

INTERAGENCY AUTISM COORDINATING
COMMITTEE

FULL COMMITTEE MEETING

THURSDAY, APRIL 14, 2022

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 1:00 p.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

PRESENT:

JOSHUA GORDON, M.D., Ph.D., *Chair*, IACC,
Director, National Institute of Mental
Health, (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary*,
IACC, Office of Autism Research Coordination
(OARC), NIMH

COURTNEY AKLIN, Ph.D., National Institutes of
Health (NIH) (representing Lawrence Tabak,
D.D.S., Ph.D.)

MARIA MERCEDES AVILA, Ph.D., M.S.W., M.Ed.
University of Vermont

MITCHELL BERGER, M.P.H., Substance Abuse and
Mental Health Services Administration
(SAMHSA) (representing Anita Everett, M.D.,
D.F.A.P.A)

ALICE CARTER, Ph.D., University of Massachusetts
Boston

JUDITH A. COOPER, Ph.D., National Institutes
of Health, (representing Debara L. Tucci,
M.D., M.S., M.B.A., F.A.C.S.)

PRESENT: (continued)

SAMANTHA CRANE, J.D., Quality Trust for
Individuals with Disabilities

AISHA DICKERSON, Ph.D., Johns Hopkins
University

TIFFANY R. FARCHIONE, M.D., U.S. Food and
Drug Administration (FDA)

MARIA FRYER, M.S., U.S. Department of Justice
(DOJ)

DAYANA J. GARCIA, M.Ed., Administration for
Children and Families (ACF)

DENA GASSNER, M.S.W., Adelphi University

ALYCIA HALLADAY, Ph.D., Autism Science
Foundation

ELAINE COHEN HUBAL, Ph.D., U.S. Environmental
Protection Agency (EPA)

CRAIG JOHNSON, Champions Foundation

ALICE KAU, Ph.D., *Eunice Kennedy Shriver*
National Institute of Child Health and Human
Development (NICHD) (representing Diana
Bianchi, M.D.)

CINDY LAWLER, Ph.D., National Institute of
Environmental Health Sciences (NIEHS)
(representing Rick Woychik, Ph.D.)

ALISON R. MARVIN, Ph.D., Social Security
Administration

KAMILA MISTRY, Ph.D., M.P.H., Agency for
Healthcare Research and Quality (AHRQ)

PRESENT (continued)

YETTA MYRICK, B.A., DC Autism Parents

LINDSEY NEBEKER, B.A., Freelance
Presenter/Trainer

MORENIKE GIWA ONAIWU, M.A., Rice University

SCOTT PATTERSON, Ph.D., U.S. Department of
Veterans Affairs (representing Matthew
Miller, Ph.D., M.P.H.)

JENNY MAI PHAN, Ph.D., University of
Wisconsin-Madison

JOSEPH PIVEN, M.D., University of North
Carolina-Chapel Hill

JALYNN R. PRINCE, B.F.A., Madison House
Autism Foundation

AMANDA REICHARD, Ph.D., Administration for
Community Living (ACL) (representing Jennifer
Johnson, Ed.D.)

SUSAN RIVERA, Ph.D., University of
California, Davis

ROBYN SCHULHOF, M.A., Health Resources and
Services Administration (HRSA)
(representing Lauren Ramos, M.P.H.)

STUART SHAPIRA, M.D., Ph.D., Centers for
Disease Control and Prevention (CDC)
(representing Georgina Peacock, M.D., M.P.H.,
F.A.A.P.)

MATTHEW SIEGEL, M.D., Tufts University

IVANOVA SMITH, B.A., University of Washington

PRESENT (continued)

TERESA SOUZA, Ph.D., U.S. Department of
Housing and Urban Development (HUD)

HARI SRINIVASAN, University of California,
Berkeley

JODIE SUMERACKI, B.A., Centers for Medicare
and Medicaid Services (CMS)

HELEN TAGER-FLUSBERG, Ph.D., Boston
University

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt
University

PAUL WANG, M.D., Simons Foundation

LARRY WEXLER, Ed.D., U.S. Department of
Education (ED)

STEPHEN WHITLOW, J.D. Merakey

NICOLE WILLIAMS, Ph.D., U.S. Department of
Defense

TARYN MACKENZIE WILLIAMS, M.A., U.S.
Department of Labor

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(NIMH) and Chair, IACC

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NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

PROCEEDINGS

DR. JOSHUA GORDON: Good afternoon and welcome to the continued Day 2 now of our IACC April Meeting. I want to thank all of the committee members for their hard work and productive discussions that we had yesterday and thank them in advance for their continued work today. I also want to thank members of the public who are following us on the NIH Videocast network.

Please note that we have updated our agenda for today. You can find these updates on the IACC website. We will start with our public comment discussion and then hear presentations in a panel on the topic of diverse communication needs followed by a discussion of that topic. After the panel and discussion, we will return to our Summary of Advances discussion that we were unable to

finish yesterday and then wrap up with round robin updates and closing remarks.

For now, we will head into the public comment session and I will turn it over to Dr. Susan Daniels, director of the Office of Autism Research Coordination at NIMH and executive secretary of the IACC to run the public comment session. Susan, take it over.

DR. SUSAN DANIELS: Thank you, Josh. We are going to be starting the oral comment session. The public comment session is in three parts. We are going to first hear the oral comments and then I will share with you the written comments that came in and then we are going to have a discussion.

The order of the oral comments is Dr. Eileen Nicole Simon, Stevie Mays, Lisa Morgan, Bob Williams, and Dr. Edlyn Pena. Dr. Simon, you may begin. Welcome. Feel free to turn on your camera if you would like to.

DR. EILEEN SIMON: The camera is not going on. It says unable to start video.

DR. DANIELS: We might be able to help you with that.

DR. SIMON: Alright. It still says it cannot start video. Can you hear me?

DR. DANIELS: Yes, we can hear you. Please go ahead. Thank you.

DR. SIMON: Failure of language development is the most disturbing concern of parents who seek help for a child. And sadly, they are often given a diagnosis of autism. Difficulty learning to speak is not a sign that is ever missed. Language is the defining feature of the human species. Social development cannot advance far without language. In October 1969, I read the article by William Windle in Scientific American on asphyxia at birth and I burst into tears. My

sweet autistic son, Conrad, ran to the Kleenex box and brought me a tissue.

Windle described damage of the inferior colliculus in the auditory pathway of monkeys subjected for only six to eight minutes of asphyxia at birth. Conrad had required resuscitation at birth and then he displayed severe jaundice during the first week of life. Conrad's developmental milestones were all right on time and he began to speak near the end of his first year. Our relief was short lived. It was Conrad's nurse's schoolteacher who suggested he be evaluated by a psychiatrist. Conrad's speech was clear with good articulation, but he used the pronoun you instead of I or me. Autism was the diagnosis he was given shortly before his third birthday.

I hope members of the committee will discuss my comments on language disorder. Thank you.

DR. DANIELS: Thank you so much, Dr. Simon, for sharing that comment with us. There you are so we can all see you. Thank you so much.

DR. SIMON: I was reading my paper so I did not see the sign.

DR. DANIELS: That is not a problem. Thank you very much.

Next, we will go to Stevie Mays.

MS. STEVIE MAYS: Thank you, Dr. Daniels. My name is Stevie Mays. I currently work at Reach Every Voice, an AAC education and activist group. I previously worked as a registered behavior technician, a supervised therapist in the applied behavior analysis field, ABA, for four years. During that time, I find that the Behavior Analysis

Certification Board, BACB, demonstrates extremely poor critical analysis of the morality and ethical responsibility of its practices regarding student's access to appropriate modalities of communication.

I believe children deserve access to education and language, using the communication method best suited for their needs. But the practice in ABA does not reflect this belief. Here, I will focus on the BACB's lack of research and education for the use of augmentative alternative communication, AAC.

AAC refers to a method of communication that does not rely on spoken language or verbalization. This may include sign languages, use of gestures, picture boards, or a large number of devices designed to assist individuals that may not be able to communicate using speech.

I ultimately left the field of ABA after my four years. I saw a pattern of students working in therapy for years and not making any substantial gains in verbal communication and yet the program forced these children to continue to rely primarily on verbal communication goals with subpar AAC education.

According to Autistic Self Advocacy Network, ASAN, one-third of autistic people fall under the category of nonspeaking and would need AAC to support or supplement their communication.

The autistic students have a difference in their brain-body connection, which affects control of their bodies. When muscle control is minimized, the resulting behaviors are considered an inherent trait of autism and this difference in muscle control is often also seen in use of voice and is often

treated as a behavioral issue in ABA and not as an accepted difference.

In ABA practices, children that have some verbal capacities are forced to prioritize their limited verbal communication when they could have full range of communication if simultaneously provided access to AAC teachings.

I called a friend who is a registered board-certified behavior analyst, BCBA, the trained and certified therapist, who certifies therapists in ABA therapy. She commented, I have to work within my education. But I have seen children make major communication gains when given access to AAC both in verbal vocal improvements and gain AAC.

However, the BACB does not have curriculum and training on AAC. I tried to mimic what I have seen speech language

pathologists do but I have to work within my training that the BACB provides. There is little AAC training and wish I had access to more.

If the BACB wishes to show a conscious effort towards ethical and moral responsible practices, they need to shift in consideration of more intensive AAC within ABA practices when targeting communication and providing access to language and education. This can be done not only by providing training to therapists but also by conducting research into the functional communication benefits for AAC use when students who show little to no progress of previous intervention efforts.

A long-term study could be done to show to examine the functional communication outcomes of students who otherwise are not showing improvements in communication goals.

Having worked directly with young adult AAC users, they have directly expressed that access to AAC has opened the world to them and I believe all students should have access to AAC education when beneficial. Thank you.

DR. DANIELS: Thank you so much, Stevie, for your comment and for being here.

Next, we will hear from Lisa Morgan. Welcome, Lisa.

DR. LISA MORGAN: Thank you. As an autistic, self-advocate, diagnosed later in life at 48 years old, I have routinely experienced people who do not understand what it is like to live with autism both in professional and personal situations. Yet these people are still considered to be the authorities on autism and autistic people.

While autistic people have been invited to the conversation more and more nowadays, I also strongly feel we are not being taken

seriously. I believe being given an invitation to join in the conversation ends there with us just sitting at the proverbial table but not being listened to in any meaningful way or even worse, being given a pat on the back for showing up so it can just look like we are there participating and being part of the solution to the many issues autistic people face in our society.

We autistic people must be the ones who drive autistic research priorities, participate in developing resources, and effect social change in collaboration with professionals, researchers, and other stakeholders.

Professionals must listen in order to truly fully collaborate. Lived experience of autistic people need to be regarded as valuable and important part of understanding challenges and developing solutions that

really make a positive difference in the quality of our lives.

We autistic people know what it is like to live with autism. We know what works, what does not work. And our experiences must be the most important part of finding solutions. No amount of book learning, training, or any number of years of experience in working directly with autistic people can come close to the knowledge and experience of living with autism of being autistic. And although our invitation to the conversation was kind of late in coming, we can make up for lost time by working together now with autistic people fully involved and completely accepted as competent, knowledgeable collaborators. Thank you.

DR. DANIELS: Thank you very much, Lisa. Thanks for being here.

Next, we will hear from Bob Williams.

MR. BOB WILLIAMS: Thank you and good afternoon. As was said, I am Bob Williams, policy director of CommunicationFIRST, the only organization led by and for the estimated 5 million people in the US who have significant speech-related disabilities, including 30 to 40 percent of autistic people. Before co-founding CommunicationFIRST, I was a senior executive at HHS. Earlier, I also worked on closing an institution. Thank you for inviting us to comment on the critical challenge, addressing communication needs of autistic people. We submitted written comments on April 1, 2022.

Due to the time limit, I will make just two points today. First, like so many of my nonspeaking autistic friends and colleagues, I was regarded as "so severely and profoundly disabled". My parents were told to drop me at the institution and never return. Luckily, in

the 1960s, I somehow was able to point to and type letters and words early, get a good education and go on to college. Today, however, we find young people and adults are denied these same opportunities that ironically federal law now is meant to guarantee as civil rights.

Second, many still are stamped with the same severe and profound threat. Having worked with individuals labeled like this my experience is that it becomes a justification for giving up on someone. I am a past board member of TASH, which removed the term from its name in 1980 because it dehumanized those whose most basic right is to be recognized as human beings. If the IACC is considering recommending certain terminology be used, we strongly urge it to make certain it does so in equal partnership with autistic nonspeaking people and their organizations.

If you have questions on our written comments or my comments today, I can answer now or in writing. Or if there is any assistance we can provide, we would be glad to do so. Thank you.

DR. DANIELS: Thank you so much, Bob, and we will have a discussion period after all the comments and people of course are welcome to ask any of our commenters' questions or make comments on their comments.

Next, we will hear from Edlyn Pena. It is such a pleasure to welcome you back, Edlyn, as a former member of the IACC to give us some comments today.

DR. EDLYN PENA: Thank you, Dr. Daniels. I appreciate it. My name Dr. Edlyn Pena. I am a professor at Cal Lutheran University and the director of the Autism and Communication Center. I served on the IACC committee from 2016 to 2020. As the editor and author of the

books *Communication Alternatives in Autism* and *Leaders Around Me*, I am thrilled that IACC has decided to focus on supporting augmentative and alternative communication, AAC, among nonspeaking and minimally speaking individuals.

One of the major debates in the AAC world is whether parents and practitioners should support text based AAC methods that require a one-on-one communication partner to prompt and support a minimally speaking individual to communicate. Some of the common methods under this umbrella include facilitative communication, FC for short, rapid prompting method, RPM, and spelling to communicate, S2C.

The chief question defining this controversy is who is the author of the message being typed? Is it the facilitator, the communication partner, or is it the

student or communicator? Thus far, experimental studies published in research journals indicate that typed responses using FC methods were either influenced by the facilitator or the communicators were not able to independently pass messages.

In some cases, the bad wrap these methods have received is fair. In other cases, it is not. There is no question that these forms of communication can be subject to influence. And yet the research studies alone offer an incomplete picture. There is evidence of students and individuals who use these various methods and become independent in their communication. That is, their communication partners sits or stands near them but does not hold the letter board or provide physical support. I have witnessed this myself.

In addition, there is documentation of individuals who use FC, RPM, and S2C methods who have communicated medical conditions, even ones that led to diagnoses as severe as cancer. And yet critics of FC, RPM, and S2C refuse to admit that what is being typed in these circumstances is authentic communication from the person typing or spelling.

I implore any researchers, taskforces, or committees focused on AAC to explore questions beyond the communicator's authorship. First, what are the circumstances under which a communicator becomes independent in their communication? What sorts of supports, fading of prompts, user profiles, communication partner training, et cetera, lead to individuals becoming progressively independent? A longitudinal study would be required for this since it

takes years for individuals to become independent.

Second, nonspeaking and minimally speaking autistic individuals contend with a number of underlying challenges and symptoms that play a role in the dynamics of communicating on keyboards and letter boards. Research must continue to uncover answer to sensory differences, motor planning differences, and anxiety, all of which have been documented to some extent in the autism literature.

The relationship among these experiences and alternative communication is not yet well understood. Doing so requires researchers and practitioners to consider multiple sources of data, for example, interviews, narratives, field notes to give us a more holistic picture beyond what can be revealed through

quantitative methods within the context of experimental studies.

Engaging in research studies to address unanswered questions will help the autism community determine the conditions under which FC, RPM, S2C, or other text based AAC methods when done ethically and with rigor can be successful.

Further the answer to these questions will enable the communities that use these methods to move past the question of authorship toward addressing sensory, motor, and anxiety challenges that impact communication as well as improving training of communicators and facilitators.

Rather than determining that a form of communication, which is subject to influence, is therefore dangerous and should thus be stopped, professionals should be committed to understand the ways in which to reduce

influence and to support the progressive independence and reliability of the communicator. Thank you for having me.

DR. DANIELS: Thank you very much, Edlyn, for that comment. Thank you all for being here with us today and sharing these comments. We look forward to discussion after we go through the written comments.

