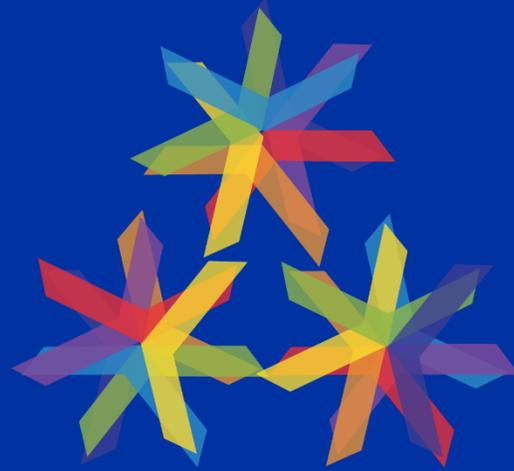# Shaping the Future of the Autism Spectrum

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Case Manager
Community of Concern, Dean of Students

Overview

- Defining Autism
- Self-Advocacy
- Cases to Consider
- The Autistic Community
- Autism Politics
- Further Reading

A Brief Disclaimer

- The views and opinions expressed within this presentation are those of the author and not of the University of Kentucky (except where practices of the University of Kentucky are discussed).

Why Autism Spectrum Disorder?

- 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).

- 32% of college age persons in the United States on the Autism Spectrum attend some form of college or university. (Wei, et al, 2012).

  - 81.33% of ASD college students attend 2 year institutions.

  - ASD students have higher persistence rates than non-ASD students in 2 year institutions (Wei, et al, 2013)

- Students on the spectrum are more likely to declare a STEM major then neurotypical students (Wei, et al, 2012).

Defining Autism

Autism as Disorder

- "Autism is a neurodevelopmental disorder that manifests as impairments in three primary areas of functioning: communication and play, social relatedness, and restricted interests and activities" (Freedman, 17)

Common Signs of Autism Spectrum Disorder

- Lack of Empathy

- Naïve, "Inappropriate," One-Sided Interaction

- Difficulty Forming Friendships and/or Relationships

- Pedantic, Repetitive Speech "Walking Dictionary"

- Unusual living habits

- Intense Absorption in certain subjects: "Special Interests"

- Clumsy, ill-coordinated movements and odd postures

  - Adapted from Attwood

Autism as Variant

- "Autism is a genetically-based human neurological variant"
  - Central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness
  - Tends to make autistic individual's subjective experience more intense and chaotic than non-autistic (neurotypical) individuals
- Exists on a spectrum of neurodiversity

Did that seem a little different?

- Developed by Nick Walker, an autistic self-advocate who created an introduction to autism that was:
  - consistent with current evidence
  - not based in the pathology paradigm
  - concise, simple, and accessible
  - formal enough for professional and academic use.
- He concludes with: "Autism is still widely regarded as a "disorder," but this view has been challenged in recent years by proponents of the neurodiversity model…Ultimately, to describe autism as a disorder represents a value judgment rather than a scientific fact."

Neurodiversity

"Holds that autism and other neurocognitive variants are…part of the natural spectrum of human biodiversity"

Neurotypical

- Adjective
- "Not affected with a developmental disorder and especially autism spectrum disorder; exhibiting or characteristic of typical neurological development"
- First used in 1994

Case Management Applications

- In both clinical and non-clinical roles we have to consider there are cases where it is important to focus on Autism as a disorder (such as when seeking accommodations) versus Autism as an identity variant (when encouraging acceptance and self-advocacy).

Self-Advocacy

Self Advocacy in Case Management

- According to NASW Case Management Standard 7, it is a goal of case managers that clients are able to work and speak for themselves, thereby developing self-advocacy and empowerment.

- This is also a critical part of the Student Affairs Case Management model by Davis (2010)

- When working with a student who is a member of the autism spectrum, such self-advocacy is critical to their future development and that of Autistic Identity.

