



The Unfolding Story of Autism Research in NJ: From Cells to Society

New Jersey Autism Center of Excellence (NJ-ACE) Summit 2015 Feedback Summary

On Friday, September 18, 2015, the New Jersey Autism Center of Excellence (NJ-ACE) convened the first statewide Summit to highlight research¹ being conducted in New Jersey to better understand the nature of autism spectrum disorder (ASD).

More than 180 individuals, representing families, educators, providers, researchers, and policymakers attended the Summit². All participants were invited to complete a feedback form to share their satisfaction with the event and their perceptions on its usefulness. Of the 186 individuals who registered for and attended the event, 85 completed a feedback form (47% response rate). The findings are summarized below.

Summit Attendees

Respondents were asked about their primary motivation or perspective for attending the Summit (Figure 1). The most frequently reported motivations were that of:

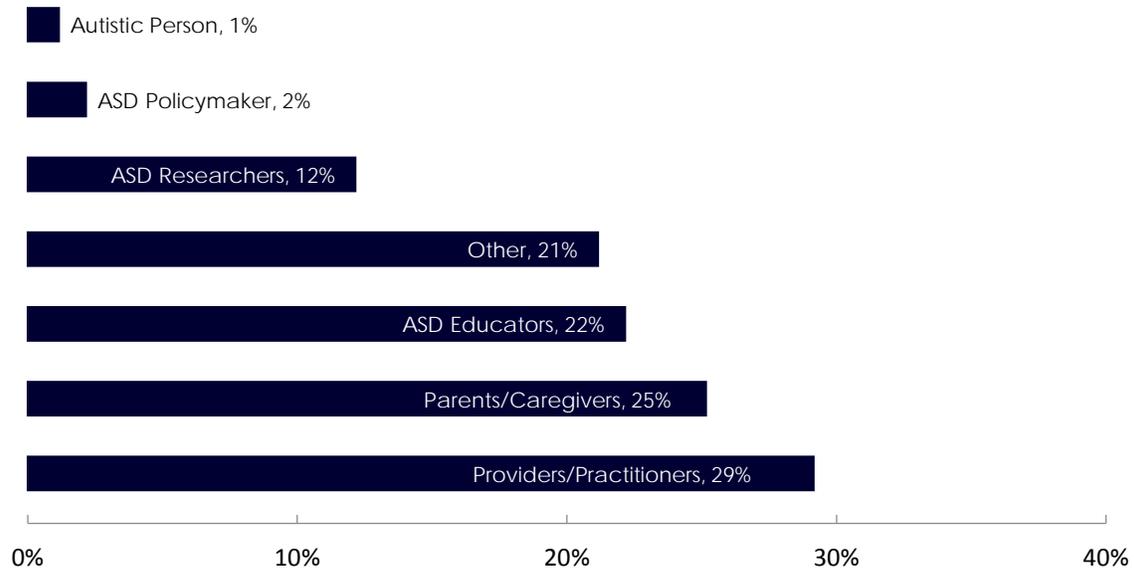
- ASD providers or practitioners (29%)
- Parents or caregivers (25%)
- ASD educators (22%)
- Other write-in roles: Case Managers, Perinatal Addictions Counselors, Special Needs Coordinator, Parent Advocate, Nurse Case Manager, Board Member, and Bilingual Lactation Counselor (21%)

Of note, one percent (1%) of respondents indicated that they were an autistic person and that this was their primary motivation for attending the Summit.

¹ Funded by the NJ Autism Center of Excellence (NJ-ACE) Clinical Research Grant Program through the NJ Department of Health's Governor's Council for Medical Research and Treatment of Autism.

² 186 individuals registered for and signed in at the event. Several individuals who did not register for or sign in also attended the Summit. As a result, the actual attendance at the Summit is estimated to be more than 200, based on the number of favors given away and meals provided.