DR. DANIELS: At this time, I am going to share with you the summary of written public comments. We had the most robust written public comment receipt that we have ever had this time around. We had 271 written public comments that came in for this meeting and they were not part of a particular solicitation. I will share with you - I am not going to be able to read all the names because there are many of them. But we will share with you what the different topics were that came in and we divided the comments into

topics to make it a little easier. Anyone who is watching this online, you can see the full text of the comments in the meeting materials that are posted online.

First, we had 153 comments that were on research and service needs, resources, and policy implications. This is the second page of names and that is the third page of names for that particular topic.

We also had some comments, 43 comments, that were about concerns about medical practices and the names are listed here.

We had 21 comments on the role of the IACC and the federal government and 22 comments on research, services, and supports for adults on the autism spectrum, 3 comments that were related to the needs of direct support professionals in the workforce, 4 comments pertaining to employment, 8 comments pertaining to potential causes of autism, 5

comments on the needs of autistic individuals with high-support needs, and 12 comments on increasing autism acceptance and reducing stigma. Those were all the comments.

Now, we have some time for IACC members to discuss the comments. I would encourage you to keep your comments somewhat short so that we can get around to everyone that wants to talk about the public comments. Go ahead and you are welcome to make some comments. Alison Marvin, I see your hand raised.

DR. ALISON MARVIN: Hi. Hello. Alison Marvin from the Social Security Administration. I am responding to the public comment by Rob Lagos and a written comment in response to Dr. Hemmeter's presentation at the last IACC meeting by IACC member Dena Gassner. Both requested that SSA take steps to better accommodate those on the spectrum. We have passed your comments onto the

appropriate key individuals within the agency.

We also wanted you to know that SSA has been working on equity-related issues for a while now and today, the Social Security Administration released its first equity action plan, supporting President Biden's whole of government equity agenda to advance equity, civil rights, racial justice, and equal opportunity for all. Our Acting Commissioner Kilolo Kijakazi stated systematic values may prevent people who need our programs the most in accessing them. Our equity action plan will help to reduce these barriers for autistic people to have access to our services.

In conclusion, I wanted you to know that we hear you and that we are actively working to make things better. Thank you so much.

DR. DANIELS: Thank you, Alison. And I also will mention to committee members that when Dr. Hemmeter was here for the last meeting, some members had some additional questions that we were not able to get to and we have provided answers to those questions that were provided by SSA in the meeting materials. You will find them in the round robin section. Thank you so much and we will be sure to add that update also to the federal news section of the IACC website after this meeting. Thank you.

Next, do we have more comments from members of the IACC and if you would raise your hands?

MS. DENA GASSNER: Yes. I noticed a pattern sort of where people were calling for more autistic people to be on the IACC. I was just wondering, Susan, if you might help to clarify this. I am not sure people understand

that the IACC invites agency representatives, but we do not get to identify who they will be. However, most of the community members or many of the community members are people on the spectrum or direct relatives of people on the spectrum. I thought it might be good if we could give them an opportunity to understand how the IACC is constructed. Sorry to catch you cold. I should have sent that to you last night. But I just had it in my notes from yesterday and I forgot to address it with you.

DR. DANIELS: That is not a problem. The Autism CARES Act of 2019 provides guidance on particular kinds of members that we are supposed to include on the committee and that includes autistic individuals, parents and family members, and leaders of national services and supports organizations, research organizations, and advocacy organizations.

Those groups are divided somewhat into three. However, many people on this committee wear more than one hat. For example, someone like Dena, who is both an autistic self-advocate as well as somebody who has a child on the spectrum or an adult child on the spectrum. Some people are both parents and advocates or parents and researchers or autistic individuals and researchers or advocates in organizations. There are many different ways that people wear multiple hats. There is an effort by the Secretary of Health and Human Services to appoint people that represent the broad variety of perspectives across the entire autism community. Feel free to check out our roster and all the bios that are on our website for the members of the committee.

MS. GASSNER: Thanks, Susan. I did want to thank you, Alison, for your great response. I would love to reach out to you

afterwards if there is anything I can do.

Thanks, everyone.

DR. DANIELS: Thank you. We have a question from Susan Rivera.

DR. SUSAN RIVERA: Thanks, Susan. It is more a comment. I really wanted to thank Edlyn for her wonderful comments about how research is needed on ACC and I also just wanted to add an idea to those comments and those guidelines that were given. There is a lot of use of technology particularly eye tracking now that can be very useful in understanding when you have augmentative communication that is more self-initiated versus being someone else's communication. I just wanted to encourage us to put out some kind of recommendation that this kind of research be encouraged, be supported and funded so that we can put some of these myths to rest and really understand and use the

technology and the resources available to us as researchers to understand these questions.

I think critically we really need to involve those who are both skeptics and supporters of IACC to really be a part of this conversation and be a part of the research so that everyone is a stakeholder and understanding the truth of this communication, who it helps, and in what ways they can help. Use what we are already using in other elements of research to unpack this question.

DR. DANIELS: Thanks very much, Susan. Of course, the IACC's Strategic Plan is a perfect place for any recommendations that the IACC would like to make. We will talk about that and many other topics at our July working group meeting.

Scott, do you have a comment or question?

DR. SCOTT ROBERTSON: Yes. Thanks, Susan. I wanted to echo with what Susan was just sharing. Susan Rivera. On AAC that I suggested, it should become a major focus that can be interwoven throughout the Strategic Plan and should be something that we should explore on the long term. It would be great for the community to explore on the long term, ways to enhance the focuses in research in terms of priorities that go for the projects and maybe the Autism Centers of Excellence, et cetera. There are different ways creatively where folks can expand the emphasis there on AAC and language and communication across the life course for folks and what that means to improve opportunities in life and quality of life and also that it would be great maybe to explore things such as maybe in October with National AAC Month. Maybe that is something that you

all at OARC or federal agencies maybe could collaborate on that on a panel of autistic AAC users or something like that to interconnect with the emphasis with that priority of making sure folks have full access to communication, which I think is a right that everyone should be able to enjoy that is in line with the priorities of UN Convention on the Rights of Persons with Disabilities, UN CRPD.

I just also wanted to mention briefly too. It is great seeing the comments on employment and access to career paths for folks. I just wanted to remind folks that we have this in our round robin updates is that we are running our research project for the next three years that it started this year and runs all the way to 2024. It is a project and research support services for employment of young adults on the autism spectrum. And

we are actually running listening sessions right now actually in April. We run a number of them also in March, et cetera. This project is continuing to learn about the perspectives on reducing work barriers and finding solutions, enhancing policies and practices.

It is great to find input from folks and also that - one of the emphases in one of the written comments was on more data in terms of what it looks like in terms of the specific unemployment, under employment, income barriers, et cetera. That is something that we are looking at too if we could do things at the Department of Labor or maybe collaborate with federal partners on that in terms of what that might look like in terms of different avenues whether it is surveys, et cetera, that we could look at as possibilities on that data end because we do

recognize that there is a large data gap, including what is available right now in the empirical literature and some of the studies have smaller ends and do not always generalize as well. I know we have some gaps there as what the knowledge base that we need to learn about, the current state of employment, under employment in terms of just barriers for folks being able to access - to fit their interests, strengths, and skills and be successful in terms of the work that they can enjoy and thrive. Really great that those comments are there on employment.

And really great to see also that folks are actively contributing overall like - the committee broke the record as far as - what did you say?

DR. DANIELS: 171.

DR. ROBERTSON: Wow. It is 119 pages or something like that of comments. That is

tremendous in terms of the engagement from the community.

DR. DANIELS: We would like to thank organizations that have sent out notes to people. Please any organization that is represented here or that is listening in, feel free to encourage people to give us comments because we want to hear from the community. Thanks so much, Scott. We will certainly follow up on some of those things after the meeting.

Paul, do you have a comment or question?

DR. PAUL WANG: Comment please. It is going to sound like I am jumping on the bandwagon here. But I want to thank the public commenters Stevie Mays and Edlyn Pena and a number of the other written commenters also for bringing attention to the issue of AAC. I think that is of the highest importance.

I do not think there is any disagreement that communication ability is central to quality-of-life issues. And we all agree that it is quality of life for the autistic community that we want to advance. If communication does not work verbally, vocally, then we need to find these other avenues through which autistic people can communicate. AAC is wonderful for that.

Dr. Susan Rivera talked about the need for research on AAC. I second that call. I want to mention that my organization, SFARI, although we are much better known for sponsoring research on genetics and neurobiology, has all the sponsored research related to this, research showing that there are nonverbal autistic people who can read who were never thought able to be able to read but through the use of eye tracking technology, we can demonstrate that indeed

they comprehend the words that are being shown to them. Clearly, those are people who may very well - some of them already do benefit from the use of AAC.

To underscore one particular point that Dr. Edlyn Pena raised, there are cases where it is the facilitator, the communicator, not the person who is communicating. We need to be able to also determine identify where that is the case because the autistic person is not being properly supported, is not being properly represented, is not being helped. The quality of life is not being helped when they are not the ones who are able to speak. We need research both on the larger level and then also we need to be able to identify the individual cases who it is really working for.

Finally, I just want to add in response to Stevie Mays' comments that I do not think

that it is the ABA therapist who is going to be best placed to help with AAC. I certainly agree that there are people who need - who will benefit much more from AAC than from ABA. But it is not the ABA person who should step into that role - it is going to be someone with deep speech language pathology training who is going to be best placed to do that. And families and individuals need to have the funding to support to get those services to support AAC and to have a highly qualified individual help them with the AAC.

DR. DANIELS: Thank you so much, Paul, for those comments. I appreciate that.

Next, we will take a comment or question from Ivanova Smith.

MS. IVANOVA SMITH: I just wanted to say I am very supportive of making sure that we can support research in alternative forms of communication. I also want to support the use

of body language as communication. For some people, especially young children, body language is the first way you communicate. We need to make sure that we recognize that and if somebody is still struggling with other alternative forms of communication that we recognize their body language as a form of communication and we do not just wave it off as a challenging behavior. A lot of times that happens. But it could be a medical thing, or it could be something going on that they try to communicate with their body language it would help if that was a solution. I think that also sign language is another form of alternative communication that is really good. I really support all the wonderful comments from nonspeaking individuals and thank you for the comments.

I think that we need to make sure that people that are nonspeaking have the same

rights as people who are speaking and that we do not justify policies that restrict their rights because a person cannot speak. Thank you.

DR. DANIELS: Thank you, Ivanova.

Next, we will hear from Julie Taylor.

DR. JULIE TAYLOR: I just wanted to respond really quickly to some of the comments around the need for work on employment and kind of piggyback on some of what Scott was discussing. Scott, you and I definitely need to have a conversation offline because we are also right in the middle of a study or actually at the beginning that is going to really take a deep dive in terms of understanding what is helpful in helping autistic adults get on a positive employment trajectory over time. I think it is a much smaller study, Scott, than what you will be able to do at DOL.

We will have 200 adults but we are going to follow them very closely over three years and do a really deep dive to understand what are the characteristics of the workplace, what are the characteristics of service systems, importable supports, what strengths people bring to the table that really helps enhance employment stability and also helping people - what is predictive of people - upward trajectories in terms of moving into careers and jobs that really fulfill needs for them.

It sounds like at DOL, Scott, you guys are doing this on a large scale. We are going to do it on a little bit of a smaller scale but really delve deeply into how people are spending their days and their employment activities to really get a lot of information about the different ways that we can support autistic adults in positive employment

trajectories over time. I think we are going to learn a lot about this over the next few years and a lot of other people are doing great work in this area too. I wanted to mention the study that we are working on that is related exactly to those issues.

DR. DANIELS: Thank you so much for sharing that, Julie. We look forward to hearing more about that study in the future.

Next, I would like to take a comment from Steven Isaacson, who is on the OARC team. I believe that Steven must have a comment to share from another IACC member.

MR. STEVEN ISAACSON: Yes. Hello. Good afternoon, everybody. I have two comments here from Hari. First one, thanks Edlyn. Everyone deserves to be included. It is like everyone is so obsessed over one issue that the entire community is gatekept from accessing opportunities that contribute to

their success, education, well-being, and even employment.

The second comment is in regards to Paul. Thanks, Paul. It is about quality of life. You can learn reading and counting from just watching Sesame Street, my favorite childhood program.

DR. DANIELS: Thank you, Steven.

Next, we can hear from Alycia Halladay.

DR. ALYCIA HALLADAY: Hi, everyone.

Thanks for taking my comment, Susan. I just wanted to make the point here that we seem to be lumping together the term AAC with FC for facilitative communication. I do not know but I am hoping that there is some sort of distinction about this made in one of the presentations. But I would just like to make sure that going forward we are very specific about the AAC and what that means versus FC or facilitated communication and what that

entails. Just to make sure that we are clear because some people know the difference and other people who are watching this may not.

DR. DANIELS: Thank you so much, Alycia, for sharing that clarification. I am sure that our speakers in that next session will be able to address that.

We have a comment from Dena.

MS. GASSNER: Just quickly. I forgot to mention this. I just wanted to make sure that we also keep the understanding that some people who are primarily verbal can have episodic mutism where their language flows in and out. I know a few people who have both verbal language but under extreme pressure to perform or with a flow of anxiety or a challenging situation, their language may no longer be accessible to them and they are also often AAC users. When we are talking about it, I want to make sure we are making

room for people who use both modalities.

Thank you.

DR. DANIELS: Thank you for that important comment, Dena, and it is a good clarification for everybody to realize that there are people that do speak at times and other times it is easier to use AAC. We welcome any kind of communication that works for them.

Next, a comment from JaLynn Prince.

MS. JALYNN PRINCE: Thank you. This is an important topic. I am a mother of a son who is basically nonverbal. He utilizes art as a way of communication, and it is deep and very profound.

But there is another hat that I wear and sometimes you are going to see me wafting back and forth between hard data research and very practical aspects because our foundation works directly with people, with parents,

with understanding how to communicate to the broader community what many of the needs are within our community of autism. As a result, we have a program that is targeted very much on Autism After 21 Day, which is next Thursday, which we have declared in Congress. It is geared toward a lot of thought leaders in the community.

As a result, we have a very interesting video that is being produced and if it ends up as good as all of the others, we have had our first edits with it and we have three young men that are being featured in this. This is a cohort of five young men that have grown up together that use augmentative communication. And one young man said as he got into this that finally he had been let out of prison because he was able to communicate. They are all extremely articulate. It is a video about four and a

half minutes because we tried to keep it brief enough that we can show it to a lot of these thought leaders and demystify things that goes very much to the point of employment because if we could have employers and others in the community understand that behind someone who may be somewhat silent verbally that there could be a lot of content and a lot of value in employing these individuals as well. It will be made available on the Madison House Autism website after the 21st of April. But if you want to show it to anyone or take a look at it and comment, we think it is important to be able to communicate not just with professionals and people involved and things like ourselves but with the rest of the community so we can have greater understanding of how we can have acceptance happen within our communities.

Thank you very much for allowing me to make my comments.

DR. DANIELS: Thank you, JaLynn. And we do have information about the Autism After 21 Day on our Autism Awareness Month webpage if anyone is interested in checking that out, which will take you to the Madison House website.

Next, I would like to hear from Lindsey Nebeker.

MR. ISAACSON: This is Steven. I will be reading Lindsey's comment. Thank you to everyone who submitted and shared your comments. In reviewing the written comments and listening to the oral comments submitted for the April 2022 Full Committee meeting, one of the primary themes that stands out is communication and the issue of not having access to adequate communication supports.

As mentioned in some of the written comments, this especially applies to autistics who have more significant support needs and have not yet succeeded in finding a method of communication that works for them. Not everyone has been able to successfully learn how to use communication devices we currently have available. I think this is incredibly important for us to pay attention to as we discuss our research priorities.

We need to continue to acknowledge and recognize the concerns raised by our community about excluding the voices of individuals with high support needs. I appreciate the IACC's efforts in beginning to improve the diversity of voices on the table. We have begun to witness those efforts take place in the current representation of our committee members.

