

Building Bridges: Collaboration as a Tool for Building Trust in Autism Research

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A dark blue diagonal graphic that starts from the bottom left corner and extends towards the top right corner, creating a triangular shape on the right side of the slide.

Background



- Theoretical physicist who has transferred to autism research
- Autistic parent of an autistic child with higher support needs
- Extremely passionate about access to healthcare and community support for disabled children and their families
- Strong proponent of collaborative approaches and inclusion of under-represented perspectives
- Other identities: transgender man, multiply disabled

Outline

- Motivation and overview of current gaps
- General steps towards inclusion
- Specific recommendations:
 - Inclusion of autistic individuals, including those with higher support needs
 - Inclusion of under-represented groups and various family structures
 - The magic of feedback

Goals– a vision for the future

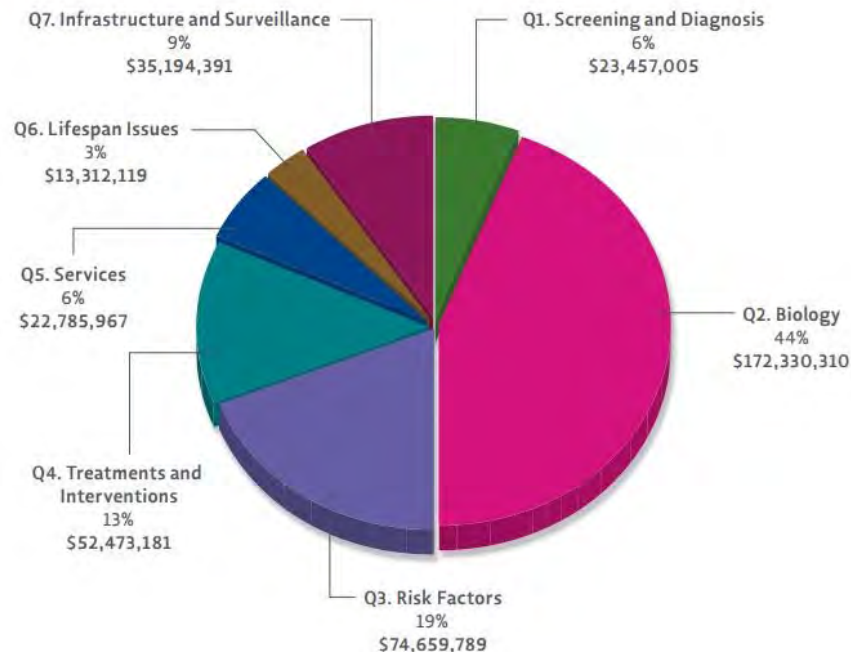
1. Remove barriers to employment, childcare and education, healthcare, etc.
1. Support self-advocacy and autonomy
1. Reduce isolation of individuals and families
1. Learn about autism from autistic individuals with different identities and perspectives

Note: Shared goals can be one of the most powerful ways to build bridges

Gaps in Perspectives

Question: which research category do you think is most prioritized by autistic individuals?

2018
ASD Research Funding by IACC Strategic Plan Question
Total Funding: \$394,212,761



Reference: IACC ASD Research (2017-2018)

Gaps in Perspectives

Based on a 2022 survey of 225 autistic adults in Scotland, the top priorities are:

- Mental health/wellbeing
- Identification and diagnosis of autistic people
- Support services and attitudes towards autistic people
- Issues impacting autistic women

Lowest priorities included genetics, causes, and treatments

Note: perspectives of autistic individuals with higher support needs are often under-represented

Barriers to trust– discrimination



Example: deep and lasting impact of healthcare inaccessibility

Barriers to trust- disparities

- 1.) Black autistic children are disproportionately likely to be misdiagnosed with conduct disorders than white autistic children
- 2.) Autistic women on average experience an 8-year delay in diagnosis
- 3.) Diagnosis and other services can be expensive. (Up to \$2000 just for a diagnosis)

Barriers to trust- disparities

“The school’s psychologist amazingly insisted that I couldn’t actually be autistic – instead, because I was adopted transracially and transnationally, he believed that I had reactive attachment disorder and therefore did not qualify for services.”

