The Developing Social Landscape of Adult Autism

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Definition

• Denoted by the root and suffix of the word “common-unity”

• A certain segment of the population is united by a familiar thread or “common thread”

• Threads can be anything which makes diversity within and between communities infinitely diverse

• People can be part of many communities, separated by time or at the same time

• Change is the rule not exception!
Communities define us
Change in the rule not exception
Experiential thread for “neuro-typical” child

- Birth of sibling
- School starts
- Tough teacher
- Change school
- Exams
- Leave school
- Start college
- Early Jobs
- Leave college
- Start college
- Leave college
- Early Jobs
- Marriage
Neurodivergence

Social

Restrictive/Repetitive

Speech/Communication
Experiential thread for “neuro-divergent” child

- Birth of sibling
- Tough teacher
- Family conflict
- School starts
- Parents divorce
- Exams
- Change school
- Leave school
- Leave home
- Failed relationships
- Failed employment
- Marriage
Infinite possibilities!

- Family-driven
- Provider-driven
- Self-driven
Autism vs autistic communities

Simplified: autistic communities consist of autistic people – everything else related to autism considered part of the greater autism community

GREEN = Autistic Community

EVERTHING ELSE = Autism Community
Autism community

• Simplified: just about everyone who has something to do with autism who is not autistic (does not have autism diagnosis)

• Extremely diverse
  • Members: families, professionals, allies, organizations and more
  • Focus can be specific or broad (vocational, recreational, family, support needs, etc)
  • Purpose is generally supportive though done in many different ways

• Long history and most common: intentional communities; support, interest, and advocacy groups

• Numerous examples - big, small, new, old, local, international

• Evolution over time
Example

“We The Daniel Jordan Fiddle Foundation was the first not-for-profit and only all-volunteer run organization in the United States to focus on adult autism and has been blazing trails since 2002. We create paths leading to fulfilling and potential driven lives. Our model programs, resources, public policy and awareness initiatives are person-centered and derive from the needs and hopes of the diverse population of adults diagnosed with Autism Spectrum Disorder (ASD) and their families.”
Autistic community

• Simplified: autistic communities consist of autistic people

• Everyone else is considered part of the autism community

• Commonly advocacy or interest based or some combination

• Much traction over past 10-15 years, but roots in 1990’s as a part of the disability rights movement
Possible forces driving growth of autistic community

- The cliff and the tsunami
- Petition against ads using negative stereotypes
- Rapidly growing use online interaction and social media
Two potential subgroupings

• Interest based: emphasis shared interests (i.e. role-playing games, animation, video games, computers, cars, etc)
  • Leverage special interests to promote social interactions
  • Led by autistic adults and/or support by other neurotypes

• Advocacy based: different ideologies, learns towards non-traditional and counterculture with emphasis on autistic pride and identity
  • Typically, more independent communicators with fewer support needs
  • Knowledge and opinions built on personal experience and observation
  • Identity first orientation
“The Autistic Self Advocacy Network 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, advocating for systems change and ensuring that the voices of autistic people are heard in policy debates and the halls of power. Our staff work to advance civil rights, support self-advocacy in all its forms, and improve public perceptions of autism. ASAN’s members and supporters include autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators, and friends.”
Evolution

From autism awareness to acceptance and pride

Autistic Pride Day was first celebrated about 15 years ago
“The Autism Wars”

Seek first to understand and then to be understood.
www.meetup.com/ProjectCASY
Since April 2014

- Cost-free, professional-supported online/local “hybrid” autism community
- Bottom line: improve quality of life
- Organic collaborative approach
- In person meetings for social recreation and sharing ideas and experiences
- Online component allows for networking, promoting diversity and curbing isolation
April 2014 – February 2020
April 2014 – February 2020
COVID-19 Pandemic: Social/physical distancing
The Third Alternative: Pivot to “distance socializing”

- Protect physical health
- Maintain mental Health
- Partnership and collaboration
Away from the ivory tower: horizontal structures over vertical hierarchies
Ginger Ale
Happy Hour
every Friday!
Technology is a useful servant but a dangerous master.

- Christian Lous Lange
Thank you!

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