However, I want to be clear that I am in full agreement that we need to do better collectively in amplifying the voices of individuals and loved ones who require higher support needs and we need to ensure they have representation on the table. We need to do better on focusing on the entirety of the spectrum particularly individuals and their loved ones who rely on 24/7 support and services to ensure quality of life.

I want to encourage that the IACC continues its efforts to improve the diversity of its members even more so and that we do not lose sight of that effort. I also want to thank Dr. Gordon for his remarks yesterday on the importance of listening and respecting each other's perspectives.

DR. DANIELS: Thank you very much, Lindsey, for those comments.

Next, we would like to hear from Craig Johnson.

MR. CRAIG JOHNSON: Thank you, Susan. I am really excited to hear just a little bit of what Scott was talking about and Julie especially when it comes to jobs. I have seen some breakthroughs happen within state organizations. I would love to explore how much nationally and statewide we are helping employers begin to provide jobs or work with different individuals. In our state, we have done three job fairs in the last three years. A place called Texas Workforce Solutions has gotten employers, over 40 or 50 employers that were willing to work with special needs adults to have them apply for jobs and many of them got jobs. I would love to see how we begin to work nationally as well with statewide in seeing some different breakthroughs and just hear from different

people on the committee what might be happening in their state or in their particular area and field. That would be amazing.

DR. DANIELS: Thank you so much, Craig. And, Scott, did you have anything to say about states and employment that might help with that?

DR. ROBERTSON: Sure. We also do - I should say in reference, we have much engagement with state and local policy at ODEP here at the US Department of Labor. We have a project on state local policy interchange called State Exchange on Employment and Disability, SEED, which has regularly engaged in collaboration - we do not force policy on folks. We engage in collaboration, technical assistance, et cetera, in terms of work and employment-related facets such as accessible technology,

transportation, et cetera. If you, for instance, do a search on Google or Bing for ODEP and state policy, I think you could get quickly to our state policy page and you can find more about like our Work Matters report and other focuses on there on the state and local.

I concur with what was shared about that engagement in terms of at the state and local level in addition to the work nationally. Thank you, also, Julie, I will be glad to connect offline too about - maybe we could have a meeting with some of my colleagues here at DOL related to your study because I think it would be very complementary to what we are doing because ours is more focused on learning about policies, practices, solutions, and barriers because we are policy shop, so it is more centered on that. And yours sounds more like original research.

I think it would be very complementary to learn about any qualitative or quantitative data that you are going to be gathering for that study over the next few years, it may be helpful for that and other research that is coming out to help inform our project that we are running for our project and research support services for employment of young adults in the autism spectrum in terms of we are always looking for input/ideas to consider for what we are thinking about for the next three years in addition to all the way through to 2024 and that includes also what we are learning, as I say, for the listening sessions, et cetera. We can talk offline on that.

But I am glad that we have a lot of convergence on this and the AAC focuses, et cetera. This is really delightful that folks feel as equally passionate about these

communication focuses and employment and other aspects of quality of life for children, youth, and adults on the autism spectrum throughout the life course. This is wonderful.

DR. DANIELS: Thank you, Scott. And thank you, Craig. We will move to Jenny Mai Phan.

DR. JENNY MAI PHAN: Thank you, Susan. Thank you to the oral public commenters and also those who submitted written comments to the IACC. I appreciate people who chimed in and just to kind of reiterate what everyone here has already said. Thank you for submitting comments about AAC use and certainly making that a priority for research and interventions.

I want to also add a plug on those who are non-Native English communicators. When we talk about AAC use, there are plenty of families who may not be speaking English as

their primary language. Maybe it is their second or third. In this conversation, I just hope that we also keep in mind that English may not be a primary language for certain autistic families. Thank you.

DR. DANIELS: Thank you very much for that comment, Jenny.

We have a few minutes left for any other comments anyone has. Does anybody have anything else they would like to share? Hari, I saw you turned on your camera.

MR. ISAACSON: I can share Hari's comment. Also as Evelyn touched on there is a huge issue. There are so many things going on behind the scenes. It is the anxiety around being expected to type at the speed of instant spoken language. Each conversation has the same pressure of a high-pressure interview. It is the lack of body schema. It is like trying to drive a car with a loose

steering wheel while trying to think on the spot and come up with coherent responses. It is the ADHD and sensory stuff all working to distract you. We really need research into understanding sensory and body schema issues so we can better support communication challenges itself.

DR. DANIELS: Thank you so much for that comment, Hari. Thank you, Steven, for assisting us with reading those comments.

I have two minutes left. Any last comments before we break? Aisha Dickerson.

DR. AISHA DICKERSON: I wanted to say that I read all the comments regarding etiology or the causes of autism. I want to say that I appreciate the committee members that provided comments on that. I think a lot of times people do not necessarily want to focus on etiology of autism. Yes, there should be a priority around services for

people with autism. But this demonstrates that there is still significant interest in what causes autism. I want to respond to some of those comments, specifically, the ones asking about parents passing genetic pre-markers for autism to their child and point out that there is a lot of ongoing research especially through the SFARI group. It is a good idea to just look at their website and see what is ongoing.

But I also wanted to say that there was one particular comment that still focused on vaccines, and I wanted it to be recorded that I am saying that is a very dangerous direction to try to point any blame towards vaccines especially in an era when we have an ongoing pandemic. I would like to say as an epidemiologist that studies have shown that vaccines are not within the causal pathway of autism. Thank you.

DR. DANIELS: Thank you very much, Aisha. Alright, we are at 1:55 so we are right on time to take a break. We will be returning at 2:10 for our next session that we are all looking forward to on perspectives on addressing diverse communication in autism.

Josh, do you have any other comments before we go to the break?

DR. GORDON: Yes. I just wanted to thank everyone for their really active and thoughtful consideration of the public comments. I am really looking forward to in the context of all the comments on assisted communication to hearing about the latest research and also hearing from individual's lived experience using these technologies. I am looking forward to the panel very much and see you after the break.

DR. DANIELS: Wonderful. We will be back at 2:10. Thank you.

(Whereupon, the Committee members took a brief break starting at 1:55 p.m., and reconvened at 2:10 p.m.)

DR. GORDON: Again, it is my pleasure to welcome everyone back. In this next section, we will have a panel on perspectives on addressing diverse communication needs in autism. We have heard from many of you out there in the community as well as around the table, the virtual table here today, about the importance of understanding the needs of autistic individuals who are minimally verbal or nonspeaking and those who may use or benefit from alternative and augmentative communication methods. We heard more about that today in many of the comments both written and oral that were delivered.

In response to this feedback, I want to thank Susan and the IACC staff working with several members of the IACC to assemble this

panel where we will hear from both recent research advances and also perspectives of autistic individuals and family members.

I want to start by introducing Dr. Judith Cooper, the deputy director of the National Institute on Deafness and Other Communication Disorders. Dr. Cooper has long been a designated alternate on the IACC where she represents that institute and at NIDCD, she oversees research activities related to autism and communication both at NIDCD and really across NIH.

Judith, it is a pleasure to welcome you here and looking forward to your introduction to this panel.

DR. JUDITH COOPER: Thank you, Josh. Good afternoon, everyone. Thanks to both Dr. Gordon and Dr. Daniels for an opportunity to kick off our panel on communication and autism.

My focus is to provide you with a brief overview of NIH's role related to communication in autism. I will address the joint actions and attention to this topic that have been paid by NIH through the years, primarily by NIH colleagues and their institutes, represented both here on the IACC and listed on the slide.

There are other federal agencies such as the Department of Education, DoD, and HRSA as well as nonfederal organizations who have also supported research on the topic. But I will not be covering their support today. My second purpose is to highlight some activities specifically led by my institute, the National Institute on Deafness and Other Communication Disorders.

As we recognize and we certainly heard it today, individuals on the autism spectrum may have a variety of communication issues

and challenges, as illustrated on the slide. And those issues and challenges can vary in severity at different points in development.

The centrality of communication has long been recognized by NIH, reflected in decades of funding of investigator-initiated research grants as well as special requests for networks and centers and other solicitations.

As far back as 1997 with the start of the Autism Centers Program and with each issuance of requests for centers and networks, we highlighted communication and autism spectrum disorders with some of the wording examples noted on the slide as we requested research focused on language and disorders of communication, understudy subgroups within the ASD population and assessment and interventions for nonverbal school-aged children with autism.

But not every autism researcher can or should lead a larger center or network and thus the NIH has offered since 1998, and reissued every few years a grant solicitation research on autism and ASD. And with each issuance, interest in and support for research on communication was noted. On the slide, you can see examples of our wording that has appeared through the years as we pointed researchers to particular topics of interest to the NIH, including communication skills, various impairments that impact communication, predictors of developing expressive language abilities, and interventions focused on communication.

Let me now shift to NIDCD and highlight some other specific activities relevant to our topic. NIDCD supports research and research training in the normal and disordered processes of hearing, balance,

taste, smell, or speech and language. NIDCD has a very long commitment to and support of autism research beyond the participation and trans-NIH activities I just mentioned. With our research support, not surprisingly, primarily focused on speech and language differences and challenges but also including other areas such as hearing and taste.

As illustrated on this slide, most of the NIH research on communication in autism is supported by NIDCD and noted in blue. Thanks to Dr. Daniels for providing the data and the slides.

Here is a flavor of some of the broad themes that characterize our communication in autism research and training projects. Communication profiles, minimally verbal individuals, effective, behavioral interventions, alternative and augmentative

communication approaches and communication differences and disorders and ASD siblings.

What has NIDCD done to address these broad issues? With just a few examples noted on the slide, through the years, we have held workshops to involve and focus the research community and we have issued research solicitation. But in 2009, things went in a new direction. It all started with a mother's advocacy for her nonverbal child. She highlighted to me that at that time, nonverbal, low-communicating, minimally verbal children with autism were a neglected subgroup of the entire spectrum, typically excluded from research projects and not a focus of research. She bemoaned that nonverbal were often referred to as low functioning with a common perception that these individuals have low intellectual abilities. She stressed that this perception

was in part because at that time, many such individuals had no way to demonstrate their cognitive capacities and their communication abilities.

She stated a need and she asked, how can we change this. How can we get this population included in ongoing research? How do we increase research interest and funding about this population? We all recognized and we agreed, and months later the NIDCD led and other institutes joined in creating first a planning committee and then a workshop in April 2010 to focus on a subgroup of children with ASD who had not developed functional verbal language by the age of five and the workshop would address the questions on the slide. Who are these children and what do we know about their developmental trajectories? How can we assess their skills and knowledge across different domains relevant to language

and what treatments and interventions are effective in improving spoken language and communication in these children?

The current state of scientific knowledge was discussed. Critical gaps in our knowledge were identified as were research opportunities. And the link on the slide can take you to a summary of that workshop and the participants.

After the workshop, a notable shift occurred. First, there was a request for applications, targeted research on nonverbal school-aged children with autism that was led by NIDCD but also supported by NIMH and this funding opportunity provided competitive supplements to RO1 holders of clinical autism grants to focus on the characterization of the population, treatment pilot studies, and assessment pilot studies.

Subsequent to the workshop, a small group of NIH staff and autism experts were organized to focus on one workshop recommendation, how to best assess this population. Between 2010 and 2012, this group dealt with particular areas of assessment that are important for this population. And then finally in 2013, as an outgrowth and a result of the workshop, two important publications appeared and are noted on this slide, one minimally verbal, the neglected end of the spectrum and assessing the minimally verbal school-aged child. This new focus and attention continued.

In 2011, NIH issued a request for applications on psychosocial and behavioral interventions. It was agreed that the funding opportunity would include requests for research on studies of adaptive or novel

treatments for nonverbal school-aged children with ASD.

Then in 2012, the NIDCD Strategic Plan, which identifies research priorities for the next five years, included a new direction. NIDCD is committed to supporting research efforts to improve the diagnosis of ASD and to develop new or improved existing treatments of language deficits in children with ASD, especially school-aged children with ASD who remain nonverbal.

Just FYI, subsequent NIDCD strategic plans contain similar wording and also included priority areas related to augmentative and alternative communication approaches.

Also in 2012, one of the prestigious and highly competitive Autism Centers of Excellence entitled Minimally Verbal ASD: From Basic Mechanisms to Innovative

Interventions was awarded to one of our panel speakers, Dr. Helen Tager-Flusberg.

Finally in 2019, an NIDCD clinical research center, a P50, entitled Predicting and Optimizing Language Outcomes in Minimally Verbal Children with Autism Spectrum Disorder was awarded to Dr. Kasari and Dr. Tager-Flusberg.

In sum, I hope you have a better sense of NIH's and NIDCD's longstanding encouragement, support, and funding of research on the communication challenges and needs of autistic individuals of all ages. We all recognize that many research questions and many issues remain. And most importantly, research opportunities and needs come from all venues, the scientific community, our own research solicitations, advisory panels such as the IACC and the discussions that we have

heard today and sometimes from the plea of a concerned mother. Thank you.

DR. GORDON: Thank you very much, Judith. I really appreciate the overview of the demonstrable commitments of the NIH in this area. As you mentioned of course, there are other partners around the table, and it was also mentioned during the public comments, who also support research in this area.

Now, we are going to hear from some of the scientists who are conducting this research. The first presentation is going to be by two scientists supported as mentioned by the NIDCD efforts in this area. I am going to introduce them together and then I believe Dr. Tager-Flusberg will start.

First, Dr. Helen Tager-Flusberg, who is a member of our IACC and also a professor in the Department of Psychological and Brain Sciences and the director of the Center for

Autism Research Excellence at Boston University.

Joining Dr. Tager-Flusberg is Dr. Connie Kasari, a professor of Human Development and Psychology at the UCLA Graduate School of Education and Information Studies and a professor of Psychiatry in the UCLA Department of Psychiatry and Biobehavioral Sciences at the David Geffen School of Medicine.

Drs. Tager-Flusberg and Kasari will be presenting together on the topic of advancing research on minimally verbal ASD. Please take it over.

DR. HELEN TAGER-FLUSBERG: Thank you so much. We are actually going to present sequentially because I think what I am going to do is present some research that focuses on two critical questions that I think serve

as a backdrop to what we are going to hear from Dr. Kasari.

I am a research scientist. My background and training are in developmental psycholinguistics. I have devoted my career to focus on language and communication both in autism and also in related neurodevelopmental disorders. But it really was not until about 15 years ago that I began to turn my research towards the minimally verbal, those who acquire very limited or no spoken language. I am really grateful to the leadership and support from Dr. Cooper at the NIDCD as well as leaders in foundations including Autism Speaks and the Simons Foundation and also to parents and clinicians who have devoted their lives and careers to working with this group of individuals from whom we learn.

Next slide. Next, next. Please, next, next. I am going to present - can you go back please. I wish I could control this.

I am going to present two areas of work that we have been doing and I am really pleased to have this opportunity. I think it dovetails well with some of the discussion earlier and as I said, segues into the next presentations.

First, I will talk about some novel approaches to assessing language. If we can't assess language both spoken and perhaps other means of communication, if we can't assess that accurately in an individual, we do not have a foundation on which to build any kind of intervention or therapeutic approach.

And secondly, I am going to explore the more basic question of why spoken language might be so profoundly impaired in minimally verbal autism.

The important takeaway from all of this is that there is enormous heterogeneity and we do have to treat each individual as an individual because no one size fits all.

Next. Next slide.

We did call this the neglected end of the spectrum, which was perfectly true. But a parent recently said to me, well, we feel we are just completely forgotten. I have renamed our group the forgotten end of the spectrum.

Next slide.

First, I just want to present some very basic data on the receptive and the expressive language skills, and this was based on a large cohort that we had evaluated. The evaluation was a parent report. We provided a large list of words and the parent checked off which words their child who was between the ages of 5 and 16,

which words they understood and which words they were able to express.

Next, next.

This shows you their expressive vocabulary. You can see there is the largest number of parents reported very few or zero words. There is not much beyond that.

Next.

For the receptive, we see a very different distribution because some of the participants indeed were reported to have very little understanding of spoken words, on the left side of the graph, but some certainly there is much more variability within that. We were very interested in how can we capture receptive vocabulary?

