



**Autistic Adults and other  
Stakeholders Engage Together**

**Year 1 Meeting  
Executive Summary**

**Tuesday July 11, 2017**

[www.autistichealth.org](http://www.autistichealth.org)

[www.facebook.com/autistichealth](https://www.facebook.com/autistichealth)

[@autistic\\_health](https://twitter.com/autistic_health)

*Community  
Council Member  
Becca Lory,  
when asked for a  
headline she  
would like to see  
that addresses  
autistic research  
priorities:*

***“It’s OFFICIAL,  
there is NO cure  
for autism.  
Funds to be  
immediately  
redirected to  
services and  
supports!”  
#AASET2017***

### **Why Autistic Adults?**

A significant majority of autism research is conducted with children as the focus, and there is limited knowledge about the adult population and the adversities they face (Nicolaidis et al., 2013). Autism is not a childhood disorder; it follows an individual throughout the lifespan. While autism does not have a direct effect on life expectancy, research has found that autistic adults have shorter life spans (Nicolaidis et al., 2013). Autistic adults are more likely to have undiscovered health problems or other diagnoses (Nicolaidis et al., 2015). The aim of this meeting was to bring together autistic adults to discuss what is known about health and health outcomes, and identify gaps and next steps desired by the autism community.

### **Identity-first versus Person-first Language**

Please note we are using identity first language in place of person first language. In our work with stakeholders who contributed to this document, especially autistic self-advocates, many prefer identity first language that does not separate their condition (autism) from who they are. This is an acceptable convention self-advocates use in print descriptions. As with any language, it is important to ask the individuals you are working with whether they prefer to be identified as a ‘person with autism’ or as ‘autistic’. This approach values autonomy and identity, and conveys mutual respect.

### **What is AASET?**

Autistic Addults and other Stakeholders Engage Together is a community of autistic adults, researchers, organizations, and other stakeholders who are committed to the following goals:

- Prioritizing positive health and healthcare outcomes desired by autistic adults;
- Identifying evidence-based interventions and best practices from the autistic community’s perspective;
- Involving other groups in implementing interventions through a patient-centered outcomes research/comparative effectiveness research studies.

### **AASET Year 1 Meeting Objectives:**

1. Discuss what we know about health for autistic adults.
2. Identify gaps and next steps for research that can improve health for autistic adults.
3. Learn about current research that includes autistic adults and family members as partners in the research.

### **AASET Project Team**

Teal Benevides, Project Lead  
Stephen Shore, Project Co-Lead  
Anita Lesko, Project Co-Lead  
Alex Plank, Social Media Coordinator  
Patty Duncan, Conference Coordinator

An #AASET2017 attendee said when asked what topics are a priority for your organization?

**“Finding doctors (or dentists) that are non-judgemental”**

### **Community Council**

Elesia Ashkenazy  
Reid Caplan  
Barb Cook  
Daria Blinova  
Dena Gassner  
Amy Gravino  
Liane Holliday-Willey  
Becca Lory  
Jamie Marshall  
Lindsey Nebecker  
Lisa Morgan  
Kate Palmer  
Bill Peters  
Jeanette Purkis  
Brigid Rankowksi  
Cyndi Taylor

### **Organizational Partners**

- AASPIRE
- Asperger/Autism Network (AANE)
- Asperger Syndrome and High Functioning Autism Association (AHANY.org)
- Autistic Self-Advocacy Network (ASAN)
- Autism Society of America
- Autism Speaks
- The Arc of Georgia
- Boston Higashi School
- The Gersh Academy
- The Global and Regional Asperger Syndrome Partnership, Inc.—GRASP
- Life Course Outcomes Research Program at the A.J. Drexel Autism Institute
- Louisiana State University, Leadership and Education in Neurodevelopmental Disorders
- Our Sunny World (Moscow, Russia)

### **Why Focus on Health and Health Outcomes?**

Autistic adults have multiple, chronic, and potentially preventable healthcare needs as compared to same-aged adults without ASD (Croen et al., 2015), but we know very little about why these differences are occurring and how to improve outcomes. Within the national literature which discusses individuals with autism, few have used client or patient engagement to prioritize next research steps and desired outcomes. This particular patient community has identified the need for more engagement in healthcare (Nicolaidis et al., 2012).

