

OPINION, Q&A

Questions for Ari Ne'eman: Partnering with participants

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Working together: Advocates are pushing for people on the spectrum to collaborate with scientists on autism research. retrorocket/Shutterstock.com.

Autism advocates are pushing for more ‘patient-centered research:’ projects that involve people with autism in decisions about studies of the disorder. The goal is to boost the research’s real-world impact by getting input from those most affected by it, a notion so practical that even **funding agencies are getting on board**.

Ari Ne’eman, an autism advocate who has the disorder, is on the frontlines of this effort. In 2006, he founded the **Autistic Self Advocacy Network** (ASAN), an organization that champions equal rights for people on the spectrum. (Editor’s note: We typically refer to people with autism, but Ne’eman’s preferred term is ‘autistic.’) The ASAN slogan, ‘Nothing about us without us,’ sums up Ne’eman’s drive to be a part of the scientific process, not simply a ‘subject’ in a study.

We asked Ne’eman why autism researchers should partner with people on the spectrum, and what he hopes will happen when they do.

SFARI.org: What does it mean for people with autism to be partners in research?

Ari Ne’eman: We want to involve the people who are the target of research from the beginning, when we’re conceptualizing our research questions and designing a study, through data collection, analysis and publication. At every step, a cross-section of autistic self-advocates should have the opportunity to review and provide input. The power relationship between researchers and these self-advocates should be equalized to the greatest degree possible.

This approach comes from work in the African-American and Hispanic communities. If you’re studying the challenges African-Americans and Hispanics face, you should involve them in every step of the study. The same holds true for autistic people.

S: What are some examples of how ASAN partners with autism researchers?

AN: For a number of years, we’ve participated in the Academic Autistic Spectrum Partnership in Research and Education. This is a research collaboration between self-advocacy leaders and researchers at Portland State University, Syracuse University and a few other institutions. The collaboration has created **autismandhealth.org**, a website that provides health and lifestyle information for autistic adults, and tips for doctors on caring for them. We’ve also produced research on health disparities faced by autistic adults.

In collaboration with the nonprofit **Human Services Research Institute** based in Cambridge, Massachusetts, we are addressing ethical concerns that autistic adults have with autism registries. These registries, which are required in certain states, collect data on autistic adults’ diagnoses, so confidentiality, informed consent and civil liberties are major concerns.

S: How do these partnerships advance autism research?

AN: I'm talking to you from Gallaudet University in Washington, D.C., a place where deaf researchers study issues in deafness. The quality of that research makes it considerably more likely to lead to outcomes that have a concrete impact on the lives of deaf people. The issues around the community of autistic adults are the same. We want to build a pipeline of opportunity for these adults to enter the research profession and to be meaningfully involved, improving the quality, validity and relevance of autism research.

S: In which areas of research would input from people with autism be particularly helpful?

AN: We see little emphasis among researchers on improving the quality of services and addressing the needs of autistic adults. There's a real gap there, and I think that's an area where the involvement of autistic people in a meaningful partnership role is indispensable.

Another area is evaluating the efficacy of interventions. We need autistic people's input to help researchers develop appropriate outcome measures. For instance, researchers should measure success as we do for typically developing children, in terms of academic, social-emotional and cognitive outcomes, rather than focusing on the reduction of autistic traits. Collaborative work is more likely to focus on, "Is this improving somebody's independent living skills, somebody's likelihood of being included in the general education classroom, their likelihood of friendships?"

S: Are there any projects underway that you're excited about?

AN: At the end of our summer leadership academy this week [at Gallaudet University], all of our participants are going to be meeting with their congressional representatives. They're going to be arguing that federally funded autism researchers need to actively recruit autistic trainees and encourage — in fact, require — their participation.

The federal government is the country's largest funder of research. We need them to step in. We need our involvement to be formalized so that we're not just pulling people in at the tail end of a process or tacking on their opinion after the conceptual framework has been established or data collection is underway.

S: Do you see any hopeful signs?

AN: I think so. Last year, several members of Congress wrote to the director of the National Institutes of Health and urged the inclusion of autistic people in the research process. I think it speaks to the growing change in conversation.

We have an opportunity to re-envision the quality of our autism conversation. It's a chance for us to build a more inclusive vision, one that acknowledges that autistic children will grow into autistic

adults. If we do our jobs right, that doesn't have to be a bad thing.