"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(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, 2005).
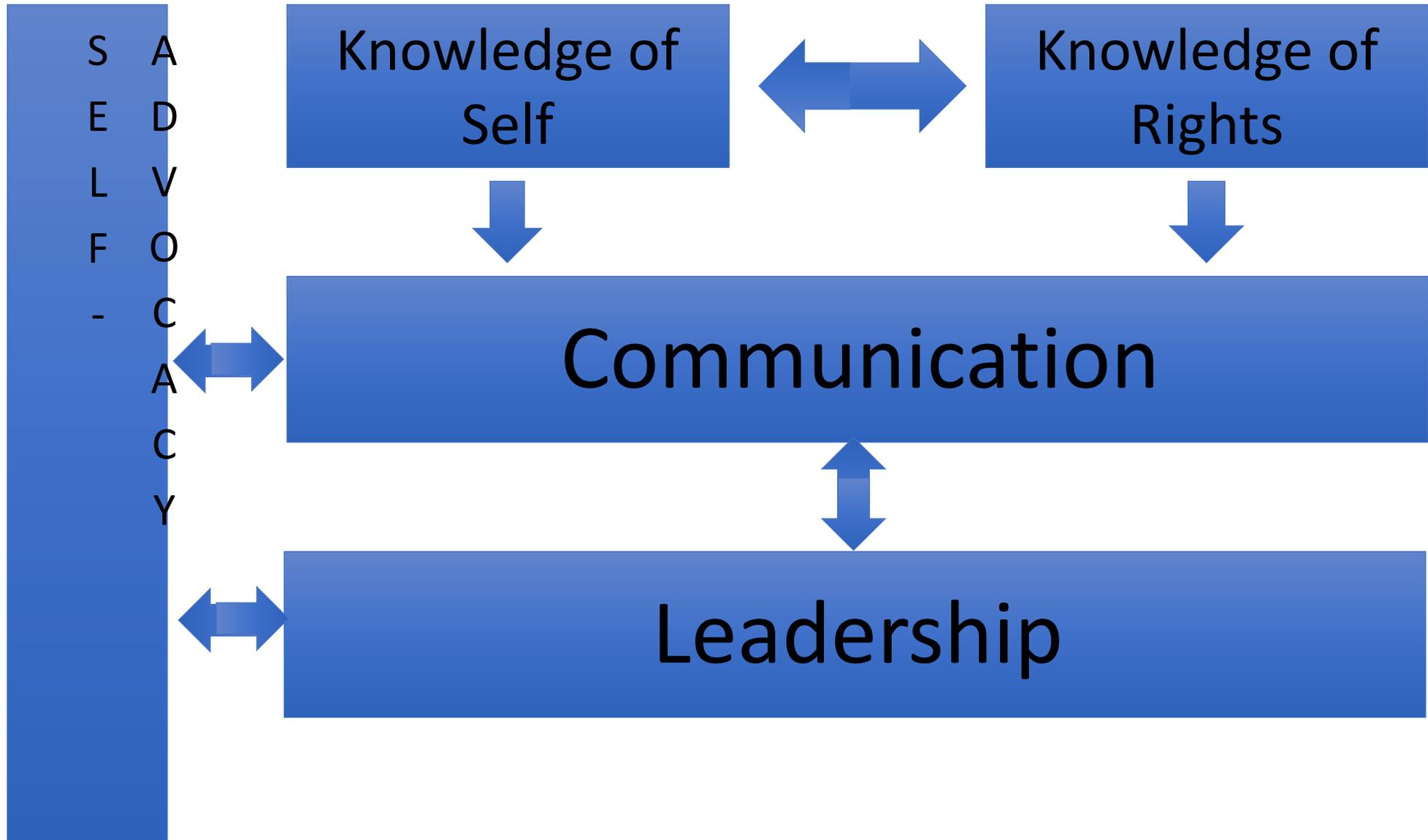
An example: The Autistic Self Advocacy Network

- 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.