An #AASET2017 attendee said when asked what they learned from the meeting:

**“That the field of mental health needs more funding to help increase quality of life [for autistic adults]”**

### **What Happened at the AASET Year 1 Meeting?**

The AASET Year 1 meeting held on July 11, 2017 involved national and international partners in discussing autistic adult involvement in the research process and specific areas of need that should be prioritized in addressing health and health outcomes. While Milwaukee, Wisconsin was the physical meeting location for this event, online participants shared their perspectives from around the globe on Twitter and by watching the live stream on Facebook Live.

Given the success of the Year 1 meeting, and the desire to involve others across the United States, additional meetings are planned for 2018.

### **Who Attended the Year 1 Meeting?**

A total of 51 individuals participated in the conference. This included 39 attendees in the face-to-face meeting, and 12 virtual attendees on FacebookLive and Twitter. Since the meeting, the live video has had additional views. Online viewers were primarily autistic (41%), or represented organizations affiliated with autism advocacy.

Of the 5 researcher speakers for the morning session, 2 were autistic adults, and 1 was a parent of an adolescent with autism.

For the breakout session discussion, among the face-to-face attendees, 17 were autistic adults (44%), 8 were family members of autistic adults (15%), 12 were researchers or organizational partners (31%), and 4 were unknown (10%). Attendees were primarily from the U.S.

### **Keynote Presentation**

#### **Anita Lesko, BSN, RN, MS, CRNA**

Anita helped the audience understand the purpose of the meeting, the importance of addressing health outcomes and interventions, and the need to learn from the experts in this process- the autism community.

### **Panel Session: Lessons on Engaging Communities in Research**

Three researcher panelists presented on their research. All panelists used powerpoints to share their materials (Speaker powerpoints are available in the Appendix).

**Christina Nicolaidis, MD, MPH** presented on the methods and outcomes of efforts used to enact participatory action research in AASPIRE. Her three take-home messages were:

An #AASET2017 attendee said when asked about the meeting experience.

**“I feel safer here than many places”**

1. Community based participatory research takes a LOT of thought and work.
2. Groups need to find ways to share power and ensure true inclusion.
3. It's possible, necessary, and TOTALLY worth it!

**Kathleen Thomas, PhD, MPH** from University of North Carolina Chapel Hill discussed two specific methods used to find out priorities of the autism community. Her three take-home messages were:

- 1.Regarding engagement: Engaging people with autism is feasible and should be extended to other research questions
- 2.Regarding how to prioritize research topics: Best-worst scaling was easier to understand and generated important discussions of underlying values of research priorities from the community.
3. We need to learn how to illustrate trade-offs in collective decision-making

**Beth Hunter, PhD, OTR/L** from the University of Kentucky discussed her participatory action research project which focuses on involving members of the community from rural locations. Her three take-home messages were:

1. Community collaboration is worth the effort.
2. Community collaboration is a marathon not a sprint.
3. All members of the community are important and needed!

**Stephen Shore, EdD** from Adelphi University involved the audience in discussing the things they learned during the meeting. Some of those thoughts and reflections are shared in quotes (left bar).

#### **Roundtable Discussion Following Researcher Presentation of Stakeholder Driven Research by Community Council member Becca Lory, CAS, BCCS**

Attendees were grateful for the presentations on existing research that was inclusive and demonstrated research activities that meaningfully included autistic adults in the research process.

