struggled academically with her upper division courses. During her junior year she failed a required course. Having used her repeat options previously, she believes that she will be unable to progress in her program. She walks in to meet with you, her hands are shaking, she is speaking loudly, and her thoughts seem to circular in nature.

• How should you interact with Christie?
• What alternative options does Christie have to resolve this?
• What can you do to prevent Christie from experiencing such issues in the future?
Case Study for Career Services

- Andrew is an autistic graduating senior. He had a Zoom interview scheduled as an American History researcher for the Smithsonian. This is an excellent opportunity in his field, and he is excited. As the day of the interview came, he realized that his camera and speakers were working, but his microphone made him “sound like Darth Vader.” He sent an email to the hiring committee asking for the interview to be delayed. After trying to resolve the issues, eventually he had started the interview via phone. During the interview, he was flustered and the interview only lasted 20 minutes with about five questions. He was told the position would be selected in the next few weeks. After the interview, he comes to you, speaking quickly, hands shaking, asking for advice.
College Autism Support Programs
College Autism Support Programs

• An Autism Support Program provides additional supports for autistic students beyond legally required accommodations under the ADA or Section 504

• Students in these programs are typically admitted to an institution through their standard admissions process and work to complete a college degree in line with institution and program standards

• Support offered may include
  • Social and Life Skills Support
  • Dedicated Mental Health Support
  • Tutoring
  • Peer Mentoring
  • Specialized Orientation
  • Dedicated Advising
Types of Autism Support Programs

• There are presently over 120 Autism Support Programs in the United States which can be divided into four categories:
  • Non-Fee-Based Programs
  • Fee-Based Institutional Programs
  • Dedicated Institution
  • Private Programs
The Support Program Market
Why NESI?

- Limited support for neurodivergent identity, social, and community development
- Needed to coordinate and centralize services for neurodivergent students
- Half of the SEC had established or are establishing Autism Support Programs
- Within 250 miles of UK, there are thirteen paid autism support programs at IHEs, one private program, and three programs at IHEs offered at no charge
- Needed more to fill service gaps for existing students than advertise to recruit and attract new students.
Introducing NESI

- Designed to supplement existing services offered across the University specifically in creating a sense of belonging and educational opportunities for neurodivergent students.

- Designed with as few barriers to access as possible:
  - No Additional Cost to Students
  - No Formal Diagnosis Required
    - All that is required is a desire to learn about neurodiversity and find a space to belong at UK.

- NESI is not a counseling program and does not replace therapy or other psychological treatment options.
Current Status

• Increased connections for staff and faculty regarding best practices to serve neurodivergent students.

• Provided education on working with and supporting neurodivergent students to many student facing staff and student workers.

• NESI Sponsored Organization
  • Sponsored by the DRC with a startup grant from the Office of Institutional Diversity
  • Started in Fall 2021
  • Student-Directed, Staff-Led Education
  • Provides a judgement-free Social Zone and education on neurodiversity, social, and life topics of interest to students.
  • Participate in board games and group activities
  • Meets weekly, usually in a face-to-face or hybrid setting.
  • 20 registered members, average six members per meeting
NESI Discussion Topics

- Academic Organization
- History of Neurodiversity
- Stress Management
- Career Development
- Managing Roommate Conflicts
- Academic Communication and Responsibility
- Managing Sensory Overload

- Resume Workshop
- Neurodiversity in the Media
- Requesting Accommodations in the Workplace
- Friendship Strategies
- Campus Social Life
- Neurodivergent Travel
- Libraries and Citation Resources
For More Information on NESI

• Visit our website:
  • https://uky.campuslab
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  
www.autismacceptancemonth.org  
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/](https://collegeautismnetwork.org/)
Selected Works Cited


Session Evaluation

Please point your phone at this QR code, or go to: tinyurl.com/AHEADeval

Your feedback helps shape future programming.
Thank you for attending!