Next.

That was what we turned our attention to initially. How could we do this? Next. Standardized tests, as we know, may not

always capture the range of receptive or even expressive language abilities in this population. While indeed we wrote a paper on how to assess, we did in fact agree that there were significant limitations. Next.

We need to explore some novel approaches from the standardized. Next slide. We looked at alternative ways to assess receptive vocabulary. Next. We did administer to a relatively small cohort of adolescents some standard methods. The Peabody Picture Vocabulary Test where you show an array of pictures, say a word, and the participant has to point to the picture that matches the word. And then we also had a parent report word list, and that too is a method that has been widely validated in the field of language development. Next.

And then we tried some novel methods. First, we picked up on this idea that Dr.

Rivera mentioned earlier in the comment section. Eye-tracking. Could we use eye tracking? In this method, we say a word, dog, and the participant is not instructed in any way, but you can see from the green dots, those green dots represent the number of times - the times the participant looks at that picture versus a foil picture. Here, you see a bird.

Touch screen. And we then also adapted next using a touch screen. This is kind of a bit old school so you can tell we did this quite a long time ago. Today, we would certainly be using an iPad, which everybody enjoys so much more.

This shows you that across several blocks of trials. In red, you can see the number of times the adolescents in our sample looked at how much time they spent looking at the target picture, the dog, or we had a

large number of words that we tested, instead of how much time they spent looking at the bird. And what you can see is that eye tracking was pretty useful.

And we then looked at validity and looked at the correlation, how well matched, how consistent was responding across our novel methods of eye tracking and touch screen with more traditional parent report and PPVT? And what you can see is that the correlations between the novel methods and the standard methods, are strong and highly significant. However, I want to point out what I am not presenting here is that there were significant individual differences in which method was optimal. So we did have participants who were fantastic with the touch screen but whose eye tracking was not a reliable indicator of their understanding of words. Next.

We then wanted to develop novel approaches. This is not novel, but we wanted to capture spoken language, their expressive language, and communication skills. There is a long tradition in the field of language acquisition to collect natural language samples, an individual, a child interacting with another individual. For the most part for very young children, we rely on parent-child interaction. And then for older individuals, we usually rely on an examiner. But what we did not have in the field was any kind of a standard protocol for which we could collect a sample. This is critical because without a standard protocol, we can't make comparisons across different studies and approaches to looking at spoken language. So we developed ELSA, standing for Eliciting Language Samples for Analysis. Next.

We developed two versions. One is the ELSA-T for toddlers and preschoolers, and ELSA-A is for older children and adolescents. And what you can see is it is a sequence of different activities that we selected based on a lot of piloting work. And we found that having a lot of different activities keeps the individual highly engaged and enjoyed. And we were able to collect language samples averaging 20 to 25 minutes without participants deciding they really did not want to be involved in this anymore. It was a lot of fun for them. Next.

One of the questions that we wanted to know was who can administer ELSA-A? Of course, we originally developed it in the lab, and we had our trained examiners do this. Next. But we wanted to know could parents do this in the home because that would open up a whole other way of picking up

an individual child's expressive language skills. Next slide.

We took a group of individuals and those same children and adolescents, we tested them in the lab with an examiner and those same ones, their parents. We sent the parents' home with a kit and instructions and videos and helped guide them and left it to them. Here is what we found.

Here, I am showing you the amount of language and type of language from the examiner presented in red and parents presented in blue. Next. When we look at frequency of utterances, twice as much from the parent than the examiner. Next. Same is true for frequency of words, next, and conversational turns. So the parents are doing so much more. This is in the same unit of time per minute. But they are just much more actively engaged with their child. Next.

What about the child's language? Next. Well, they too spoke twice as much with their parent than with the examiner. Next. Twice as many words. Next. And about twice as many conversational terms. There is of course enormous variability. But we did find that consistently parents were really useful in eliciting these expressive language samples from their children.

We think that this is very promising and we have been very excited to see more and more papers recently returning to this idea that the way we should be assessing expressive language is through natural language sampling. Next.

Now let me turn to the second part of my talk, why don't they learn to speak spoken language? What is going on here? Next. There are many potential explanations. I want to emphasize that I am really scratching the

surface with what we have managed to cover so far. Next.

We began by asking about behavioral predictors, impaired understanding of intentionality in communication or joint attention skills, symbolic deficits as represented through play, impaired imitation skills, which we evaluate using manual imitation. Can they copy object and hand movements? And also intellectual disability or the individual's level of nonverbal cognition. Next.

We were also interested in exploring speech motor impairments in this population. Next. And finally, I will talk about auditory processing impairments, which we hypothesized would be most related to the variation and receptive language skills that I talked about earlier. Next.

Let me talk about the behavioral correlates of expressive language. We had a group of almost 60 children and adolescents, 5 to 16 years old. And we had measures, objective measures of different aspects of joint attention from behavioral regulation to initiation to response to joint attention, an objective measure of their developmental play skills, imitation, nonverbal cognition, and of course age, which varied. And we asked, to what extent are these correlated with their expressive vocabulary? Next.

What we found was that in these older individuals, joint attention was not a significant predictor, and neither was age. We did find, however, that cognitive level, imitation and play were all significantly related and even when we controlled for nonverbal cognition, play and imitation, two foundational social communication skills were

significantly correlated. But when we asked statistically what is the most significant predictor, the one that came out was imitation. Those older children and adolescents who had better imitation skills would have somewhat higher expressive vocabulary.

What I think this work on behavioral correlates tells us is that it is really important to be paying attention to the behavioral profile of an individual because we need to think about perhaps training some of these critical skills. The reason joint attention was not significantly correlated in these older individuals was that many of them in fact did have joint attention skills. That is not true for much younger children with autism where we know we need to focus our interventions on joint attention as a foundational precursor to language. But we

need to be concerned with the full array of behavioral predictors. Next.

What about speech motor impairments?

Next. We were very interested in this rare neurological disorder, which occurs in people without autism as well, called childhood apraxia of speech or CAS. This refers to impairments in speech movement precision and consistency. It is about speech planning primarily, and it is neurologically based. And we were asking the question, do minimally verbal - do some minimally verbal children have co-occurring childhood apraxia of speech? We knew from other work in the field that this is not true for more verbal individuals with autism. Even though they may have prosodic or other speech issues, they do not have this more severe issue of childhood apraxia of speech.

So we collected - we had some structured protocol for collecting speech production. This was just repeating words and then had them coded by three experts, three expert speech clinicians, including the lead author shown here, Karen Chenausky, to code for CAS. Next, slide please.

And what we found was there were indeed high rates of CAS. Across our sample, we saw on the left about a quarter of the sample did not show any speech motor impairments. A little more than a quarter had some speech disorder but not sufficiently severe to call it CAS. About a quarter did have CAS, and about a quarter were completely nonverbal. And you could not code for speech motor problems if there was no speech production at all. Next. Next. Next. In fact, we might argue that 75 percent have some speech motor disorder, and I will say that we are now

continuing to try and unravel what this means in a mute cohort of children. Next.

Now let me turn to auditory processing. Next. You see here Emily, who is one of our most fantastic participants, the most tolerant young woman I have met. You see her here covering her ears. This is something we see a lot in people with autism because they have auditory sensory sensitivities and that is something we know is quite extensive. We are interested into what extent are these auditory sensory sensitivities related to their receptive language. Next.

We had observational coding. We videotaped a group of minimally and low verbal autistic children and adolescents and those are shown in red. And we had a group who were age and sex matched verbal autistic children shown in blue here. And during about a 20-minute interaction, we coded

observations of different behaviors that the individual would exhibit, would say to us, this looks like they have some sort of auditory sensory issue, either sensory seeking or sensory avoidance or filtering.

And what you can see on this graph is that in terms of visual sensory sensitivities, the two groups were equivalent. However, when we looked at their auditory sensory sensitivities, we saw far more in the minimally verbal group. Next.

And here you see that the percentage where we are showing what is the relationship between this and their receptive language and we see that the more time that an individual in this study spent covering their ears or showing any other kind of auditory processing problem to lower their receptive language skills. Next. Next.

Finally, we looked for whether we could identify a brain marker for these auditory processing difficulties in minimally and low verbal adolescents. Here, you see Emily being fitted with our EEG cap. We use electrophysiology because it is very tolerant, and we were very successful in getting most of our participants to be able to provide us with good high-quality data using electrophysiology. Next.

What we did was while Emily is sitting there, she is just hearing a whole series of tones and most of them are at exactly the same, the same repeated tone over and over. And then occasionally about 15 percent of the time, the tone will be either louder or softer, and that we call our deviant tone. And when you are listening to a stream of sounds like that, the brain responds differently to that so-called deviant sound.

You see that here in the top graph. You see the higher amplitude in red, the response to the deviant sound.

What we found in this group of adolescents was that that amplitude, how high that response was to the deviant sound, was actually related to the amount of time they spent exhibiting those auditory sensory sensitivities. Next. Such that, next, the amplitude was smaller to those deviant tones. The brain is not responding as much to the different tone that they are hearing in those who have more auditory sensory behaviors. So there is clearly something different going on in the brain here, and we are really just scratching the surface of this. Again, this is an area that we are now continuing to explore in our new clinical research center grant. Next.

I just want to summarize. Despite every effort, some children do not acquire spoken language. We have now methods for assessing receptive and expressive language, but we need to tailor them to each person. We have many explanations. And the key takeaway is that there is really significant individual variation not only in the methods for assessment but also in what explains the difficulties in acquired spoken language across this group of individuals. It is that individual variation that I think can inform interventions, and we will hear more about that in the next talk. Next.

I want to thank all my collaborators, and especially my team at CARE. Next. I want to thank the funders of the research that I have presented to you today, next, and most especially to all the families, the children and the teenagers, who have given us so much

time and support and insight from whom we have learned so much. Thank you.

DR. GORDON: Thank you, Helen, for that really excellent talk. We will now move on then to our second speaker who is Dr. Connie Kasari who will continue on discussing research on minimally verbal ASD.

DR. CONNIE KASARI: Thank you so much. I am going to share my screen because I am going to have control here. Thank you for having me from the West Coast. It is still morning here. I am going to talk about interventions for young minimally verbal school-aged children with autism.

Interventions for minimally verbal individuals is - they are increasing but we have not had many of those that have been published. We were influenced by a number of reviews, a couple that Judith already mentioned. We know that minimally verbal

children are often excluded from intervention studies even at young ages. And then our assessments are pretty poorly designed to accurately determine needs. People are relying on standardized assessments, and we just heard from Helen about some new measures, which I think are really exciting and especially language samples in real-world situations because they are more likely to yield information.

We also were influenced by a review of interventions from minimally verbal individuals that were school aged. And the window or the opportunity for learning spoken language appeared to be greatest in this very young school-aged years so 5 to 7 years of age.

The interventions themselves actually focused more on requesting language so getting children's needs met and less often

on conversational terms or joint attention commenting language.

The workshop that Judith mentioned was really influential in that what we learned was that most nonverbal individuals really were not nonverbal but were minimally verbal. It was really defined by the number of functional words spoken. And at that meeting, we determined that around age 5 or 6 that children who had fewer than 20 functional words were classified more as minimally verbal. Younger children under 5 we considered to be pre-verbal that they would talk but they were just still learning to talk.

In this group of 5- to 7-year-old children, there is still that potential for spoken language. That does not mean that people do not continue to learn to speak and in fact, there are many reports of adults who

are speaking their first words as adults. One should not ever not have facilitation or interventions for speaking.

The other thing we learned was that some children can speak but they rarely do or they only do it in some contexts or they speak with more scripted phrases so familiar phrases. They may use a phrase that is not connected to a particular context but is really used to communicate about that context.

And then for interventions, what do we do? Intervention is often to do just more of the same so to increase the number of speech and language sessions, for example, or worse, we take away interventions and we blame the child for their lack of progress. These situations still continue.

But I think there are a lot of important considerations around interventions. What

approach should we use for facilitating language? Especially since current early interventions are having less success with about a third of our children still not having fluent spoken language by the time they enter kindergarten.

How long should we try an intervention before we change something about the intervention? If we are going to change something, what metric do we use to determine response to the intervention? What dose is necessary? What is a meaningful and realistic outcome?

Our ultimate goal is really to personalize interventions with a meaningful outcome with that recognition that a single intervention is just not going to be effective for all individuals.

We have been really focused on adaptive intervention designs. These are designs that

came out of cancer research or substance abuse research and we applied it for the first time to autism research. It is a way of really trying to systematize clinical practice. You can imagine that the therapist that everyone says is magical with children is the therapist that every parent wants their child to see. The problem with that is that that particular therapist does not have the bandwidth to see the numbers of children that he or she could see.

And that person probably has a lot of tools in their toolbox and a lot of good clinical judgment. But trying to replicate that across all of the children that they see or when they try to train other practitioners is really difficult. This kind of design can actually systematize what happens and when it should happen.

The definition is a sequence of decision rules that specify whether, how, when and based on which measures, you are going to change something about the intervention whether that is the dose or the type or the delivery of treatment at a decision stage in the course of the intervention.

We applied this kind of model or design around a particular question at the time. There is a controversy that using an augmentative device will delay or prevent spoken language. This is a pretty common issue. I still hear this issue that parents sometimes do not want their young children to use a device because they think it is going to delay or prevent spoken language. In fact, there are therapists that also have the same viewpoint.

We did an intervention with minimally verbal children with autism. There were 61

children ages 5 to 8. They had fewer than 20 functional words based on our assessments. They already received two years of intensive early intervention. We did not want to have children that had never been exposed to an intervention but had actually already shown that they were having slow progress towards spoken language.

One of the things that happens in intervention research is that randomized controlled trials are done with an experimental intervention compared to treatment as usual. In this case, the children's treatment as usual had not been very successful. We wanted to provide all children with something novel, something that they probably had not been exposed to. All of the children got one of these naturalistic developmental behavioral interventions, in this case, JASPER. And we blended it with a

spoken language intervention referred to as Enhanced Milieu Teaching, which is out of Vanderbilt by Ann Kaiser. All the children got the same intervention.

And the question here is can an augmentative device actually facilitate more spoken language. Half of the children were randomized to receive a device in the context of that intervention.

The sample was primarily male. About half of the children were ethnic racial minorities. The average age was 6 and the number of functional words on a number of different assessments all together was about 17 words. And the nonverbal scores, IQ scores, ranged from 38 to 140 so incredible heterogeneity even amongst this cohort of children.

And the two interventions were JASPER, which really prioritizes engagement and

social communication to teach language. You will see the core domains there. And Enhanced Milieu Teaching, which really structures language prompting procedures. They use time delay strategies and then a prompting procedure that is really focused at the child's communication level.

Here is the design, which is actually a very simple one even though it looks kind of busy. The behavioral interventions called JASPER for short. Children were randomized. And in this case, it is a SMART design so that is a Sequential Multiple Assignment Randomized Trial, which means that there is more than one randomization. Children were randomized to receive just the blended intervention or the blended intervention with an augmentative device.

The first-stage treatment was for 12 weeks. It was two sessions a week so about

two hours of intervention with the therapist per week. At the end of that 12-week period, we determined whether the child was a fast responder or a slow responder. And response was determined to be 25 percent improvement on the primary outcome, which I will describe which was socially communicative utterances. These are utterances spoken that are socially related.

After that first phase then children could - if they were responders, would just stay the same course. If they were slow responders and they had the augmentative device, they could get another session a week. If they did not have the device, they had the opportunity to be randomized to either get the device or to get an increase session. During the second phase, we also did parent training specifically. You will see

that there are some embedded interventions in the second stage treatment.

Here is our primary outcome measure so a natural language sample. It was a 20-minute interaction between the adult and the child. It is very systematic. The language samples were then transcribed using SALT. And we had these independent coders who noted each utterance for generativity so non-scripted and communicative function so whether it was a comment or a request. And then both spoken and speech generated produced utterances were transcribed. That primary outcome is a total spontaneous communicative utterance.

