

Please use this space as you need or prefer!

Feel free to pace, rock, stim, leave and come back, or anything else you need to do to make this space more comfortable or accessible.

# **Self-Advocacy in Transition: Embracing Neurodiversity in College and Beyond**

**Reid Caplan - ASAN**

# About ASAN

The Autistic Self Advocacy Network (ASAN) is a 501(c)(3) nonprofit organization run by and for autistic people. ASAN was created to serve as a national grassroots disability rights organization for the autistic community. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!



# About Reid

- Runs the Autism Campus Inclusion (ACI) Summer Leadership Academy and Autistic Scholars Fellowship programs.
- Graduated from Beloit College in 2016.
- Worked in Beloit's Disability Services office for 2+ years.
- Founded a disability advocacy student group (Beloit Cross-Disability Coalition).



# Self-Advocacy

Self-advocacy is the ability to speak up for yourself and the things that are important to you.

- To ask for what you need and want and tell people about your thoughts and feelings.
- To make choices and decisions that affect your life.

The goal of self-advocacy is for YOU to decide what you want, then develop and carry out a plan to help you get it. It does not mean you can't get help if you need or want it.

# The H.O.P.E.F.U.L. Approach

**Honest** about your needs and wants

**Observant** about what works and doesn't work for you

**Prepared** to meet your own needs

**Educate** yourself and others about what your disability means to you

**Focus** on your strengths and talents

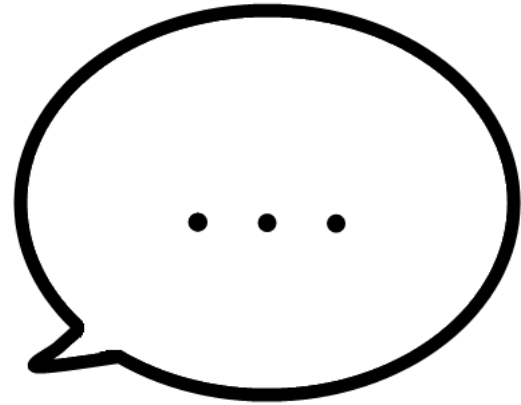
**Use** available resources

**Live** your life to the fullest!



# Self-Advocacy in Action

- My strengths are...
- I have difficulty with/I need to work on...
- My goals are...
- I need help with...
- You can help me by...

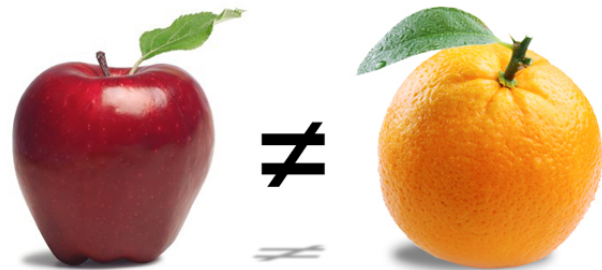


Can be done on a personal level or more broadly (using individual experiences to work as a group to make positive change).