Factors to Consider

Another Disclaimer

- The following slides rely on publically available information involving these incidents

- As case management know, that is often not the whole story. (ex. due to FERPA/HIPPA, etc.)

- Also: Trigger Warning for disturbing imagery and frank discussions of what can be reasonably defined as "torture"

Tasmin Parker

- 25 year old artist and animator
- In April 2018 she was ejected from a British Film Institute repertory cinema in London for 'laughing too loudly' during a showing of the 1966 'Spaghetti Western' *The Good, the Bad, and the Ugly*.
- Another man who spoke to her in a derogatory manner was later thrown out as well.
- Witnesses say Parker was laughing at the appropriate parts of the movie.
- The non-profit theater later apologized
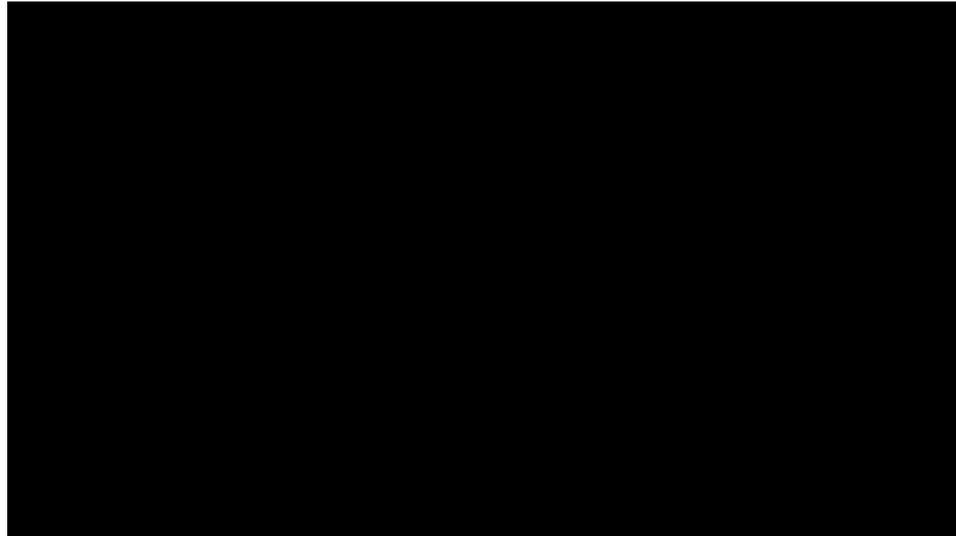
Questions to Consider

- Does my institution offer sensory-friendly events?
- Do my mandatory activities consider autistic people and others with disabilities?
- Are front-line staff (student and professional) trained on working with people with disabilities?

Buckeye, AZ
Autism/Police interaction

- In January 2018, police believed a 14 year old autistic teen was under the influence of an inhaled substance, when he was engaging in self-stimulating behavior

- The police officer grabbed the teen and attempted to restrain him, creating a meltdown situation.

- 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

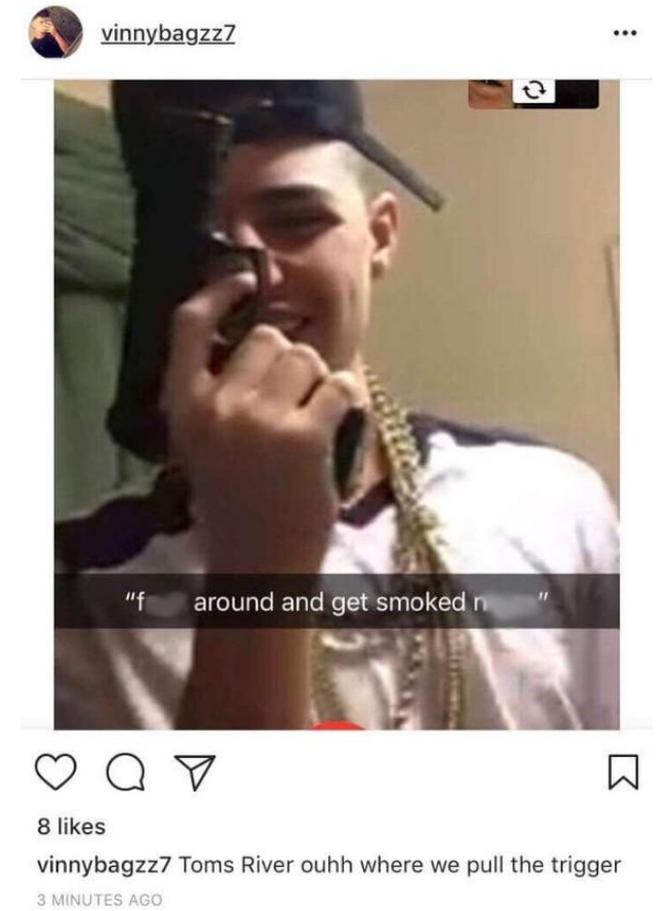https://www.youtube.com/watch?v=gjh81so
mDco