What did we find? The black line on the top is the group that got the augmentative device and the red line are the kids who have the intervention without the device. And what is interesting is that there is a huge increase even in that first 12 weeks of

spoken - these spoken utterances. Having the device mattered for increasing spoken language. The group without the device was making slow and steady progress but it is not nearly as fast as having the device.

We also found similar findings for novel words and comments. If you have the device, you also produce more novel words and more commenting or joint attention language.

That analysis was the whole sequence so starting with the top half and the bottom half. But we can also look at these embedded interventions. What happens when we tease apart these second stage treatments? Let me go through this. On the lefthand side is the outcome of the primary outcome, which was the total social communicative utterances and on the righthand side is a different outcome. It is the child initiating joint attention.

You can see here that the black line at the top are kids who got the speech-generating device and then stayed with the speech-generating device. The red line in the middle are kids who started with no speech-generating device but then got randomized to get the speech-generating device. And the blue line on the very bottom are kids who never had the speech-generating device.

For both of these, the black line - getting the device increased the primary outcome but it also increased initiating joint attention. You get some benefit if you get the device in the second stage after three months but it is not nearly as great as if you get it right from the beginning.

The importance of the speech-generating device added into a behavioral intervention. Right from the beginning it is pretty clear from these data. Approximately 10 percent of

the coded utterances, the primary outcome, were generated on the speech-generating device. The majority of what kids were saying was spoken. And that surprised us. But it is great because spoken language if we can develop spoken language is much more efficient than using the device. But for children who need the device then they have access to communication. That was a win-win both ways.

But the importance of the behavioral intervention should not be overlooked. If we just gave a child an SGD, it probably would not be successful. The child - and remember, these are children who are learning to use language. They need support to learn and they need a context for communication. In this intervention, we did adult modeling on the device in the context of play interactions to prioritize communication. Imitation, as Helen

had said in the first talk, is really important and it was important here too because children would imitate us modeling on the device.

The importance of the interchanges between the adult and the child, again, within the context of an intervention is shown here. These are all the children in the same data set. And it is showing you that what is adult initiated and what is a child-initiated interaction. At entry, we still have more child-initiated interactions than adults even at the beginning. But over the course of the intervention so you see at midpoint and exit, the gray part of the bar graph are child-initiated interchanges and those are growing whereas the black part of the bar are adult-initiated interchanges and those are staying stable. The importance of the interaction should not be overlooked.

Summary. Minimally verbal children can benefit from interventions that are supported by technology. Speech-generated devices do not inhibit the development of speech but they rather support that development. And these devices provide communication access. Even if a child does not develop spoken language, it is important to provide some access to communication.

But we need more research on what the active ingredients of these interventions are because they are likely to be multi-component and we need to understand what components are really important for which children.

We also have questions about how early we should add in technology to early intervention. We have been adding it in now with even pre-verbal children so 2 and 3-year-old children who have interest in using the device. What we find is that they will

use an iPad, for example, with the software in the context of intervention and then discard it once they learn to speak verbally more. It is a good transition.

And then we also need to understand the mechanism of how the speech-generating device provides benefit. Is it the motor aspect of pressing the button? Is it the added visual and auditory support? We do not really understand that but I know that this is something that Janice will talk about next and knows much more about. But I think that that will be important to try to understand as well.

And then finally, I think we need more studies on these kinds of intervention designs that can really personalize interventions so that we know that if a child is not responding, how long do we wait, at what dose should we provide the intervention,

and what should we shift to if this intervention is not doing what it needs to be doing to help the children to speak or to communicate.

Thank you. I also want to give appreciation to the funding for this kind of research and in the research that we have continued that were in the midst of doing with this population of individuals. Autism Speaks primarily funded this past study, NIDCD and NICHD, and of course all of the various therapists and families and children and everyone who participated to finish this. Thank you.

DR. GORDON: Thank you very much, Dr. Kasari. We will have questions for both Dr. Kasari and Dr. Tager-Flusberg during the committee discussion at the end. I am going to move right along to the next presenter who is Dr. Janice Light. Dr. Light is the Hintz

Family Endowed Chair in Children's
Communicative Competence and professor of
Communication Sciences and Disorders at Penn
State University. Dr. Light's presentation is
titled augmentative and alternative
communication supports for individuals with
autism. Dr. Light, welcome.

DR. JANICE LIGHT: Thank you so much. If
it is okay, I will go ahead and share my
screen. First and foremost, thank you so much
for the opportunity to talk with you today. I
am just absolutely thrilled to hear that the
IACC is interested in the area of
augmentative and alternative communication.

I wanted to start by thanking the many
children and adults with complex
communication needs and their families who
have really allowed me to be a part of their
lives. I have learned a tremendous amount

from them and I hope to share some of the lessons that I have learned with you today.

As some of you know, there are more than five million Americans, more than 97 million individuals worldwide, that have minimal or no speech and are not able to rely on their speech to meet all of their communication needs. This is an incredibly diverse group that cuts across the lifespan and it includes individuals who have a wide range of needs and skills, including those that have faced communication challenges since birth. It includes individuals with acquired disabilities or conditions such as those that result from traumatic brain injuries or stroke. It includes those with degenerative neurological conditions such as ALS or Alzheimer's. And it includes individuals with temporary conditions such as those that might be ventilator dependent due to COVID and of

course that includes many children and adults on the autism spectrum. It is this group that we will be talking about this afternoon.

Without access to speech, these individuals face substantial challenges in expressing their needs and wants, interacting socially with others, and being able to share their experiences and to share information with others. They are severely restricted in their participation in all aspects of life, including education, employment, health care, family life, community living.

Fortunately, over the past 30 to 40 years, there has been tremendous advances in the area of augmentative and alternative communication that are known as AAC. And AAC indeed offers the potential to augment speech, enhance communication both comprehension for those who have difficulty understanding spoken language as well as

expression for those who have difficulty using speech to meet their communication needs.

There has been a somewhat narrow view sometimes of AAC within the field of autism with the belief initially that AAC equals PECS or the Picture Exchange Communication System, and more recently, the belief that AAC equals Proloquo2Go. But in fact, AAC involves a wide array of tools, strategies, and techniques that can be used to enhance communication. It includes the use of unaided AACs such as signs and gestures, the use of low-tech, nonelectronic systems such as this visual schedule, and the use of a wide range of assistive technologies that include very different representations, organizations, layouts, selection techniques, and outputs of language.

I have the honor and the pleasure to serve as the principal investigator of the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication. This national center that is funded by the National Institute on Disability, Independent Living and Rehabilitation Research has a mandate to conduct research to advance our knowledge, improve services, and improve outcomes for this population of individuals who have complex communication needs to conduct development to improve AAC technology solutions, training to build capacity in the field, and dissemination to reach all stakeholder groups to increase awareness and knowledge. Our goal is to expand what is possible for individuals who have complex communication needs and cannot rely on their speech and to ensure that what we know is possible from the research, in fact, becomes

what is probably going to occur within the lives of individuals who have complex communication needs.

I am going to share with you today not a single research project but rather snapshots of a wide variety of research and development projects that we were engaged in at the RERC on AAC and they will be brief snapshots, but I have tried to provide quite an extensive list of references at the end so that you can track down further information about any of them.

I am going to focus on those projects that have immediate application to children and adults with complex communication needs. But I also wanted to let you know that we are engaged in a wide range of research to address the needs of the entire population and this is just a small example in the photo here of some of the work we are currently

doing on brain computer interface, work that we are doing on leveraging multi-modalities, including brain signals, EMG signals, eye tracking, et cetera, and the use of artificial intelligence to try to disambiguate what can be noisy communication signals so that individuals can actually express in an independent and self-determined way their messages.

And I do believe that all of this work has implications for all of us because it allows us to build a society that is much more inclusive and much more accessible to all of us.

Our vision ultimately is to ensure that all individuals, including those with the most complex needs have access to effective AAC technologies and interventions to allow them to realize what is a basic human need, a

basic human right and a basic human power of communication.

What do we know about AAC for individuals with autism? There is a solid and rapidly growing body of research. And it demonstrates the following. First of all, AAC interventions enhance communication for individuals on the autism spectrum, increase turn taking, increase requesting, increase commenting, et cetera.

We also have evidence that AAC interventions enhance language development, increase the acquisition and use of vocabulary, increase the complexity of messages that can be communicated to others.

We know that AAC intervention can increase participation in society, in education, in employment, in community activities. We know that AAC intervention can decrease significantly the challenging

behaviors that too often occur when individuals do not have ways to communicate effectively with others and need to rely on challenging behaviors to express themselves.

As Connie just illustrated to us, all of these benefits come at no risk to speech development. In fact, the research demonstrates that AAC enhances speech production, including for children and adults on the autism spectrum.

But these benefits are predicated on equal access to AAC intervention a sufficient intensity to attain meaningful gains. And Connie just talked to us about individuals having access to two hours of intervention one on one in AAC to realize the meaningful gains within her study.

I wanted to share with you some disturbing results from a recent study that one of our doctoral students, Lauramarie

Pope, just finished hot off the press. And the results showed that 35 percent of white preschoolers were receiving less than 60 minutes of AAC intervention per week and this was not limited to one-on-one intervention, any type of AAC intervention in the week. And most disturbingly, 65 percent of black children received less than 60 minutes of AAC intervention per week, nowhere near enough to attain meaningful gains in their communication and language skills. Clearly, there is an urgent need for system change to address these inequities and ensure equal access to AAC services regardless of race, ethnicity, first language, et cetera.

Given the benefits of AAC, I am going to argue that we need to provide AAC intervention as soon as possible. AAC should not be considered a last resort. Connie's research, the research that I am going to

share with you demonstrates clearly that AAC supports communication and language development as well as speech production. We need to start as early as possible before children with autism fall further and further behind their peers. In our work in our lab with a wide variety of children with complex communication needs, we are working with individuals well under 12 months of age and many of them with access to appropriately designed assistive technologies are expressing and acquiring their first words at 10 months, 9 months of age well before some of their typical peers are learning how to speak.

But having said that, it is never too late to provide AAC interventions and unfortunately, many adolescents and adults never received access to AAC. Even at those later ages, they still lack ways to

communicate effectively. And the research in our lab would suggest that we can still attain meaningful changes by providing access to appropriate AAC.

We need to leverage AAC to build communicative competence. Too often are AAC interventions focus solely on requesting. But as one mom said to me, there is more to life than just asking for cookies. We need to be targeting independent communication to fulfill a wide range of communication needs, not just the expression of needs and wants, but social interaction to build meaningful relationships with others, information exchange, commenting to allow people to share their experiences. These last two functions are especially important because these are some of the core challenges faced by children and adults who are on the autism spectrum.

In order to attain these goals, we require effective AAC. And unfortunately, most of the AAC technologies that are currently available in the marketplace are not research based. They have been developed by neurotypical adults often by computer programmers or engineers or clinicians and they reflect how those individuals think about the world. But they do not reflect the ways that children and adults with complex communication think about the world. As a result, they may be difficult to learn and they may not be very appealing to use.

I am going to argue that AAC technologies need to be redesigned to better reflect the needs and skills of the individuals themselves who are using them, those that have complex communication needs. They need to be redesigned to reflect the science, what we know about motor

development, vision development, hearing, cognition, language development. They should be so appealing that everyone wants to use them, so easy to learn and use that no time goes into learning to use the technology. There is no inherent value in being able to operate an AAC device. It is simply a tool to allow us to communicate and interact socially and the value comes from those end goals. These systems need to be powerful to provide access to communication and participation.

Far too often we see that AAC technologies are prescribed not based on the needs and the skills and the preferences of those individuals who will be using them but rather based on clinician familiarity or the familiarity of families. As Helen said earlier, one size does not fit all and we need to develop a greater range of AAC technologies that can be personalized to meet

the individual's needs, skills, and preferences, including the vocabulary that we provide, the representation of that vocabulary, its organization and layout, its selection and output.

We have quite a bit of research in our lab that is looking at the visual cognitive demands of using AAC technologies and the motor demands of using AAC technology and this research consistently demonstrates that even very small changes to AAC displays, changes in color, changes in layout, changes in spacing and organization impact significantly the accuracy with which, the efficiency with which individuals are able to communicate. We need to figure out which AAC technologies work best for whom under which conditions.

What we have traditionally done in this field is use what are known as grid displays.

We try to identify the vocabulary that is required within any communication situation. We find picture symbols to represent that vocabulary and we kind of lay those out within a grid layout of rows and columns. But the research consistently indicates that children have difficulty learning to use these systems. They seem to require at least some level of metalinguistic skills. And one of the reasons is because they take the language out of the context in which it is learned and used and that means that they are especially difficult for beginning communicators at the very early stages of communication who are learning first words.

We have been working on the development of alternative approaches to AAC displays, including the use of visual scene displays and video VSDs. And these are simply photographs or videos of meaningful events

within the child's or the adult's life within the beginning communicator's life. Here, we snapped a photo of Lucy with one of her favorite games is playing telephone with her mother. And what we are going to do is simply take this life event in which Lucy is learning language and embed vocabulary concepts as hotspots within the visual scene display so that she can touch, for example, the phone to retrieve the speech output telephone. Touch the hotspot around her hand, waving bye-bye to retrieve the output bye-bye, or around her mouth to say talking.

These visual scene displays or video visual scene displays seem to offer tremendous advantages from a linguistic and cognitive perspective for very early communicators at the first word stage.

They also offer significant advantages visually. Our eye-tracking research has shown

that in fact these types of displays are attended to longer and attract attention more quickly than grid displays and they are in fact processed more rapidly by individuals on the autism spectrum.

Interestingly enough, these displays drive visual attention to the key language concepts in the event the people, the actions, and the shared activity, in this case, the little boy, Trevor, his dog Blue, and of course kisses or wet kisses.

And these are indeed the first words or language concepts that emerge in language development both with children who are neurotypical as well as those on the autism spectrum.

VSDs and video VSDs are especially exciting because they are so easy and quick to program that they support just-in-time programming of vocabulary in the moment as it

is required. And that means that as I am interacting with a child and they show interest in an event or in an object or an activity, I can quickly and easily capture that event and provide the child immediately with access to the needed vocabulary. And even more exciting is the fact that our research shows that kids as young as 12 months can be actively engaged in capturing their own events and their own vocabulary by helping to take the pictures or videos, defining the hotspots, et cetera.

Introduction of AAC technologies with VSDs and video VSDs, our research shows support increased communication turns, increased vocabulary acquisition, and expression and greater diversity of vocabulary expressed.

VSDs and video VSDs are particularly exciting because they are also very easy for

peers to understand and learn. We have had a series of research studies led by some of the doctoral students or former doctoral students in our lab that have looked at investigating the impact of VSDs and video VSDs on social interaction between children on autism spectrum and their peers, including studies by Michelle Therrien that have looked at shared book activities, a study by Shelly Chapin that has looked at interactions around preferred videos, and several studies by Emily Laubscher that have looked at play between school-aged children with autism and their peers.

These benefits are not just limited to children but actually extend to adolescents and adults as well. Here is just a quick overview of a study recently completed by Salina Babb, one of our former doctoral students, that focused on the introduction of

video VSD technology to adolescents on the autism spectrum and their peers. And the results of that study showed that when we provided access to this technology and a very brief, less than five-minute training in how to use the technology, we saw significant increases in social interaction between the individuals with autism and their peers and we saw high levels of consumer satisfaction both for those on the autism spectrum as well as for the peers.

Video VSD technology does not just support social interaction but also can be leveraged to increase participation in a wide range of community activities and vocational activities. We have leveraged that technology to provide access to video models of steps within what can be quite complex community or vocational tasks. And the exciting thing is the technology allows us to embed the AAC or

communication supports within those video models, allowing access to communication at key junctures as required within the task. We have a series of research studies, ones conducted by Tara O'Neill Zimmerman, Salina Babb, and a larger scale research study now headed up by David McNaughton from our lab and the RERC on AAC at Penn State. And these studies have consistently shown substantial increases in successful independent communication and participation in a wide range of community activities, including grocery shopping, riding public transit as well as vocational activities, such as checking in books at the elementary school library or working at the local food bank.