Figure 1. Primary motivation for attending NJ-ACE Summit



Summit Satisfaction

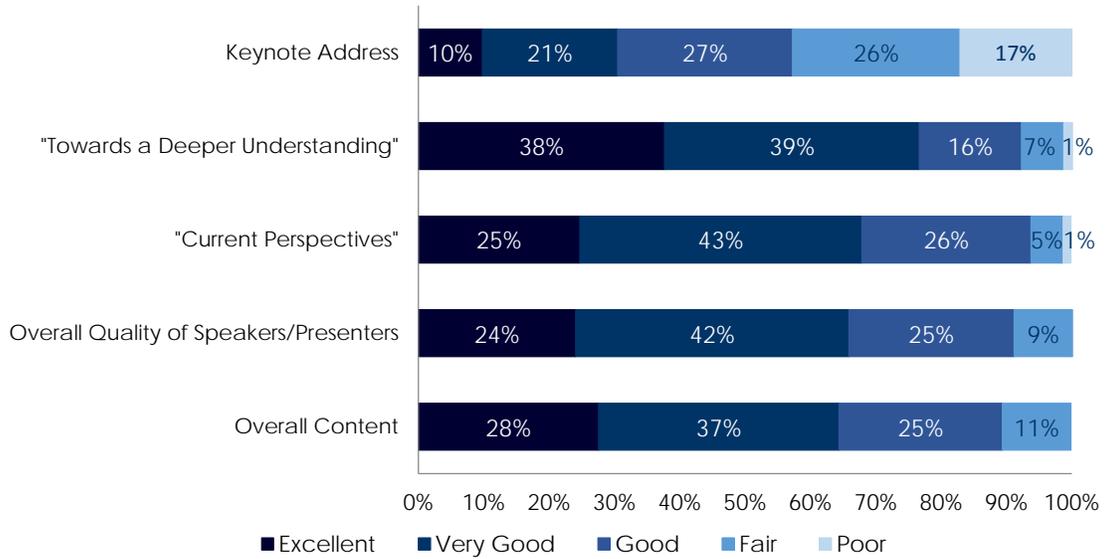
Content

Respondents were asked to rate (on a scale of poor, fair, good, very good, or excellent) their satisfaction with the content of the Summit including the keynote address and presentations (Figure 2).

Most respondents reported that they were satisfied with the content of the day. Two-thirds rated “excellent” or “very good” both the overall content of the Summit (65%) and the overall quality of the presenters (66%).

- 77% of respondents rated the presentation “Towards a Deeper Understanding” by NJ-ACE researchers as “excellent” or “very good”.
- 68% of respondents rated the presentation “Current Perspectives” by NJ-ACE researchers as “excellent” or “very good”.
- 31% of respondents rated the keynote address from Dr. Willis Overton as “excellent” or “very good”.
 - Of note, 43% rated the keynote address as “fair” or “poor”. The frequency of these “fair” or “poor” ratings varied by identified group.
 - 80% of respondents who identified as ASD researchers;
 - 48% of respondents who identified as providers/practitioners;
 - 45% of respondents who identified as parents/caregivers; and
 - 33% of respondents who identified as ASD educators rated the keynote as “fair” or “poor”.

Figure 2. Satisfaction with content of Summit



Several respondents offered specific feedback regarding the content of the Summit in the open-ended comments section of the survey.

"Being exposed to such brilliant and dedicated researchers and their work. Learned so much and deeply thankful. The booklet with its detailed explanations of each talk was very helpful."

"I enjoyed the diversity of researchers and the wealth of information I gained from them. I also enjoyed meeting other parents, educators, and researchers focused on improving the lives of our ASD children."

"Nice to see research taking heterogeneity into consideration. More collaboration and cross-disciplinary renew/research! So good to see investigators sharing ideas and data."

"The afternoon sessions were informative, easy to follow, and well presented. Terrific job."

"The second half science talks were excellent! Researchers did a great job of keeping info accessible. Very interesting topics too."

"A reduction in research presentations and increase of available resources to aid individuals and families of ASD. Presentations including evidence-based interventions would be most helpful."