Questions to consider

- Is my Campus Safety or Police trained on working with individuals with disabilities?
  - What is "Stimming"?
  - Why do you think he started shouting, "I'm okay"?
- If this happened on a college campus, how would I handle it?

Vinny Smith

- 15 year old in Toms River, NJ with Asperger's posted this picture of a pellet gun March 12, 2018
- Picture was taken in December at his father's house.
- Taken into custody by police, charged with creating a false public alarm.
- Taken in for a psychiatric evaluation, released next morning.
- Suspended from school for 10 days with requirement for second psych eval.
- Previously in trouble with police for breaking a bench and arrested after an altercation with a school administrator.
- Has previously been suspended for 10 days earlier that month for fighting.
- Parents at a school board meeting were upset due to a lack of details due to FERPA.
- The student has since been enrolled in online schooling.

vinnybagzz7

"f   around and get smoked r   "

8 likes

vinnybagzz7 Toms River ouhh where we pull the trigger

3 MINUTES AGO

Questions to Consider

- What would your campus Threat Assessment Team do?
  - Do you have a plan or experience for assessing threats from social media involving gun-like devices?
- What sort of conversation can you have with this student?
- Can you tell people if a student is no longer enrolled at your institution?
- Think about case in context of Conduct policies or Involuntary Medical Leave. Where would this be in those procedures on your campus?

Iris Allen

- Allen was an autistic trans first-year student of color at Hampshire College in MA, studying Music Theory.

- 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 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."

- 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 struggled with transient living after the suspension.

- 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,"

- Friends have a YouCaring page open for Allen. There was also a petition to reinstate Allen.

Questions to Consider

- Are your Behavioral Expectations Agreements legally enforceable?
- When doing threat assessment, how much weight should be given to current mental status (i.e. a meltdown)?
- Does your institution have a plan if it has to suspend or interim suspend a homeless student?
- How to react to cases that have a sympathetic media following and sympathetic on-campus following?

The Judge Rotenberg Center

- Residential facility in Canton, MA

- The center uses, 'electric shock, sensory assault, food deprivation, and a host of other horrifying and aversive "treatments."' (Source: ASAN)

- The FDA has been considering a rule to ban the high level shock devices used exclusively at the JRC since 2014, but the process has stalled.

- The center has been consistently criticized by various organizations including the United Nations Special Rapporteur on Torture and the Department of Justice.

- In 2016, three staff members were arrested in two separate incidents and charged with assaulting students at the center.

https://www.youtube.com/watch?v=oFYae6WyTWs

#StopTheShock

- For more information on how you can help: please visit http://autisticadvocacy.org/stoptheshock/

The Autistic Community and the Internet

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

Jim Sinclair, Loud Hands, Chapter 2

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.

Case Management Applications

- Could these differences in communication lead to students being better served by online classes?

- How can we encourage positive interactions for these students?