Ultimately, our goal is independent, generative communication and we know how incredibly important literacy is to meeting that goal. Literacy skills are absolutely

essential to all of us for participation in society and more important for individuals who have limited speech because it is only through literacy that they have access to independent generative communication without relying on others to provide them with access to picture symbols to allow them to communicate.

It is disturbing to see that more than 90 percent of individuals who have complex communication needs enter adulthood without functional literacy skills. There are a wide range of reasons for this but one of them is that current AAC technologies do not support the transition from picture symbols to literacy.

We are working as well on a series of what we refer to transition to literacy features that we are embedding into AAC technologies to support individuals with

complex needs in making the transition from picture-based systems to orthography-based systems.

With this feature, the individual selects a picture symbol from an AAC device whether a grid or a visual scene display. The written word then appears dynamically on the screen and we know from the visual cognitive processing literature that motion is an incredibly powerful attractor of visual attention. This motion on the screen drives the user's visual attention to the written text and supports the orthographic processing that needs to happen for the development of literacy skills. The word is then spoken or sounded out supporting the phonological processing required for literacy learning.

We have conducted a wide range of research studies that have looked at the effects of this transition to literacy or T2L

feature embedded within AAC apps on the literacy skills of participants, including those on the autism spectrum. Work by Sue Boyle, by Jessica Caron, by Christine Holyfield, Kelsey Mandak, and Lauramarie Pope and that work shows that 89 percent of those participants simply with exposure to the T2L feature have demonstrated significant increases in their literacy skills. And those can be increased even further when paired with appropriate and effective adapted instruction and literacy skills.

I focused so far primarily on assistive technologies to support individuals who have complex communication needs. But I did want to also talk a little bit about the need for technology supports for communication partners. Many communication partners are not trained in AAC or in autism and many individuals on the autism spectrum will tell

you that the most significant challenges that they face in their communication come from those communication partners who preempt them from opportunities to communicate and to participate. We need to develop assistive technologies to better support family members and other communication partners in society, including first responders who may not have the skills to interact effectively with individuals who have minimal speech.

We are in the midst of some exciting development work right now to develop and evaluate a really user-friendly app that will allow individuals with complex communication needs, their families, their service providers to quickly and easily create mobile trainings for communication partners that provide checklists of the steps that should be followed as well as video demonstrations of those steps. These are very short

trainings that can be deployed just in time as required, pushed to the EMT as they are arriving to provide services.

I hope I have given you just a little bit of a taste of many of the exciting advances that have happened in the area of AAC. But I want to emphasize for you that we have barely scratched the surface. We have tremendous work that is left to be done. We desperately need research to advance our knowledge to be able to determine which AAC interventions work best for whom and under what conditions. We need development to improve AAC technologies so that we have a new generation of tools that are truly research based and that are driven by the needs and skills of end users.

And we desperately need training and dissemination to build capacity so that we can close the gap between what we know is

possible from the research but what is actually happening in the lives of many individuals on the autism spectrum. And we need system change to ensure equal access to AAC.

At the end of the day, the success of our AAC technologies and interventions are going to be best evaluated by the extent to which they enhance independent communication and participation by the individuals who use them, meaningful participation in valued activities of everyday life.

Thank you so much. I really appreciate the opportunity to talk with you.

DR. GORDON: Thank you, Dr. Light, and really wonderful conclusion and really hopeful vision of the future.

It is now my pleasure to transition from hearing from some outstanding researchers at the cutting edge of using communicative

support for individuals with autism and turn to individual's lived experience. Today, we will be hearing from two such individuals. I apologize in advance. We had a third planned speaker, the mother of a young child on the spectrum receiving a communicative intervention but that speaker unfortunately had a last-minute schedule conflict and was unable to be here.

We are going to hear instead from Ms. Jordyn Zimmerman, a nonspeaking autistic adult, currently the director of professional development at the Nora Project and on the Board of CommunicationFIRST. In March, she was appointed by President Biden to the President's Committee for People with Intellectual Disabilities.

After that, we will hear from Ms. Benita Shaw, a proud mother of two young men, one of whom is on the autism spectrum. I will have

more about Ms. Shaw when she is about to speak. But first, we will hear from Ms. Zimmerman.

MS. JORDYN ZIMMERMAN: Hi. Hi, everyone. I am Jordyn Zimmerman. Thank you, Dr. Daniels, and the committee for inviting me. It is great to see a few familiar faces. For visual access, I am a white woman with wavy brown hair. I am wearing a black blazer and I am sitting in front of a window with white curtains and colorful piece of artwork to the side.

During my presentation today, I am going to share my own lived experience as a nonspeaking autistic person, not a nonverbal person, who has been called severe and profound and as I do that, I will include some policy recommendations for the IACC to consider. I communicate by typing letter by letter on an iPad, which then speaks my word

out loud. While my words are pre-typed out for the purposes of my presentation today in day-to-day interactions, there are many pauses of silences as I communicate.

And while I am extremely honored to share some of my story with all of you, I want to point out that an estimated 30 to 40 percent of the more than 5 million autistic people like myself in the United States also rely on communication support. I think it is a shame, an absolute disservice that I am the only person presenting from an actual lived experience in a two-hour session on autistic communication. I am only one nonspeaking autistic person and while we may have some things in common, I can only share my experience alone and do not and cannot claim to represent more than a million others. My first recommendation is that the IACC appoint more nonspeaking autistic members to the

committee and solicit the views of more IACC users to advise on its priorities.

I grew up in Hudson, Ohio, a small town between Akron and Cleveland. My parents moved to Hudson for the schools, which are considered top notch unless you are a student who needs services and supports. When my brother started school, he flourished. When I began school, my parents had a startling wake-up call about disability inequity. Although the Individuals with Disabilities Education Act expects that students start in the general education classroom, the school seemed to assume that because I could not communicate reliably with speech and had what they referred to as challenging behaviors that it was not the place for me. But as we know, legally, I had every right to be there. Access to reliable communication should have been provided to me but it should not have

been a prerequisite for me to learn alongside nondisabled students.

I had a few spoken words in elementary school - "of course" and "of course not" and some other repetitive phrases, but the process of producing those words was difficult. It was not that I was lazy, socially disengaged, or anything else. It was simply that speech was a motor movement and my body had to work extra hard to think about the process of producing each word and even when I was able to speak those few words, I had no way to share my likes, my aspirations for the future, how I planned on changing the world, and the challenges that were happening in my life.

When I went home with bruises from being restrained, my family had to rely on the school's version of events if they shared anything at all. At most, I was given access

to picture cards to request items, but that system never worked for me. As I progressed through the school without access to robust communication support, my experiences became more and more traumatizing.

By the time I entered high school, I had been sent to multiple alternative schools, none of which could adequately support me. Without access to the communication support I needed, I communicated in the only way I could, with my body and what people called challenging behaviors. In ninth grade, I was suspended and restrained with handcuffs by the school resource officer. Another time I was restrained by a teacher and experienced an acute brain injury after my teacher hit my head against the ledge of a chalkboard holder. There were hundreds of other times I was restrained and secluded in school due to my lack of access to AAC.

Nonspeaking autistic people are one of the largest groups facing restraints and seclusion as a direct result of not having the support and services we need. This is one reason the IACC must prioritize communication supports for students who need it as early as possible and push legislation that bans the use of restraints and seclusion. Those are my second and third recommendations.

When I returned to the local public high school during my fourth year of high school, I was once again placed in a room by myself with an intervention specialist. This time, the teacher spent much of her time looking for her next job in front of me. She eventually quit with just two days of notice. It was an absolute shock to everyone except me. That teacher had no training or support on how to meet my needs. My fourth recommendation is that the IACC push for

educators to be provided with extensive training on getting students communication support as early as possible. This should not be just the responsibility of a speech therapist nor a special educator, it is on everyone.

After staying home and not having access to instruction for numerous months that summer I returned to the high school. My curriculum consisted of basic activities such as putting teacher's name cards in alphabetical order, washing windows at the bus garage, and going to stores to put clothes on hangers. I think it was the way I moved that led teachers to assume I could not understand anything more than basic language.

At 18 years old, I was being asked to touch my nose and touch my head, then was given candy for complying. Eventually, the district decided it wanted to send me to Farm

Day Rehabilitation Program. My teacher and one of the high school assistant principals took me to visit without first informing my mom. At the subsequent meeting with my mom where this opportunity was presented, they shared how I had already been there and how I loved it. While I deeply enjoyed visiting the animals for that brief 20 minutes, no part of me could envision spending hours of each day in that space. When we do not have access to effective and reliable forms of communication, people in power make destructive decisions about our lives. This is why my fourth recommendation is so important.

In high school, I received an IQ score of 61. The assumptions underlying my IQ score has such a negative impact on people's perceptions of me as well as my perception of myself. Professionals talked around me

thinking I did not understand. While there is nothing shameful about a low IQ score, they ultimately were conveying to me that I was a failure in society because of my poor motor skills and apraxia. My fifth recommendation is that the IACC prioritize policies that make sure IQ tests are not given to people who do not have access to reliable or effective communication. We must constantly remember that speech is a motor function, not a cognitive function.

A few months before my 19th birthday, there was another restraint incident that the district blamed on me and tried to expel me for. My mom got in touch with Disability Rights Ohio. It was during this time at home due to the lawyer's intervention, that I very slowly began utilizing an iPad to help me communicate. Having more reliable communication access via an iPad, did not

immediately decrease my frustrations and need to communicate with my body in ways that led to the staff deciding to restrain me. It was simply one support that I needed and a support that would take time for me to learn to use. Unfortunately, rather than supporting my use of AAC, my special education teacher used my iPad to bully and make fun of me. She typed in crude jokes about my appearance and then would play them as if they were my words.

The following summer my mom found a public school an hour away serving autistic students within a larger district. It was not at all radically inclusive and it was a long drive each day, two things that were very hard for me. However, they helped me in the moment. My local public high school was steadfast in saying they could not support my needs full time.

After spending a year at Mentor's Cardinal Autism Resource and Education School, I slowly realized that Mentor High School, though an hour's drive each way, was my best chance. Even the leading Hudson High School was in a way my choice, I felt a combination of anger and devastation when I first started at Mentor High, not only for myself, but for all students who are treated inequitably by a system that should be committed to their education. Segregation in the public school was almost all I knew. I was not used to eating in the cafeteria or being in classes with 20 other students.

For the first couple months of school, I screamed often, banged my head a lot, and ran out of the building. I am not sure my team fully grasped the challenges I would experience. I also needed solid communication

partners to support me to go to my iPad when I was feeling a range of emotions.

It took over a year of intense support to become truly fluent at using my AAC to be effectively understood with others. With collaboration and communication as the keys, I started to develop relationships and I slowly got used to the new environment. I began adjusting and for the first time, I was fully immersed in the community with others, learning real academics, including math, English, business, law, and others.

As time went on, I also joined cheerleading. I participated in clubs, and I even joined the speech and debate team. I was meaningfully included and felt I belonged. But my access to free and appropriate public education should not have only been available an hour away and should not have started at age 19.

In mid-2016, at the age of 21, I graduated from high school and at fall, I began my college journey at Ohio University. I really enjoyed college, but people made a lot of harmful assumptions. My actions and mannerisms were constantly pathologized and I was judged against a different standard. The university presumed I would be unsuccessful and set fairly high standards for me in an attempt to push me out. I persevered and graduated in four years with a bachelor's in education policy.

In August 2020, I enrolled in a Master of Education program at Boston College. In my final semester, I student taught high schoolers in a substantially separate environment within the Boston Public Schools. It was really challenging to be on the other side to see students who could be meaningfully included if provided with

appropriate services and support but stuck in the same system I had found myself in due to systemic and ableist barriers. In many cases, students in my class between the ages of 13 and 15 were still trying to gain meaningful access to effective AAC. In December, I graduated with my Master's in Education and since that time, I have been working at the Nora Project as director of professional development, helping educators and community leaders think critically about disability as diversity and the human worth of all people.

Additionally in the last year, I have been featured in a documentary called This Is Not About Me and I co-created and was featured in LISTEN, a short film about nonspeaking autistic people. I serve on the Board of Directors of CommunicationFIRST and have keynoted several conferences. Last month I was appointed by President Biden to the

President's Committee for People with Intellectual Disabilities. None of these activities would be possible if I had not given access to robust AAC. Even though I now have access to AAC, my voice still is often questioned or disregarded by professionals.

Last summer before a minor procedure, I shared that I had an allergy with the anesthesiologist. While my mom confirmed this with the doctor, I was still ignored and later woke up in the intensive care unit where I spent multiple days. This is why access to AAC alone is not enough.

My sixth recommendation is that the IACC push for and support our right to communicate about ourselves and our needs in the ways that work best for us. We are the experts on ourselves.

As the IACC considers how to better serve the nonspeaking autistic population in

its work and recommendations, I strongly urge you to include more nonspeaking autistic people in this planning and consideration. Representation matters in all facets from education and research to medicine and funding.

More than one or two AAC users should be involved in the IACC. AAC users should be invited to help shape the research and funding agenda in meaningful ways. I believe that most of the research that has been done on people like me to date is deeply flawed. The IACC has a responsibility to fix that. As President Biden proclaimed on World Autism Day two weeks ago, we need to do more to incorporate the lived experiences of individuals with autism into their research. The IACC must do a better job of ensuring that each of us who need it is given access, training, and support to be able to use

robust AAC that works for us as early as possible. Without it, we cannot fully participate in our communities or lead fulfilling lives of dignity and respect as President Biden has called for. Too many people like me are written off and subjected to lives of oppression and segregation. Too many educators and caregivers give up too quickly or assume we cannot learn to use language when we fail to use spoken words or picture cards in expected ways.

In a system that is designed to fail individuals like me, I count myself lucky. However, people like me should not have to rely on luck or chance to be seen as worthy or to have access to reliable communication or inclusive education. While my story is one story, this issue is not about me. As horrifying as my lived experience may be, I am a relatively privileged white woman. And

while my story should not be the standard, it should not be assumed to be unusual. Thirty to forty percent of autistic folks, over one million people, need AAC. But the majority of us especially autistics of color are still denied access to communication tools and support that are effective for us. Everyday people like me are being deprived of contributing to our communities and our communities are being deprived of knowing our humanity. The only thing unique about my situation is that the right people happen to step in when I was 18 years old to push to set up the right communication support and training that worked for me. We have to change this, and I encourage the IACC to lead the way. Thank you. I am happy to take any questions you may have.

DR. GORDON: Thank you, Ms. Zimmerman. We very much appreciate your testimony today to

this group and your recommendations as well. We will hopefully have some time for questions and comments at the conclusion of the panel. But I want to introduce our final speaker of the day, Ms. Benita Shaw. As I mentioned, she is a proud mother of two young men, one of whom is on the autism spectrum. She works as a community education specialist at the UC Davis MIND Institute in the Resource Center and is a facilitator for the Sankofa parent support group at the MIND Institute.

MS. BENITA SHAW: Good afternoon, everyone. Ms. Zimmerman, my hat is off to you. I am trying to get myself composed together to speak because you radiated everything that was in my heart as a parent of a person who has minimal speech and uses a device. Continue to do what you do because you are doing it for others like my son and

thank you. I will proceed to share with you a little bit of my soon. Excuse my scratchy voice because just listening to her I am in tears, and it makes me realize how much hope I still have for my individual.

As you stated, I do work at the MIND Institute and I wear multiple hats. I am a single mom of two boys. My youngest is now 20 and he was diagnosed with autism at two and a half. He was labeled as nonspeaking, minimal words. As I listened to the researchers today and Ms. Zimmerman, I realized that because of who he is and what he looks like, he was not able to get the proper education that he needed to.

He started off with a textbook when he was young. Because of sensory integration, he had great challenges with his behavior. It just took a lot in order for him to be able to be taught. So we did that for a while. I

decided that when he first started, he was in a non-public school. I thought the best way to do was to integrate him. You know it is very hard when people give you such negative feedback when you are trying to push and include your child in an appropriate education that any average mother would want.

Initially, in transitioning him into a public school system, his teacher wanted to let me know when we left that nonpublic school system that it wouldn't work for him because he had too many behaviors and challenges.