# Medical vs Social Model of Disability

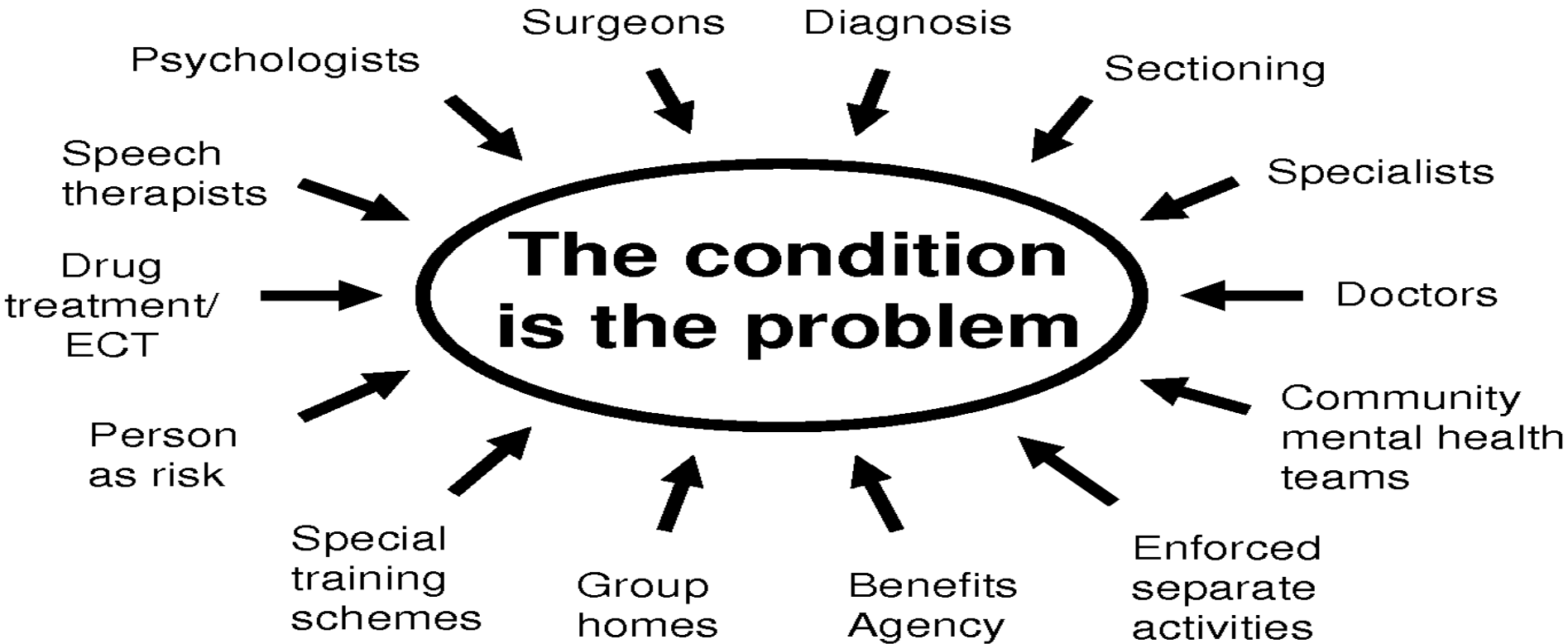
Framework:

- What/who is the problem?
- What is the solution to the problem?
- What is the social role of the disabled person?
- What is the desired outcome for the disabled person?
- Who has control over the life of the disabled person?





# Medical Model of Disability



**Disabled People as passive receivers of services aimed at cure or management**

HELP THE ABLE BODIED



Committees are formed. Many people are worried about what becomes known

A medium shot of a Black man with short grey hair and glasses, wearing a grey cable-knit sweater. He is seated in a black office chair and is speaking, looking slightly to his left. The background is a plain, light-colored wall with a vertical orange stripe. The video is framed by black bars at the top and bottom.

## **What is the social model of disability?**

Disabled people tell Scope what it is and what it means to them

# Disability Pride

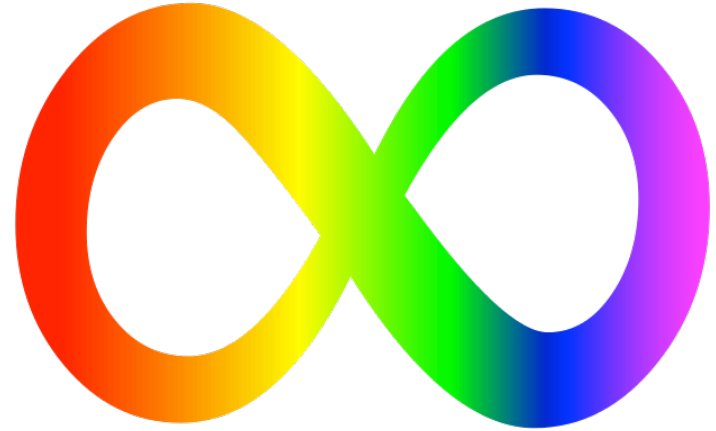
- Ableism: Discrimination or prejudice against disabled people.
- **Institutional** and **individual ableism** results in spaces and activities that are not accessible or inclusive.
- Disability pride is a tool to fight against ableism by affirming one's self-worth as a disabled person in an ableist society.
  - An important component and natural extension of the social model!