A Matter of Language

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

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

Loftis, *Imagining Autism*, 2015

Additional Language Issues

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

Loftis, *Imagining Autism*, 2015

Case Management Applications

- Using what a student is comfortable with

- Informing them of identity options

- Do functioning labels serve a purpose?

The Politics of Autism

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)

- 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)

Narrative and Counter Narrative

- The main narrative for Autism today is provided by Autism Speaks, the world's largest Autism charity.
- Autistic Self-Advocates have significant issues with the organization including:
  - A lack of Autistic Representation at the executive board level
    - In December 2015, Autism Speaks addressed this by adding two autistic people to their board
  - Language
    - Autistic Self-Advocates take issue with language used by Autism Speaks that considers Autistic people as "tragic burdens."
  - Scientific and Funding Issues
    - Autism Speaks continued to advance the idea of vaccinations as a cause of Autism, long after the theory was discredited
    - Much of their funding is currently devoted to prevention and prenatal testing for autism. Only 3% of the entire budget goes to funding services.

ASAN, Autism Speaks

Context: The Cure Debate
Should there be a cure for Autism?

- For Autistic Self-Advocates, it is equivalent to a cure for left-handedness, a world where they do not exist (Harmon, 2004).
- Conversely, parents of those with severe disabilities see it as a hope for a future for their children to not be "different" (Harmon, 2004).
  - Some Self-Advocates who are more severely affected by autism try to refute this by explaining that they still advocate despite their difficulties, with using the bathroom, verbalization, and self-injuries (Harmon, 2004).
- Autism Speaks said that it supports research toward a cure until late 2016.
- Conversely, the Autistic Self-Advocacy Network, an organization with significant autism representation considers a search for a cure "misguided"
  - Focuses "on empowering and supporting autistic people and all people with disabilities to live the lives we wanted" (Autistic Self Advocacy Network, 2014).
- Within the autism spectrum the division is rather severe.
  - The pro-cure group seems to separate autism from the person while the anti-cure group seems to think the two are integrated in such a way that they cannot and should not be separated (Bagatell, 2010).

# In Depth: Applied Behavioral Analysis

- Developed in the 1960s

- A type of intensive therapy for autistic children around pre-school age.

- Often times, it is the only type of behavioral therapy funded by government grants/programs

- Results vary, but randomized trials have shown that children who participate in some variants of ABA show progress.

- 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 Developmental Individual-difference Relationship-based Model (DIR)/ Floortime.

ASAN, *The Atlantic*, Etc.