I think then that initially started my advocacy for my son, Christopher, to fight for him for him to have what everyone else has. While yet my oldest is quite gifted and there was no issue providing for the things that he needed. It has been a fight for the

past 15 years to allow my son to be included into the educational system.

He had speech. He had occupational therapy. He had music therapy. I truly believe that young man is brilliant in his own right. But because each time we were always dealing with this challenging behavior and I believe because of his size and his skin pigmentation, it was a struggle for him to be educated the way he deserved. We spent 15 years of trying to get him to utilize a device that would help him to get his needs and wants met.

He also had to listen to people around him speak negatively about him, including his teachers, including the people that were supposed to be there for him, his one-on-one aides where he was bullied to the point my son started doing things not just with behaviors, self-injurious behaviors and other

things because he was not being heard. I would tell people all the time, just because he cannot speak the language that we do does not mean that he is not competent in his own right. He understands what is being said around him, to him, and what is happening. And because of that, there are reactions that comes out of him because of that. We spent years in fighting for that.

It was interesting with one of the people who spoke today when they talk about literacy. It is just now in his age of being 20 that because of the fight that I have had to do with the school district to make them pay for this - multiple fights, complaints and what have you to where we had to include attorneys and what have you to fight for what he needed and what was right for him. We are just possibly getting into the literacy

issue. But we figure, we are like 15 years behind the eight ball.

When Ms. Zimmerman spoke to you guys and had these ideals and had these suggestions to you, I truly hope you take it to heart because I think my son could be one of those people that could be here today. Because of the lack of people not believing in him, not giving him that opportunity, prejudging him because of the size that he is because he is quite tall, because of the skin tone that he has that he felt that he is not capable of learning, it just was not right.

Because of a caregiver and a mom advocating, it is something you should never have to advocate is for the education for your child. The educational system is not set up for people who have devices or use augmented communication for a device. It should be that way. Smart TVs into the

classroom to where he feels that he is included.

I believe one of the things that was a challenge for him is because he felt that there was not anyone else around him doing the same thing. And the device was used for other people to get something out of him, which was not right.

For me, I think that it is to realize everything that people are talking about, research. When you are doing research, there is a multitude of other people who are older that truly need this intervention in regard to research to where they are looking to be considered. They need to be a part of the community too because you are going to learn so much of whatever occurred or did not occur in them that could be helpful going forward.

I know that we are short on time. As Ms. Zimmerman said so much of what I wanted to

say and I illuminate absolutely everything that she said. My hat is totally off to you. I am going to stop speaking.

DR. GORDON: Thank you very, very much, Ms. Shaw. I think we all share with you the intensity of the need in this area. We appreciate you coming and sharing your own story of your son as well.

There are a lot of people who want make comments and perhaps from the IACC. First up is Sam Crane. I am going to ask each of the people who are making comments or questions that if you do have a question, please let us know to whom it should be addressed.

MS. SAM CRANE: Hi everyone. I just wanted to echo what Ms. Shaw was saying about the need for research on how to get high-quality AAC supports for adults. There is a lot of research, still not enough research. But when we look at research on AAC supports,

it is largely focused on language learners, including children and we have so little information on how to make sure that the AAC works for adults. As we know, there are critical periods for language and people learn language and learn communication skills very differently in adulthood versus childhood. There is no reason to believe that that is not true for autistic people even though we know it is true for non-autistic people. We really critically need that research because there are so many people who have not been served who missed out on getting those services as children and we cannot leave them behind.

DR. GORDON: Thank you very much, Sam.

MS. YETTA MYRICK: Thank you all for your presentations and your work around AAC. Ms. Shaw, I just want to thank you specifically right now because I know you are trying to

still compose yourself. But I want you to know that I see you as a mother and take your deep breaths, keep fighting that fight.

I agree that more research is needed around AAC, specifically as it relates to parent interventions with AAC as Dr. Kasari shared. By doing so, I hope that this will help to bridge gaps between various disciplines and service systems and create more opportunities to provide individual supports and services.

Unfortunately, Dr. Light, I am not surprised by the disparities and access to AAC. In my experience supporting my son, I found it difficult to generalize and adopt use of AAC at home with him as we are faced with providers both in the school and with community providers who would not adopt AAC. I am not going to say that they did not try. But the response is always that he did not

take to these supports and/or he can talk.
Why do we - we really want to support his
verbal communication.

Looking back now and listening to what
you all shared today, I can see that training
is needed across discipline to support the
use of AAC and obviously cannot say this
enough, more research. I think most of us are
agreeing here today about that.

In addition to thinking about
communication to access education,
employment, community, et cetera, I would
also like to add that not being able to
communicate also becomes an issue of safety.
If you cannot communicate, how can you report
if you are sick or if there is abuse, et
cetera?

Ms. Zimmerman, thank you so much for
sharing your experience and recommendations.
Could you share which program you are using

on your iPad to communicate? I am not sure if I missed that. And what advice could you provide to family members who are trying to figure out the best AAC support for their loved ones? Thank you.

DR. GORDON: Ms. Zimmerman, would you like to respond?

(Pause)

MS. ZIMMERMAN: I currently use Proloquo4Text. The communication needs of every individual varies and fluctuates throughout the life, which is why my first recommendation around more AAC users on the IACC is so vital.

DR. GORDON: Thank you very much for that response. Next, we have a comment or a question from Dena Gassner.

MS. GASSNER: I just want to thank all of our speakers today. It was a really excellent presentation. I just wanted to say to the

moms, just keep the good fight up. My son was not provided access to technology until he was well into college. I do have relative privilege and I did have to not work and try to help my son get through school and I still could not win that battle. Just hang in there.

I just wanted to thank you. Jordyn, Chloe says hi. I just wanted to say thank you so much for your comments especially around the idea of trauma. I do hope that we can continue to discuss and dialogue in the research that even though a person develops some language capacities, it does not mean that we should not continue to offer AAC.

As Yetta inferred, I want to go into a little bit greater detail about that. My son speaks with directives. By the way, he authorized me to share this. He speaks in directives. He is highly fluent in his area

of special interests. He does not use interrogatory language at all at 32. He was stalked at his high school by educators and singled out, tormented by them. And to this day, I still do not know exactly what happened because he cannot communicate anything around language when he is emotional. I believe we would have those answers if he had not been withheld from having access to technology so very long.

When we think about trauma in this population, the denial of the access to technology is directly linked to our inability to help people therapeutically process trauma. If you cannot write about it and you cannot draw about it and you cannot speak about it, how do you unpack a traumatic event? I just cannot emphasize enough how important it is that we provide both options very early on.

I am very excited about Dr. Light's research with pre-verbal children. And I am wondering if the combination of interoceptive work and this pre-verbal access to communication could reduce the need for behavioral interventions because kids will have lower frustration levels. I am just wondering. Are you seeing anything like that, Dr. Light? Are you seeing any better coping skills, better self-regulation, anything like that in the kids who were given technology so much earlier?

DR. LIGHT: We are seeing a variety of things. I do want to emphasize that there are kids that are suspected of having autism within the group. But clearly, often the formal diagnosis comes later on as well as kids with other types of developmental disabilities.

We are intervening as young as 6 or 7 months with many of those children introducing AAC technologies. As I said, we are seeing increases in turn taking and communication, social participation, and language, first words coming earlier than we might typically expect and making gains. We have seen very low levels of behavioral problems because the root of most of those, as we know, is the lack of ability to communicate effectively with others. Interestingly enough, many of the kids that we have tracked taken through our project have also entered school with literacy skills. I will say that that has dramatically then changed their whole educational experience because they have proved and now it is up to the educational system to support them. And we need better supports for these

kids so that they have the ability to share their capabilities and skills with others.

MS. GASSNER: That is glorious. Thank you so much.

DR. GORDON: Thank you. I believe Steve has a comment from one of the members who submitted it via the chat.

MR. ISAACSON: This is a comment from Hari. The first one is to thank you for the excellent presentations. I would love to see --

DR. GORDON: Steve, your audio is echoing or broken up. I am not sure exactly why.

MS. GASSNER: I think he needs his headphones.

MR. ISAACSON: Can you hear me now?

DR. GORDON: Same problem with the audio. Maybe you make sure the microphone is switched. Try again. It is still broken up. I will go on to the next person and then we

will come back to you. See if you can fix that.

Maria Fryer, please, is next.

MS. MARIA FRYER: Thank you so much. I appreciate the speakers and the comments. I just wanted to say two things, one of a personal nature and then one more speaking to the trauma and safety issues. From the Bureau of Justice Assistance, I am definitely interested in more of the safety aspects and responding to students that may have been victimized.

On a personal level, I just wanted to say again to the moms to echo that, keeping up that fight. My daughter did not speak her first words until after she was 4. On a happier note, she did go through lots of therapy - again, occupational therapy, speech therapy. One day at the dinner table, she just started singing. Going back to that

research, it is really interesting when you talked about imitation. I know that I experienced that firsthand. I am hopeful and I am optimistic there in the research and I appreciate the personal stories.

And on a professional level, I am very interested in how in terms of training, we could do better in terms of training our school resource officers, especially through a lot of our grant-funded programs. One in particular I am thinking about is the STOP program that basically - this is where we are beginning a whole new area of this program in training school resource officers and teachers and educators, about students on the autism spectrum and how to better connect them with treatment. I would like to learn more about how to respond to students who are nonverbal that may have trauma and may need to unpack those issues of what their

experience was and how to make a report and perhaps talk about the victimization and how to connect them to appropriate treatment and services. I am very interested in learning more about what is available in terms of actual training for staff and for school resource officers. I will stop there. But thank you so much for the presentations today. They were incredibly informative. Thank you.

DR. GORDON: Thank you. We are going to go to Matthew. Actually, we are going to come back to Steve and see if his audio is working better.

MR. ISAACSON: Can you hear me? This is Steven.

DR. GORDON: Much better. Please go ahead.

MR. ISAACSON: Thank you very much. This is a comment in three parts from Hari. Thank

you for the excellent presentations. I would love to see more research on apraxia auditory processing sensory systems and body schema. Current technology is not always intuitive to use and sometimes confusing in what you are supposed to do, has short battery life, and has too many menus to navigate in addition to crowded, noisy, over-stimulated screens.

My PECS finder, as a kid never had any Indian foods on it. Also, speech apps mess up foreign words including the way it even says my own name. Also, technology does not function well when you are at the pool or at e-soccer even though communication is required in those environments. This is a question. Are VSDs and T2Ls available to the general public?

The second part is Jordyn, your experiences - many of your communication, educational barriers and medical barriers

like ending up hospitalized was déjà vu for me. Thank you for a brilliant presentation.

And the third part. Thank you, Benita.

When you are nonspeaking, often it is parents who are the best advocates as they are truly invested because no one else really cares or bothers to care and you are pushed through and exited out of the system at age 22 with no supports or skills and then everyone complains about what a burden this group is for all of the behaviors.

DR. GORDON: Thank you, Hari, for those comments. There was a question in there that I do not know if any our panelists can answer about the availability of some of these tools for the general public. I know that many of them are included in many technologies. But I am wondering if anyone has more specific comments or answers to that question.

DR. LIGHT: I can take that on. Hari, they are available from a variety of different assistive technology manufacturers and app developers. If you want to fire me an email afterwards, I can send you more of the specifics about it. I just wanted to emphasize again. I really appreciated your comments about the limitations of many of our current apps and technologies because I believe that we have not by any means exploited the full capabilities of assistive technologies and technologies generally. We need to be thinking through many of those challenges and problems that you have talked about and figure out how to design more effective supports that really meet the needs of those people that are using them as opposed to just applying the technologies that we have and forcing people to learn how to use them instead.

DR. GORDON: Thank you. Matthew Siegel. I am just going to make an editorial note. We are running a little bit late. There is such a desire for discussion on this point that we will extend this and curtail other parts of the program. Go ahead, Matthew.

DR. MATTHEW SIEGEL: Thank you, Josh. Matthew Siegel from Maine Medical Center, member of the committee. I have a comment and a question. The question is for Dr. Cooper. Thank you so much to this panel. This was an extraordinary panel and presentation from the researchers who spoke and Dr. Cooper to the people with lived experiences. It is one of the best presentations on communication autism I think of recent memory.

A further comment is there has been a lot of discussion about how to move things into practice and someone said it more eloquently than that in their presentation

and that is the challenge in many areas. Looking at interventions in autism as well as across the rest of medicine, the point of the realm is randomized controlled trials. When you have large randomized controlled trials that is what gets things paid for. That is what gets them disseminated. That is what gets clinicians to use them and recommend them and prescribe them.

In autism, we have some dozens of studies of medication, using randomized controlled trials. We have a few dozen studies of what are called psychosocial interventions such as cognitive behavioral therapy, et cetera, for different things in autism. And in communication interventions, we have exceedingly few large randomized controlled trials. In a Cochrane review from 2018, it identified two and perhaps there has been a little more since then.

This is an area that we have a fair number of small and sometimes not randomized trials. We have excellent work being done as we heard about today. But in order to gain the access and meet the needs that we have heard about so greatly today, we need large randomized controlled trials or other large ways to generate evidence for this area.

My question is to Dr. Cooper. How can we move in that direction to get the kind of support that is needed for funding and greater dissemination for these critical interventions?

DR. COOPER: Thank you for the comment. Certainly, for my institute, we would welcome such an application, such a focus. I tried to highlight - we have been encouraging some of these areas that are needed. We are in a sense waiting and hoping. There are things we can do to maybe encourage by making the kinds

of announcements and that sort of thing that we do. I appreciate your comment.

Clearly, as I said at the end, there is still a lot more that we do not know and sometimes a randomized clinical trial, which our institute does have a clinical trial program. If there were a group out there that is listening to this meeting and has the idea, then I say come on in. We, at the NIH, will certainly talk, I am certain, about all the comments that we have heard today and what else can the NIH be doing to move this area along a little bit. Thank you very much for that comment.

DR. GORDON: Thank you. I do not know if any of the investigators would care to respond to that comment before we move on.

DR. KASARI: I have a comment.

DR. GORDON: Please, Dr. Kasari.

DR. KASARI: I think what a lot of people brought up, the mothers' autistic individuals, is how traumatizing the school experience is. I think it is not just NIH funding, but it is Department of Education or IES, and really getting everybody around the table to take on the challenges of inclusion, for example. We are working towards that. But it is challenging unless everybody is around the table and discussing that. Maybe in joint funding or those kinds of things. That is how we get it into school systems where the majority of children are educated.

DR. GORDON: I think, Dr. Kasari, you are really pointing out the fact that the currency of health care systems and of health insurance systems and hospitals is the randomized control trial. But here and we have seen this all over. Lots of school-based interventions at NIMH has funded large

randomized controlled trials as far as even a successful randomized controlled trial is not necessarily enough for a school system to adopt an otherwise efficacious program. I think you are pointing out that it is not only that in and of itself. Thank you for that comment.

We will move next to another member of the committee, Scott Robertson.

DR. ROBERTSON: Thanks, Dr. Gordon, and thanks to the presenters. It was excellent presentations. I think this focus is such a long time coming. I would like to add to some of the other comments that not only for research, but I think for our federal policies, practices, initiatives that we should have more on this focus for employment, education, health care. I feel like, and this applies, for instance, for research is the - sometimes the focus is just

general access to AAC or communication and not necessarily access and opportunities in specific settings where barriers exist, for instance, for AAC users who are on the autism spectrum to access gainful employment, to access inclusive education in K to 12 and higher education to have full or equal access to health care and community living and community-based services and support systems.

We need to grow the literature base on the research end to make it broader, and then have federal policies and practices that align for this that emphasize communication first and empowerment and how this cross connects to, for instance, our emphasis in the federal government on diversity, equity, inclusion, accessibility, DEIA, and our executive policies, including the executive orders that have come out. I think there is very much in alignment. I look forward to -

and maybe this is something even separately from IACC that maybe the federal collaborators, the sister agencies could connect on, for instance, for FIWA, the Federal Interagency Workgroup on Autism, about how we could be making policy and practice adjustments to reduce barriers to access for AAC folks and make sure that there are better opportunities out there and what targeted funding and resources could be used to enhance this focus in line with the values that we have I would say under the Autism CARES Act where AAC use and just full access to communication folks, they need to thrive in life as children, adolescents, and adults. That should be a recognized right I think as quality of life and a really major priority, I think, for autistic people. I am just so glad that we are discussing this today.