"Present not just on current studies but conclusions from recently concluded studies. Give specific 'take home message', have each presenter provide tangible information that we can use. Also, present on more broad research, not esoteric microscopic research with lack of conclusion."

"I believe presentations should be more interactive and include language that is inclusive of varying levels of knowledge about autism. Some of the jargon speakers used were too complex. Keynote speaker should reach parents and people with ASD."

"Keynote speaker did not use a vocabulary that the audience could relate to. Way too many theories and very vague explanations as to the relationship with autism. It was difficult to comprehend and looking into the audience, it looks like many people seem perplexed."

"Maybe 2 simultaneous panels or 'tracks'/concentrations of breakout sessions to highlight neurobio vs. epidemiology on genetics vs. behavioral? Give panelists more time and better fit/match the audience."

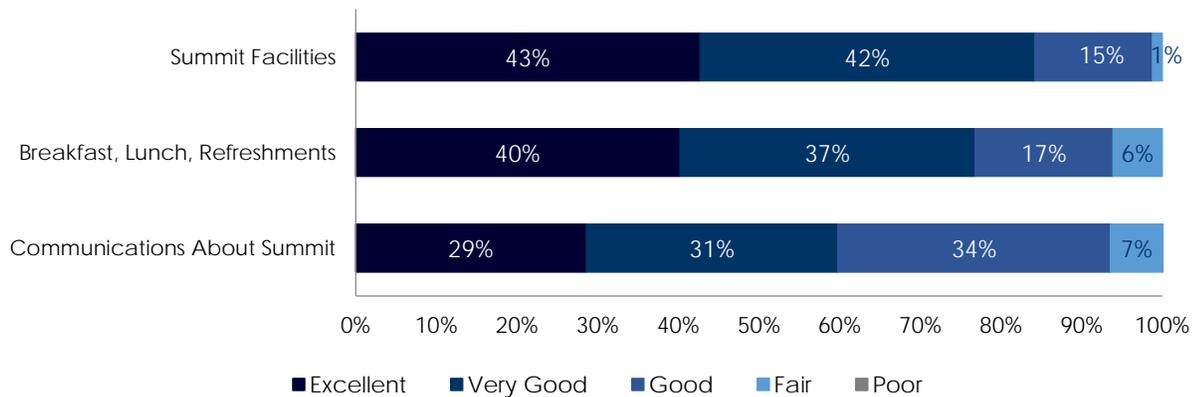
Logistics

Respondents also were asked to rate (on a scale of poor, fair, good, very good, or excellent) their satisfaction with the logistics of the Summit including the facilities, food, and communications (Figure 3).

Respondents rated positively the facilities for and communications about the Summit.

- 85% rated the Summit facilities at MSU as “excellent” or “very good”.
- 77% rated the meals and refreshments as “excellent” or “very good”.
- 60% rated the communications about the Summit as “excellent” or “very good”.

Figure 3. Satisfaction with logistics of Summit



Several respondents offered specific feedback regarding the logistics of the Summit in the open-ended comments section of the survey.

“Great job of planning a very full day!”

“I liked the venue and how organized the event was.”

“The gifts were great/thoughtful thank you!”

“I had a very good experience overall, just better technical support for future presentations.”

“Lunch was really good and innovative! Coffee in the afternoon would have been ideal.”

“The food was too specific. Fish/chicken choice would have been better. Better audio-visual. Tea/coffee should be available for the whole conference, particularly in the afternoon.”

“Consider food in a different room to avoid noise from set-up and clean-up. Better signage on campus.”

“Coffee in the afternoon please! Also a 5 minute break after 4 presenters would be nice. One talk after another, no matter how short, can be very taxing.”

“Better information to the community. I heard about this by accident and I am a local practicing psychologist.”