# Neurodiversity Movement

Neurodiversity - the diversity of human brains; the idea that no 2 brains are exactly alike.

The neurodiversity movement believes that neurodiversity is a natural and valuable form of human diversity, and that there is no one “normal” type of brain - only brains labeled by society as “normal” and “abnormal”.



# Amazing things happen



# Neurodiversity Movement (continued)

Neurotypical - Brains considered “normal” by society.

Neurodivergent - Brains considered “abnormal” by society (having a neurological condition).

Goal of the neurodiversity movement is to promote inclusion and equality for neurodivergent people.

In the autistic community, neurodiversity means that our autism is part of who we are, and so we oppose the idea of 'curing' it.

# Neurodiversity isn't...

- Saying that neurodivergent people shouldn't seek treatments for their conditions if they so desire it.
  - Focus should not be on appearing neurotypical; rather, treatments should focus on making the individual's life easier (medication to manage mental illness, occupational therapy, etc).
- Only for autistic people
  - The movement was started by autistic people, but is inclusive of all neurological conditions (developmental disabilities, learning disabilities, mental illnesses).
- Saying that neurological conditions aren't disabilities
  - Remember the social model - disability arises from lack of accommodation.
  - Neurological conditions as a difference and a disability.



# How do these movements affect self-advocacy?

- Focusing on wants and needs vs deficits
- Pride = less shame = asking for help when you need it
- More easily identify potential accommodations
- Coalition-building



# Transitioning to College

Autistic people face unique challenges when pursuing higher education.

- Different expectations of secondary education vs college
- Different rights for people with disabilities
  - IDEA (IEP) vs 504/ADA (reasonable accommodations)
- Living independently
- Social expectations/building relationships
- Change is hard!



# Applying Self-Advocacy Skills to College

- Focusing on wants and needs vs deficits
  - More likely to use coping skills to avoid burnout (lighter course load, sensory-friendly social events, etc).
  - Higher satisfaction with college (focusing on what is going well) = more likely to stay in school.
- Pride = less shame = asking for help when you need it
  - Higher likelihood of seeking support from disability services, tutors, professors, etc.
- More easily identify potential accommodations
  - Self-advocacy -> self-knowledge.
  - Applying accommodations used before to new situations.



# Coalition-building

The disability pride and neurodiversity movements teach disabled people that they deserve equal access and inclusion, and give them the tools to seek this access and inclusion through self-advocacy.

Working as a community of disabled people = ability to advocate together for improvements.

This is even more important in college!

- Misconceptions that disabled people can't/shouldn't go to college
- Lower retention rates for disabled students that do go
- Many colleges don't allocate enough resources towards ensuring students with disabilities can succeed.

# Strength in Numbers

Disability student groups can:

- Promote disability pride/the neurodiversity movement
- Create social opportunities
- Connect students to accommodation resources
- Raise campus awareness of disabled students -> lead to better accommodation of these students across campus.



# Autism Campus Inclusion (ACI)

- Started in 2012
- Week-long summer leadership training
  - Disability rights movement history
  - Neurodiversity movement
  - Student group formation
  - Disability Policy
- Bi-monthly check-ins from the conclusion of ACI until completion of college.
- Connection with ACI Alumni network.







# Case study: College A

- 10% of students have a documented disability and receive accommodations; it's estimated that 25% of students have disabilities in total.
- Disability services office is understaffed and oftentimes ineffective.
- A student starts a disability student group to talk about these problems with their peers.
- Awareness is raised of these issues and it comes to the attention of administration.
- Administration sets aside funding to evaluate and improve disability services.