More on Autism Identity

Imagining Autism: Fiction and Stereotypes on the Spectrum
by Sonya Freeman Loftis
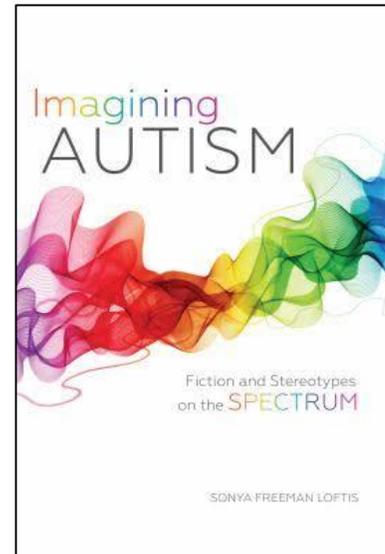
Loud Hands: Autistic People, Speaking
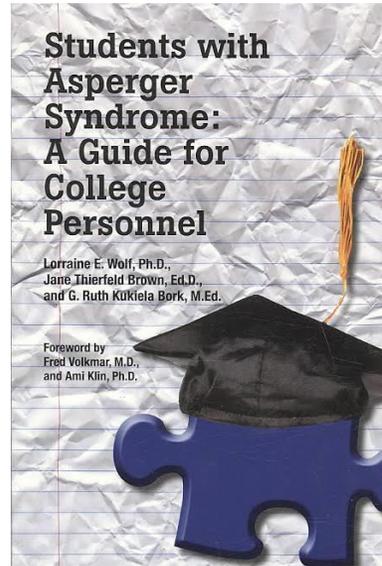Edited by Julia Bascom
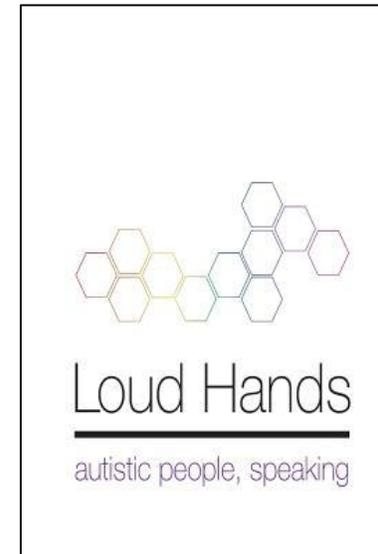
ASAN Sites:
Autisticadvocacy.org
www.autismacceptancemonth.org
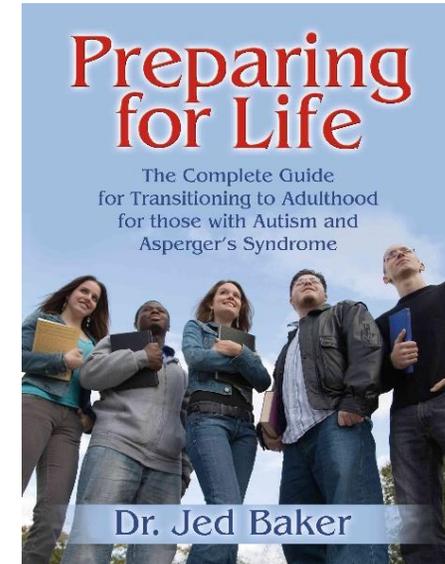Disability-memorial.org

The Bookshelf: General Autism Resources

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

Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger's Syndrome
By Jed Baker

Selected Works Cited

- Attwood, Tony. *The Complete Guide to Asperger's Syndrome.* London: Jessica Kingsley, 2007.

- White, S. W., Ollendick, T. H., & Bray, B. C. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism, 15*(6), 683-701.

- Wei, Xin, Jennifer W. Yu, Paul Shattuck, Mary McCracken, and Jose Blackorbhy. "Science, Technology, Engineering, and Mathmatics (STEM) Participation Among College Students with an Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* (2012) *SpringerLink*. Web.

- Wei, Xin, Elizabeth R.A. Christiano, Jenifer W. Yu, Jose Blackorby, Paul Shattuck, Lynn A. Newman. "Postsecondary Pathways and Persistence for STEM Versus Non-STEM Majors: Among College Students with an Autism Spectrum Disorder" *Journal of Autism and Developmental Disorders* (2013) *SpringerLink.*

- American Psychiatric Association. (2013). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.). DOI: 10.1176/appi.books.9780890425596.514988

- Armstrong, T. (2010). *Neurodiversity : Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences*. Cambridge, MA : Da Capo Press. Retrieved from http://www.ebrary.com

- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos, 38,* 33-55. doi: 10.1111/j.1548-1352.2009.01080.x

- Brown, L. (2011). *Identity-First Language.* Retrieved from: http://autisticadvocacy.org/identity-first-language/

- Centers for Disease Control (2014). *Data and Statistics | Autism Spectrum Disorder | NCBDDD.* Retrieved from http://www.cdc.gov/ncbddd/autism/data.html

- Harmon, A. (2004, December 20). How about not curing us, Some autistics are pleading. *The New York Times.* Retrieved from http://www.nytimes.com/2004/12/20/health/20autism.html

- Jordan, J. (2010). Evolution of autism support and understanding via the world wide web. *Intellectual and Developmental Disabilities, 48,* 220-227. doi:10.1352/1934-9556-48.3.220

- ONeil, S. (2008). The meaning of autism: Beyond disorder. *Disability & Society, 23,* 787-799. doi:10.1080/0968759082469289

- 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,* 43-54.