



**Autistic Adults and other Stakeholders Engage Together
Lay Conference Summary Report
Patient Centered Outcomes Research Institute Engagement Award EAIN#4208**

Background

What: Autistic Adults and other Stakeholders Engage Together (AASET) Year 2 Meeting

When & Where: November 10, 2018 at the Renaissance Hotel in Washington, D.C.

Objectives of Meeting:

1. Discuss research priorities to address health for autistic adults¹ learned through a PCORI Engagement Award.
2. Identify best practices for engaging the autistic adult community in collaborative partnerships and research.
3. Develop an action-oriented plan to address research priorities through collective impact.

Conference Summary

Overview of Meeting

This was the second annual meeting for AASET, and it aimed to build engagement between researchers, partner organizations and the autism community to discuss priorities for future research and engaging autistic adults authentically in the research process. We collaborated with the Association of University Centers of Disability (AUCD) to host the meeting the day prior to their annual meeting.

Attendees

- 80 attendees registered for the meeting, which was our maximum registration. Of the 80 registrants, 64 (80%) attended.
- Of the 64 attendees*:
 - 37% were autistic adults
 - 24% were family /caregivers/support person of an individual on the spectrum
 - 41% were academic researchers
 - 8% were academic affiliates
 - 22% were representatives of disability organization

*Note: Many attendees fell into more than 1 category; percentages don't add up to 100 because people could select more than one option.

Materials Provided in Advance of the Meeting

Attendees received an email with detailed information about the meeting. Our attendee "Meeting Information and Accessibility Guide" (see Appendix) was provided 1 week before the meeting to assist attendees in understanding what the meeting was about, and what to expect at the meeting.

What role did patients and stakeholders play at the conference, and how did their engagement enhance the experience for all attendees?

¹ Please note we are using identity first language in place of person first language. Many prefer identity first language that does not separate their condition (autism) from who they are. Although not all prefer this convention, we are using this at the request of many project partners.

- The meeting was planned, run, and facilitated by the 18 member AASET Community Council and Project Team. A smaller committee participated in setting the meeting goals, agenda, speakers, and planned activities for the meeting, in collaboration with the Project Team.
- Priority areas discussed at this meeting emerged from online engagement of over 230 autistic adults and in-person focus group meetings held with 18 autistic stakeholders.
- At the meeting, attendees had the opportunity to hear from multiple speakers. Of the 5 sessions attended by the entire audience, 3 sessions were led by autistic members of the project team or Community Council. Each of the 3 Breakout Sessions were led or co-led by autistic Community Council members.
- Audience stakeholders had an opportunity to discuss and contribute to the top 10 research priorities at the Breakout Session of their choice: Access to Healthcare, Gender & Health, and Mental Health.
- Engaging stakeholders in Year 1 and Year 2 helped us to plan a meeting that met attendee needs. We carefully reviewed the meeting spaces and assessed lighting, sound/noise, ease of access, and availability of quiet spaces for breaks. Our Conference Coordinator and one autistic Community Council member trained the hotel staff to learn about ways to support our autistic attendees. We hired a CART transcription company to meet the needs of individuals who process written language better than auditory (spoken language), and this company had a running transcription for sessions at the bottom of the powerpoint. These accommodations, which were available to all attendees, were essential for a successful meeting.

Key Findings

Speakers Reported on Methods and Approaches Used to Support Engagement for Organizations and Policy Makers

Keynote speaker Paul Shattuck, PhD, provided information about making sure government, funders, and communities are engaged in autism research. Dr. Shattuck reflected on the following key points:

- Connection to systems and communities is key to increasing participation in stakeholder-driven approaches;
- Understanding the *leverage, alignment, and value proposition* for stakeholders will help create the best collection of people to 'move the needle'.
- Engagement happens when people feel that they have a role to play, no matter how big or small.

Priority Setting and Engagement Guide Presentations

- The priority areas were supported through audience discussion and questions. Audience members wished to share the priority-setting survey with others, and wanted a copy of the results.
- The Engagement Guide was seen as an avenue to facilitate future research collaborations, and was requested in PDF format. This is in the Appendix for use by other researchers.

Evaluation Results

- Attendee evaluation forms were completed by 26 of 64 attendees at the end of the day. An emailed version of the evaluation was also sent as a follow-up.
- A 5-point Likert scale (1-Strongly Disagree, up to 5-Strongly Agree) was used to evaluate meeting (see Appendix for evaluation form).
- Average ratings ranged from 4.60 to 4.87 for speakers and 4.66 to 4.82 for the content. This means that attendees overall Agreed or Strongly Agreed that the speakers met expectations, and that content was valuable and relevant.
- Open-ended responses to the Evaluation form question "*What are three things you will do as a result of this meeting*" fell into 3 main categories. Responses showed us that attendees were committed to a variety of actions following the meeting:
 - **Developing relationships** within the autism community, including advocating for inclusion and accessibility to research, telling others about AASET, starting their own initiatives to help individuals on the spectrum,
 - **Changing work or practice behaviors** to better support autistic adults, including

ensuring availability of other means of communication for healthcare providers (e.g. provide visual or non-spoken opportunities for communication); speaking with supervisors about ways to modify environments of care; and educating other healthcare providers about autistic priorities,

- **Ensuring autism research is** respectful and accessible, seeking funding related to priorities, exploring quality of life outcomes when considering research outcomes, and creating advisory board positions for autistic adults in research projects. Researchers also expressed an interest in using the provided Engagement Guide (see Appendix).
- *What 3 things would you change for future meetings?* Responses were primarily about future meetings having more workshops, more speakers, and more time for networking. Several attendees requested a 2-day meeting. Many people wanted to have more autistic speakers. One participant indicated they wanted to see more diversity in the audience and speakers.

Lessons Learned

- Comments indicated that attendees felt 'safe'. This meant that our meeting space created a welcoming and supportive place to talk about important priorities.
- Time and support is necessary to ensure that all team members running the meeting, including Community Council members, are adequately prepared to assist. Multiple planning sessions, no longer than 40-60 minutes, occurred over the span of 8 months to develop the agenda and meeting materials collaboratively. Allowing enough time for discussion and input was important.
- While the desire for improved mental health, quality of life, and overall wellbeing are frequently discussed at the individual-level, there also is a need to focus on system-level change that needs to occur in healthcare environments (e.g. physical and sensory environments), and with healthcare provider education.

Areas for Improvement

- Diversity of the attendees was limited, and is an area for improvement.
- The day was long, and therefore it was suggested that the next meeting take place across two shorter days.
- More opportunities to meet others and connect on a personal level was desired.

Plans to Share Results

Products to be shared with the community:	Sharing results can be helped by:	Ways this information can be used:
<ul style="list-style-type: none"> ● Meeting Agenda & Accessibility Guide ● Short Summary of Year 2 Meeting ● Engagement & Compensation Guide 	<ul style="list-style-type: none"> ● Social media outlets (Facebook and Twitter) ● Word of mouth ● Feedback from community ● Sharing on project website, PCORI's website ● Share with organizational partners ● Share with researchers through peer-reviewed publication 	<ul style="list-style-type: none"> ● To educate researchers about autism community priorities ● To expand what we know through additional meetings to involve more people around the country ● To develop a compensation plan to describe guidelines for payment of autistic adults in research ● To develop standards for trust and reciprocal relationships for members of research teams

Appendix

AASET Year 2 Meeting Agenda

Materials Provided at the Meeting:

- *AASET Meeting Information and Accessibility Guide*
- *AASET Engagement & Compensation Guide*

Evaluation Tools: AASET Year 2 Meeting Evaluation Form