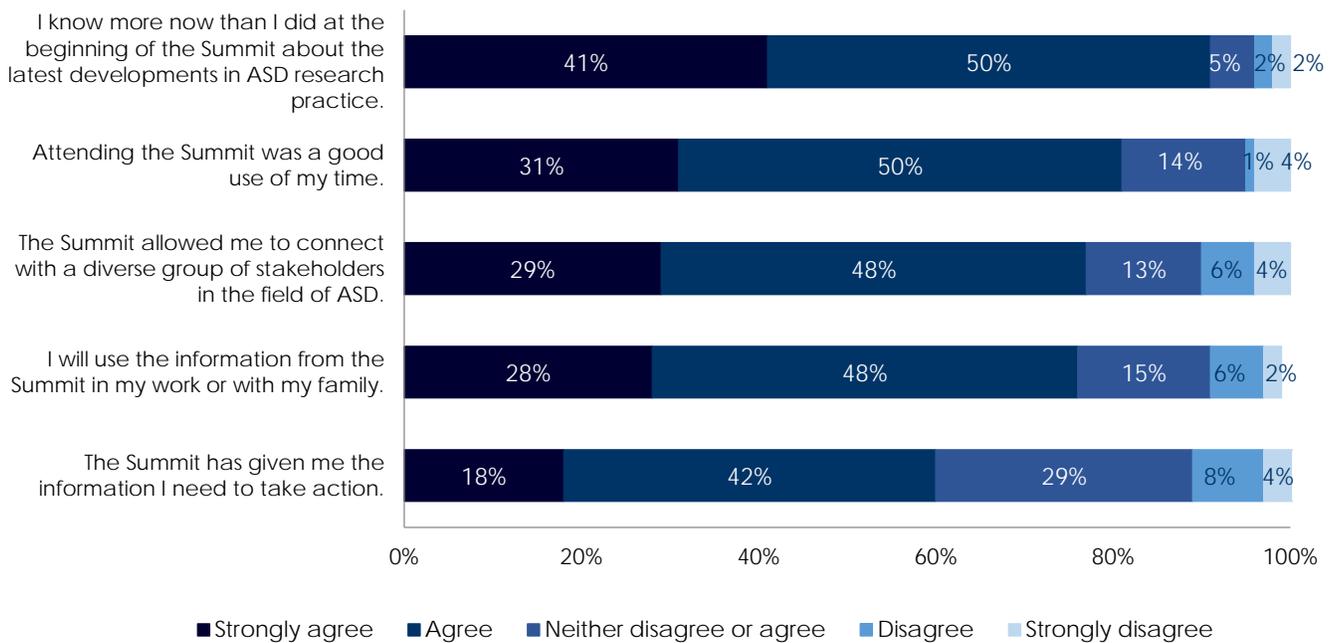
“Timing of conference very bad. To expect people to travel to Montclair at 8am and leaving at 4:30pm on a Friday is poor planning because of NJ traffic patterns. Room is too cold! Offer something other than water to drink without sugar.”

Summit Usefulness

Respondents rated (on a scale of strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree) the usefulness of information provided, knowledge gained, and the use of their time in attending the NJ-ACE Summit (Figure 4).

- 91% “agreed” or “strongly agreed” that they know more now than they did at the beginning of the Summit about latest developments in ASD research and practice.
- 81% “agreed” or “strongly agreed” that attending the Summit was a good use of their time.
- 76% “agreed” or “strongly agreed” that they would use the information from the Summit in their work.

Figure 4. Agreement with Summit Usefulness



Action Steps

Respondents were asked to share an action they will take as a result of attending the Summit. Many mentioned sharing information with families, service providers, and staff. Some were interested in learning more about the studies and helping to recruit participants for the research.

“Share information with teachers and colleagues in my district.”

“Facilitate a training for staff.”

“Refer families to published research studies and refer them to become part of the research projects.”

“As a parent of an autistic child, I will be investigating genetic testing for him as well as signing him up for various studies. The study regarding ABA/VB vs. RDI was particularly interesting to me since I am deciding which one would best benefit my child.”

“Watch for BPA-free plastics.”