– Lydia X.Z. Brown



Barriers to trust– lack of representation



- Autistic individuals have historically not been included in autism research or advocacy
- More generally, autistic individuals are rarely represented in leadership or mentorship roles
- Perspectives of autistic individuals with co-occurring intellectual disabilities are often left out– even in the neurodiversity movement

Motivation for building trust with autistic individuals

- Autistic individuals have firsthand knowledge of what would most improve their quality of life
- Autistic people can describe “autism from the inside” and prevent misunderstandings
- Autistic people often have unique strengths and perspectives

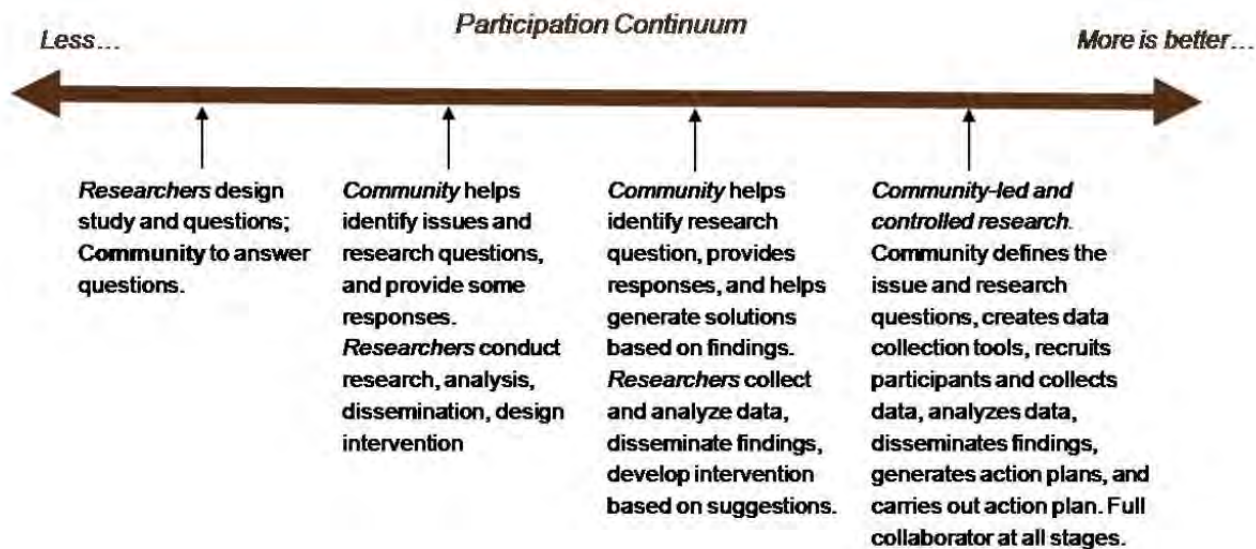
Motivation for building trust with caregivers

- Quality support for autistic individuals also needs to be logistically practical for caregivers!
- Understanding and supporting caregiver mental health can often benefit the full family
- Parents can sometimes be the most unwavering advocates for their children

Step #1- seek out autistic perspectives

Opportunities to include autistic perspectives:

- When parents receive an autism diagnosis for their child
- During graduate school programs for clinicians
- During the autism research process



Understand autistic strengths



1. Straightforward communication style
2. Willingness to question social norms¹, tendency to “think outside the box”
3. Honesty
4. Hyper-empathy (in some cases)
5. Less likely to conform to the bystander effect
6. Strong adherence to ethics in both public and private²

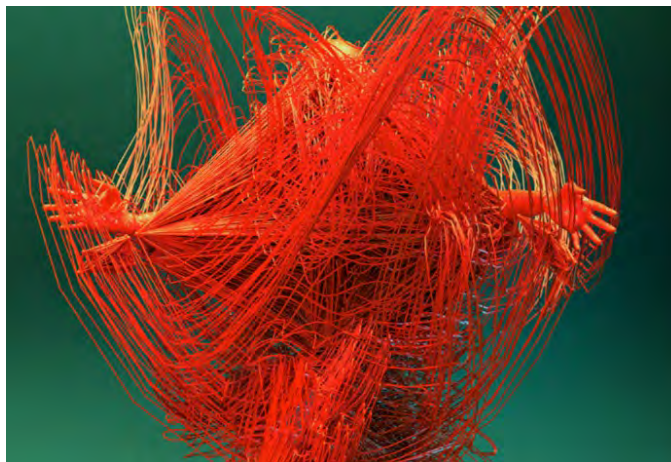
1.) Implicit Social Biases in People With Autism. *Psychol Sci.* 2015;26(11):1693-1705.
doi:10.1177/0956797615595607

2.) Reference: Journal of Neuroscience 24 February 2021, 41 (8) 1699-1715; DOI: 10.1523/JNEUROSCI.1237-20.2020

Understand autistic traits

Example: stimming (repetitive movements) were historically seen as nonfunctional. By listening to autistic people, we know that stimming can:

- Help with relaxation and alleviating anxiety
- Help with focus
- Convey emotions (in some cases)



Understand autistic traits – an example




*“One of my colleagues shared with me how hurtful it was for her that her autistic son didn’t make frequent eye contact with her, because she associated eye contact with caring. **She relayed that one of the best homework assignments an SLP gave her was to spend a week observing and writing down all the ways her son showed her that he cared about her.**”*

- Laura S. DeThorne

Step #2 – proactivity

This is a safe place



Movement. You can move, sit, or stand however is comfortable for you. It is okay if you rock back and forth or flap your hands or fidget.