# Case Study: College B

- While this school has a good amount of resources available for disabled students, they aren't well-advertised.
- On-campus centers exist for students of color and LGBT students to support and connect them to resources, but not for disabled students.
  - -> disability is left out of events that discuss social justice, civil rights, etc.
- A disabled students forms a student group to encourage the creation of a Disability Cultural Center.
- Works with the LGBT center to write a proposal to administration.
- The Disability Cultural Center is created - a physical space for disabled students which promotes disability pride and helps students navigate Disability Services.

# Tips for Success



- Start teaching self-advocacy skills early!
  - Involve children in their IEP meetings and in household decisions (independent living skills).
  - Figure out what works best to keep you on track (having a calendar app on your phone? Setting alarms? Scheduling out free time vs work time?)
- Research accommodations/disability services during the admissions process
  - Does the school have an autism-specific support program? A disability student group?
  - If possible, talk to current students.
- Keep in mind your wants and needs when researching schools
  - What student organizations are there? How are the dorms? Roommates? Class structure?
  - The school that looks the most interesting and the school that is the best fit may not be the same!

# More Tips

- Read resources directed at autistic youth preparing for college:
  - ASAN resources: [Navigating College](#) and [Empowering Leadership](#)
  - Organization for Autism Research (OAR): Guide to Navigating College (coming soon)
- Connect autistic youth with autistic adults
  - Best teachers of neurodiversity/disability pride
  - Check local Arc chapters, ASAN affiliates, Autism Society, etc.



**WELCOME TO THE  
AUTISTIC COMMUNITY**

# Beyond College

The skills we have discussed can be applied to all aspects of life, not just college!

Knowing yourself and being able to self-advocate can help you figure out which post-college opportunities are best for you.

Staying connected to the disability community can help you find more opportunities.



Video: [Autistic Adults in the Workplace](#)

# Employment

- Think about whether or not you want to disclose your disability to your employer.
- Think about which accommodations will be helpful to you on the job.
- Volunteer or intern in your field of interest during college.
- Many colleges have a career center to connect students with opportunities, practice interviewing, resume-building, etc.



# Autism-Specific Programs?

- Who is in charge?
- The goal should always be competitive, integrated employment - Real jobs for real pay.
- Pros: More understanding of needs/ accommodations.
- Cons: Lower wages, fewer opportunities for advancement, segregation.
- Attitude of “special people need special jobs” can lead to mistreatment.



# Disability Employment Resources

- Connect with organizations that connect disabled employees to businesses, like the [US Business Leadership Network](#)
- Look into potential employers on the [Disability Equality Index](#)
- Look into organizations participating in [National Disability Employment Awareness Month](#) (happening now!)





# More Employment Resources

[Job Accommodation Network \(JAN\)](#) has information about what accommodations an individual can receive at school or work, and provides free consultations about employment accommodations.

[Career One Stop](#) has a webpage to find job training and employment opportunities for disabled people. They can also help you connect to Vocational Rehabilitation services.

[National Collaborative on Workforce and Disability – Youth Employment Resources](#)

# Independent Living

- Decide whether it is best for you to live alone or with roommate(s).
- Identify which independent living skills you need the most help with.
- Connect with your local Center for Independent Living (CIL) - they can help you learn independent living skills, offer peer counseling, and more!



# Easing the Transition to Independent Living

- One way to get used to independent living while in college is to transition towards independent living in steps. For example:

Freshman year: Live with a roommate

Sophomore year: Live by yourself in the dorm

Junior year: Go off the campus meal plan/get a smaller meal plan

Senior year: Consider living off-campus



# Other Resources

[National Council on Independent Living - Disability Pride Toolkit](#)

[DREAM - List of Disability Student Groups](#)

[Organization for Autism Research - College Central](#)

[ASAN - Roadmap to Transition](#)

# Thanks for listening!

Questions/comments?



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