By the way, Dr. Light, it is really good to see you after a long time. I am a little bit biased in this area because I am an alumnus of Penn State. I did my PhD at Penn State. It is great to see Penn State trailblazing with AAC research and also the other presentations here on the research and lived experience. Thank you.

DR. GORDON: Thank you, Scott. I know we have three more people waiting to comment. Actually, two more people. But one of the speakers raised her hand. Ms. Shaw, would you want to respond?

MS. SHAW: I just wanted to say because I know I left a lot out because I was very emotional. I am asking for forgiveness for that. But one of the things that came up is that Christopher did have quite a few different devices that they spoke about today and a couple of the programs was Proloquo2

and TouchChat. But I will say as the enriched conversation came about, I would say a lot of the people - a lot of the challenges were the connection of people having no training for the technology. You have the speech pathologist and you only have that once or twice a month. During the week, it was never a collaborative with his planning for his curriculum nor with the teacher. With having that lack of training and having that lack of being able to include that technology, I think was also in a fall in regard to the system, the educational system.

When I think of things if I had to share the things that is the most now that I am no longer emotional, it is important that there was no connection in regards to I felt, advocating for my son is because he communicated with a device as far as books, as far as materials, all those things were

not tangible for him in a manner that he could learn from because of how he communicated. I think it is part of the educational system that we need to look at adjusting for ones who do not - who speak with a device and what have you. I just wanted to make sure I stated that and it was important for me to share that he did have different devices that he did use and that he is using currently and that he is also in a literacy program now. Thank you for the opportunity.

DR. GORDON: Thank you for sharing that additionally and you do not have to apologize. You have been a remarkable help to this committee in your conversation.

Next, we have another comment that Steve will read for us.

MR. ISAACSON: Hi there. I have two comments. One from Hari (Srinivasan) and one

from Sam (Crane). The first one is from Hari. Dena, my communication shuts down during intense emotions. AAC is not much use at that time but still expected to communicate fluently. This is not understood. Do typical people not choke up when they cry and have a hard time forming sentences and words during that state?

The second comment is from Sam. I would like to just quickly note that there is often limited insurance coverage, including Medicare and Medicaid coverage for AAC devices. This is a policy issue we need to address.

DR. GORDON: Thank you for both of that - both of those comments. And I will just respond quickly to Sam's comment that that is I think one of the reasons why Dr. Siegel suggested the need for randomized controlled trials that those are typically the currency

with which insurance providers and others, including Medicare and Medicaid agree to pay for services.

For our final comment or question on this segment, we will call on JaLynn Prince.

MS. PRINCE: Thank you very much. When our son was 14, he really came to a point where his communication was extremely challenging for him. Prior to that point, there were a couple of catch phrases that the school kept using. He is in a language-rich environment, which really did not mean a whole lot to him. He could have used so much more to be able to get him to a point of communication.

There was a crisis that happened in his life when we moved just a couple of blocks away that he could not communicate about those issues. He went into a situation where he could not attend school for 18 months and

had to be schooled at home. It got to be so extreme that he was pulling baseball-sized blocks of hair out of his head because he was so frustrated about not being able to express the things that he needed. It was the first time in his life too that he was required to take some medications to help him modulate what he wanted to modulate and to be who he wanted to be, which set a whole path of other things with weight gain and so forth. It goes right down a huge path.

I wonder more about how speech and helping us with other educational possibilities can really enhance things. We have wanted to continue for him at age 33 now - continuing speech classes. In the Washington and Baltimore area, we were able to identify two. Only two speech pathologists that would even consider working with an adult. One ended up starting a family and is

no longer instructing. And the other decided that she only wanted to work with children. The dearth of possibilities for adults to continue learning or to improve the state of language that they have is extremely limited and there is such a need for supports for adults because it just does not exist.

DR. GORDON: Thank you for that. And although I said that was the final one, I see Sam Crane. Sam, I will let you have the last word in this segment.

MS. CRANE: I just wanted to add that while I also support the necessity of randomized controlled trials that is not always a prerequisite for coverage of durable medical equipment, which AAC would be classified under. We very rarely see insurance companies requiring randomized controlled trials of wheelchairs before covering wheelchairs for people who need

them. It is both a policy and a scientific issue.

DR. GORDON: Fair enough. Thank you, Sam.

I am sorry but I am going to have to - I will take one more. Alycia Halladay, go ahead.

DR. HALLADAY: It is okay. I just wanted to point out that we are talking about interventions here instead of durable medical equipment. Again, we are kind of mixing together interventions delivered through AAC rather than just providing an iPad or providing something. There is still some question about the role of interventions and independent communication and how that occurs, and we just heard that behavioral interventions are absolutely necessary for that. I want to just kind of make sure that when we use the word AAC, we are very specific about what we are talking about.

DR. GORDON: Thank you for that and I think we can all appreciate the challenges here of ensuring that we have sufficient evidence and know that we are doing the right thing and at the same time, advocating to make sure that the procedures, devices, therapies that are needed to be able to assist individuals with autism to maximize their communicative abilities are available through both the educational system and the health care system.

Thank you to all of the speakers. Really wonderful series of presentations by the scientists. Quite evocative, personal stories from those with lived experiences. I will point out that we do have several members of this committee who use either exclusively or regularly assistive communication devices and they have made valuable contributions to the

IACC so far and continue to do so. We really appreciate their participation.

I also want to point out that avid listeners and sometime participants to this group you have already heard from include members of the institutes at the NIH that would support this research. But listening behind the scenes that you may not be aware of are many of our program staff who actually develop the programs and I know that these conversations will influence them.

You also heard that many of the federal partners here are deeply interested in these inputs to make sure that we try to overcome barriers and collaborate across federal agencies to encourage the development and use of these kinds of tools across the federal government. Thank you very much for your participation.

We have now unfortunately run right through what was to be a brief break in the afternoon and I apologize. I know that for many of you, it is difficult. It is difficult for me as well to sit through a long meeting such as this without a break. But at this point, I think what we are going to do is go right into the round robin updates. We were to have a brief consideration of the summary of advances discussion, or I should say a continuation of the summary of advances discussion from yesterday, but given the enthusiasm and interest in the previous topic, I made the decision on the fly that I hope you will forgive me for to postpone that summary of advances discussions. Dr. Daniels and I will try to arrange a time where we can all get together to perhaps in a brief extra session but in a public way to discuss these.

We do now give the opportunity for members of the IACC to make announcements that they would like to share with their fellow members and/or the general public. Before we do that, I mentioned yesterday that we want to celebrate the achievements of IACC members. And one was pointed out to me this morning and I just wanted to share that Dr. Scott Robertson from the US Department of Labor was recently awarded the prestigious Henry Viscardi Achievement Award by the Henry Viscardi Center in New York. This award is for exemplary leaders in the global disability community who advance work to help empower children, youth, and adults with disabilities to protect their rights and to expand access to supports and services. Scott is one of the first two autistic persons to receive this international award since its inception in 2013. Congratulations Scott. You

have been a valuable member of the IACC and we are really pleased that you received this recognition.

DR. ROBERTSON: Thanks, Dr. Gordon. I appreciate that.

DR. GORDON: I am going to turn it over to Susan to moderate the round robin. I believe she has one announcement from one of our members who had to leave. I see several members who are raising their hands to make announcements. Susan will call on you in turn. Go ahead, Susan.

DR. DANIELS: Thank you so much and thank you to the previous panel. We really, really, appreciated all that input and what you shared there. Thank you to those who helped organized that panel as well, to Judith Cooper and Helen Tager-Flusberg, and we just - we will continue working on that topic and

I assure that we will be talking about it in the FIWA as well.

Now, I want to share an announcement from the Department of Education. Unfortunately, Larry Wexler had to log off at 4:30 and wanted this to be shared that there is a Subminimum Wage to Competitive Integrative Employment demonstration project that he wanted shared. He said that on March 21st, the US Department of Education's Rehab Services Administration or RSA, released this notice inviting applications for Subminimum Wage to Competitive Integrated Employment demonstration project aimed at increasing access for people with disabilities to jobs that pay good wages.

There are several different points in here. Given the time, we will add this all to the round robin document. But at the bottom, it says that OCRs will conduct a pre-

application meeting specifics to this competition on Wednesday April 20, which is next week at 2 p.m. Eastern Time to respond to questions. You can check RSA grant info for more information. We will put this in the round robin document. If anyone listening has a question about it, feel free to email me or feel free to email Larry Wexler to get all the information. And the deadline for submissions is June 21, 2022. Thank you for that.

And now, we will take a comment from Alison Marvin.

DR. MARVIN: I am from the Social Security Administration. I just wanted to ask people to go to the meeting materials tab and then the round robin's documents - and the federal agency public member community update's document for updates. But they include additional information relating to

today's release of SSA's first equity action plan, which I had mentioned earlier.

Information about SSA having added more in-person appointments at local offices and starting again to offer walk-in services for those without an appointment. Again, for more information, please go to [SSA.gov/coronavirus](https://ssa.gov/coronavirus). And also a heads up that the next opportunity to apply for SSA's Interventional Cooperative Agreement Program, the ICAP grant, is coming soon. Information on how to receive an alert when the funding opportunity application period opens is included in the document.

And also under the round robin documents is the document that contains SSA's responses to the additional questions relating to Dr. Hemmeter's presentation at the last IACC meeting. Thank you so much.

DR. DANIELS: Thank you, Alison.

Next, we have an update from Alycia Halladay.

DR. HALLADAY: Hi everybody. I wanted to announce that ASF is collaborating with the Phelan McDermid Syndrome Foundation, the International CDKL5 Foundation, and Indiana University on an NCATS-funded project. It is a two-day meeting on GI issues and neurodevelopmental disorders. In addition to the two-day - there are two half days in June. It will be June 8th to 9th. There will be a number of presentations looking at not just the association but also about recommendations, including different outcome measures, continuing education, and education of physicians and biobanks. We are also circulating a survey. Whether or not you have a rare genetic disorder is irrelevant. You can have idiopathic autism or any neurodevelopmental disorder and fill out the

survey about GI symptoms. The website is www.candidgi.com. CANDID stands for the Consortium for Autism, Neurodevelopmental Disorders and Digestive Diseases. You could just go to that website and get information and registration will be up soon.

We also just announced our undergraduate research fellowships, which can be found in our new website, which launched about a month ago. We also have videos from the March 30 Day of Learning, which included presentations on the prevalence of autism, mobile technologies for early detection and intervention and the importance of leisure activities. You can go to our website to see that.

DR. DANIELS: Thank you, Alycia, for those updates.

Next, Steven. Do you have some comments to share some updates to share on behalf of one of our members?

MR. ISAACSON: Yes, I do. Thank you. Dr. Jenny Mai Phan wanted to share that along with Dr. Kristy Anderson and Dr. Lindsey Shea, is presenting at the AIR-P Autism Awareness Month Double Webinar on April 19 on the importance of research on puberty and autism. And the day is called the Intersection of Autism, Health, Poverty, and Racial Equity.

I also wanted to share on behalf of the OARC office in response to the interest in housing resources in our resources section are on the IACC website. We do have a number of items that will be listed in the round robin document after the meeting along with the link to the AIR-P presentations.

DR. DANIELS: Thank you, Steven. I have shown a slide here on our housing resources page in case anyone is interested in that. Thank you.

Amanda Reichard.

DR. AMANDA REICHARD: Thank you. I just wanted to - in addition to the NOFOs that are going to be listed in the round robin report, is that what you call it, I want to draw your attention to those.

But I also wanted to let you know that the Administration for Community Living is pleased to announce that Jill Jacobs was appointed as the commissioner of the Administration on Disabilities. In addition to her professional experience of more than two decades and very qualified, she also brings extensive lived experience, both as a person with a disability and as a mother of two disabled adults.

At her last job as the executive director of Independent Center of Northern Virginia, which is a center for independent living, she drafted and successfully advocated for the passage of two state laws that explicitly upheld the civil rights of people with disabilities. She developed innovative approaches to providing services and supports to people with disabilities during the COVID pandemic. She has always been a grassroots organizer for disability issues. I just wanted to make you aware of that great new addition to the ACL.

DR. DANIELS: Thank you so much.

DR. GORDON: Susan, I wonder if you might take this opportunity to remind everybody about the event we have - the IACC is putting on later in the month if you have those details.

DR. DANIELS: Yes, I do. In fact, I have some slides that are part of the closing remarks. I do not know if there were any other round robin updates.

DR. GORDON: Let us just wait. Any other round robin updates from other IACC members?

MS. GASSNER: This is Dena. I will be presenting at the ASHA Conference this year on a panel but also, I am presenting on a new framework of understanding autism and masking. If anybody is going to be at ASHA, they can look for me.

DR. GORDON: That is great, Dena.

Susan, why don't we move into the closing remarks?

DR. DANIELS: Would you like to start us off here, Josh, with any remarks?

DR. GORDON: Sure. I want to thank everyone on the committee for the work today and yesterday. It has been a really wonderful

meeting. We learned a lot, not without a little controversy here and there. But we learned a lot and we treat each other with respect. We also heard from members of the public on a range of different issues. It gave us a lot of food for thought for the Strategic Plan and it gave a lot of the members here around the table who support research and care efforts. A lot of food for thought with regard to the various issues that we discussed, both housing and communication.

I am going to then turn it over to Susan. Before I do that, let me thank Susan and really her entire team for putting together this meeting and for all the intervening work. Really, it is a wonderful job by the IACC staff. I want to thank and recognize them. Susan.

DR. DANIELS: Thank you. Yes, I also would like to echo what Josh said that it has been a terrific meeting. We really appreciate people's thoughtful engagement on all of these issues and the work that we did. I feel like we did a lot of work toward forming that collective voice. That is what the IACC is all about. Thank you all for your efforts in this regard and we look forward to the next meeting.

Just as a reminder, some of our upcoming action items for the committee are with the Summary of Advances, Josh and I will confer on what would be the best route to continuing to refine the 2021 IACC Summary of Advances list, whether we would do that somehow via email or if we would need to convene any other additional meetings to complete that. But we want to put out the document as soon as possible and be keeping your eyes open for

the 2020 IACC Summary of Advances to come out in May.

We will be also sending to IACC members a survey on the IACC mission values and vision. You can be expecting that as well as we will provide a way for you to provide additional comments on the rest of the Strategic Plan as we want to collect all that input along the way so that we can get the draft to what it needs to be. We will welcome that and we will certainly send you some more emails with the details.

This summer, again, we will be looking for global feedback on the draft of the IACC Strategic Plan that we will present to you in early July and the meeting that we have scheduled is for July 13th and 14th. It will be a virtual meeting similar to this one that will be both afternoons unless we decide we

do not need both afternoons. But we will work on that agenda and get that out to you.

And the next IACC Full Committee Meeting is on October 26. For now, it is either virtual or hybrid. We will let you know when we get closer as we see how things progress.

Again, just a reminder to join us for the NIMH Special Event for Autism Awareness Month, Animating the Future for Exceptional Minds. We think this will be an exceptional event and we look forward to having you there. We also will record it.

I would also like to let people know that you can tune in for the INSAR Annual Meeting that is going to be taking place in San Antonio, Texas, but also will be available virtually. It is on May 11th through 14th for those who want to find out the latest in autism research.

There is an upcoming Autism at Work Research Workshop May 16 through 18 that you also may be interested in. We have also provided the link there.

Thank you so much for everything. And we want to say thank you again to the OARC staff for all their terrific work as well as to our support team from the Bizzell Group that helped us with all the technical and support issues for this meeting. We really appreciate all your efforts. Thank you so much. We look forward to seeing you next time.

(Whereupon, the meeting adjourned at 4:55 p.m.)