However, a vast majority of the conversation revolved around beliefs that existing research efforts did not address priorities that are important to the community. Central to this theme was the expression that researchers engaged in actions that undermined trust in the research process. **Trust was a central theme of the roundtable discussion.**

An #AASET2017 attendee said when asked about 3 most important takeaways:

1. The diversity & complexity of these issues
2. The need for flexibility & creativity
3. The importance of funding

Suggestions for improving trust included:

- Involving the community in the entire research process;
- Ensuring that autistic adults are compensated appropriately for their intellectual contributions;
- Ensuring that the feedback loop to the community about research outcomes and activities are intact and providing information about research outcomes in a timely manner.

### Initial Outcomes Identified as Important in Breakout Sessions

Participants broke into smaller groups to discuss infographics, which presented existing research on health outcomes and interventions among autistic adults (See Appendix for Infographics). Discussion of the infographics led participants to identify gaps that require additional exploration by researchers. Additionally, discussion of possible funding allocations to each of these areas represents preliminary areas identified by the community as worthy of future research topics.

Outcomes Discussed by Priority Rank	Percent of “Funding” Recommended for Each Area
Mental health outcomes	51%
Injury and mortality outcomes	17%
Physical health outcomes	32%
Obesity outcomes	0%

### Initial Treatment Approaches Identified as Important in Breakouts

Interventions Discussed by Priority Rank	Percent of “Funding” Recommended for Each Area
Healthcare providers & environments	21%
Mental health interventions	25%
Access to health services	21%
Interventions to address social well-being (not originally ranked; identified through discussion)	35%

### Accommodations and Adaptations to the Venue Were Important to Attendees

The meeting venue was willing and able to accommodate changes to the environment for maximum participation of individuals requesting modifications. These included:

An #AASET2017 attendee said when asked what they learned from the meeting:

**“We need social change to improve health care access and accommodation for people with autism”**

- Previewing the venue in advance of the meeting
- Ensuring we used only rooms with natural sunlight (as opposed to overhead fluorescent lighting)
- Providing a quiet room with alternative means of viewing the speakers
- Providing images of their venue to publish in advance of the meeting to allow participants to familiarize themselves with the location

### **Recommendations for Improving the Next Meeting**

Of the 25 attendee evaluation forms completed, 12 (48%) indicated that they would not do anything to change the meeting. Of the additional comments received, they can be identified as falling into the following areas for improvement:

#### ***Modify the Structure of the Meeting to Include:***

- More time to be outside/ have fresh air
- Making support animals available
- Making graphics available prior to the meeting
- Shortening the meeting by 1 hour

#### ***Modify Breakout Sessions to Include:***

- Introductory and icebreaker activities
- Allow for bottom up investigation of health issues using index cards for card sorting
- More discussion on implementing direct action from discussion points
- More discussion about educating the healthcare community

#### ***Consider Adding:***

- Autistic individuals telling personal healthcare stories to illustrate challenges

#### ***Expand Participation Options/Outreach to:***

- Invite more researchers
- Expand outreach for even more voices

An #AASET2017 attendee said when asked what they learned from the meeting:

**“Including autistic adults is needed and possible”**

### **Next Steps**

1. Hold additional face-to-face meetings to connect with more autistic adults elsewhere in the country.
2. Invite additional dialogue on social media to ensure those who are unable to travel are able to contribute perceptions.
3. Develop a Compensation Plan in collaboration with the Community Council to address concerns related to assuring that compensation is aligned with contributions.
4. Provide information and feedback to the community participants through social media and email to ensure an adequate feedback loop, allowing for input and revision.
5. Share results with organizational partners and invite conversation about how autism and disability advocacy organizations, funders, and researchers can address preliminary needs of the community.
6. Hold a Year 2 meeting to involve both the autism community, researchers, funding organizations, and other organizational representatives to discuss shared goals and next steps.

### **Funding Acknowledgement**

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### **Appendices**

**Appendix A:** Meeting Agenda & Accessibility Guide

**Appendix B:** Speaker Bios and Panelist Presentations

**Appendix C:** Infographics Presented at Year 1 for Discussion

**Appendix D:** Participant Evaluation Form