Sensory. You shouldn't have to feel pain. If the lights are too bright or if there is too much noise, you can tell us.

Communication. You are good the way you are. You don't need to be "normal". The most important thing is just to be kind.

You don't need to make eye contact or talk a certain way. It is okay if you want to write or use a device to communicate instead of talking. It is okay if you need breaks.

Experiences. You deserve to talk about what being neurodivergent means to you. You are the expert on how your brain works.

by Sam Brandson of All

Why proactivity? Many marginalized people might be hesitant to ask about accessibility or inclusion due to previous negative experiences

- Visual signifiers of inclusion
- Automatically providing accessibility options to all – not only those who have disclosed a diagnosis!
- Share information about steps that your organization has taken to be inclusive of various identities

Step #2- checklist

Consider offering a list of potential accommodations, such as:

- Appointments that start and end very punctually
- Opportunities for frequent breaks
- Accommodations for the caregiver
- Having more researchers around if possible
- Having as few people present as possible
- Ability to wait in the car or hallway and receive a text message when the team is ready for us to come in for the appointment
- Meetings that are kept as short as possible, even if that means scheduling more frequent meetings or filling out paperwork prior to coming to the appointment
- Frequent reassurance or encouragement
- Translations

Step #2- IDD inclusion

How can we address the missing perspectives of autistic adults with intellectual disabilities?

- Plain language tool- Flesch-Kincaid calculator
- Option of private meetings, adjusted formats
- Inclusion of support person
- Inclusion of topics such as guardianship, disability benefits, etc.

Flesch-Kincaid Grade Level



Step #3 – feedback



Sample language:

We greatly value participant feedback and strive to make our research studies as accessible as possible. If you have any questions, concerns, or suggestions please don't hesitate to contact either Person 1 at [email 1] or Person 2 at [email 2].

Other considerations:

- Alternative feedback methods
- Demonstrating follow-through
- Check for disparities in feedback to identify ways to increase equity

Feedback from children with higher support needs



Best practices remain an open area of research!

Potential approaches:

- Speak directly to the child
- Use a smiley-o-meter, emotion wheel, or other visual scale
- Use a simple “social story” with pictures of key points in the study, gauge child’s reaction to each picture
- Other cues (phrases unique to the child, measuring requests to leave/stay, etc.)

Step #4- ongoing collaboration



Many marginalised people are tired of being studied or consulted with briefly (but not knowing if or how much impact their consultation had)

How to combat this?

- Ongoing collaboration with individuals and local organisations.
- Two-way support
- Check whether you are fully engaging with all relevant areas of your collaborator's expertise

Step #5 – language as an indicator



General guidelines:

1. Follow guidance of autistic community (or impacted community) as well as individual preferences
2. Switch from deficit-based to neutral language (e.g. “failure to make eye contact” → “makes less eye contact”)
3. Use the “tall” test to check for accidentally pathologising language
 - a. “Risk of tallness”
 - b. “Person with tallness”
 - c. “Group A consisted of tall children and group B consisted of healthy controls”

Step #6- patience

Trust takes time



Healthcare suggestions



1. Create affinity group for disabled/neurodivergent healthcare staff and allies
2. Host focus groups or listening panels where clinicians can learn from patient and/or caregiver experiences
3. Connect to community organisations, sensory events for post-diagnosis or post-discharge patient resources
4. Specialised trainings that work with staff time constraints:
 - a. De-escalation strategies
 - b. Sensory checklists
 - c. Patient communication guides

Education suggestions

- Include student in IEP goals wherever possible
- Allow clinicians to observe at the child's school (to see the child in various environments)
- Adaptive skills/daily living skills assessments to clinicians

Reducing isolation



- ❑ Connect parents with parent mentor

- ❑ Connect parents with autistic adult mentor, especially one who shares key traits with their child

- ❑ Recreational community events:
 - ❑ Sensory events
 - ❑ Respite care
 - ❑ Childcare during events aimed at parents
 - ❑ Varied options for volunteering– offer a sense of purpose

Signs of growth



- Feedback, even (especially!) if initially difficult
- Increased diversity
- More people hearing about an opportunity, organically sharing it with friends/coworkers
- People choosing to volunteer or invest in an initiative

Thank you!

