INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, OCTOBER 26, 2022

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 10:00 a.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 FERRELL AKLIN, Ph.D., National Institutes of Health (NIH) (representing Lawrence Tabak, D.D.S., Ph.D.)

KRISTIE BRACKENS, Department of Justice (DOJ) (representing Maria S. Fryer, M.S.)

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.)

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

AISHA DICKERSON, Ph.D., Johns Hopkins University

PRESENT: (continued)

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

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, B.A., Champions Foundation

JENNIFER JOHNSON, Ed.D., Administration for Community Living (ACL)

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

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

LEAH LOZIER, Ph,D., US. Department of Housing and Urban Development (HUD)

ALISON R. MARVIN, Ph.D., Social Security Administration (SSA)

MATTHEW MILLER, Ph.D., M.P.H., U.S. Department of Veterans Affairs

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

YETTA MYRICK, B.A., DC Autism Parents

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

PRESENT: (continued)

MORENIKE GIWA ONAIWU, M.A., Rice University

JENNY MAI PHAN, Ph.D., Children's National Hospital

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 Maryland

SCOTT MICHAEL ROBERTSON, Ph.D., U.S. Department of Labor, (representing Taryn Mackenzie Williams, M.A.)

STUART SHAPIRA, M.D., Ph.D., Centers for Disease Control and Prevention (CDC)

MATTHEW SIEGEL, M.D., Tufts University

HARI SRINIVASAN, Ph.D. Neuroscience Candidate, Vanderbilt University

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 (DoD)

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PROCEEDINGS

DR. JOSHUA GORDON: Good morning and welcome to this meeting of the Interagency Autism Coordinating Committee. I'm JOSHUA GORDON, the Director of the National Institute of Mental Health at the National Institutes of Health, and the Chair of the Interagency Autism Coordinating Committee. I'm joined by Dr. Susan Daniels, the Director of the Office of Autism Research Coordination at NIMH and the Executive Secretary of the IACC, as well as the Acting National Autism Coordinator.

I'm really pleased that we can get together today on this video cast for the public, and I'm very much looking forward to the exciting day that we have for us today. I want to take a moment to acknowledge some important updates about several of our committee members. First, I'd like to welcome Dr. Leah Lozier or Leah --I'm not sure which way it's supposed to be pronounced. You'll let us know -- From the U.S. Department of Housing and Urban Development. Dr. Lozier is a Social Science Analyst in the Office of Policy Development and Research at HUD. Dr. Lozier, maybe you'd like to introduce yourself.

DR. LEAH LOZIER: Thank you and good morning. Can everybody hear me okay?

DR. GORDON: We can hear you just fine.

DR. LOZIER: Great. Thanks. As Dr. Gordon said, my name is Leah Lozier. I'm a Social Science Analyst with the Department of Housing and Urban Development, or HUD. I joined HUD in 2014 as a Presidential Management Fellow under the OBAMA Administration when there was a push to try to bring folks with STEM degrees into the federal government. I have been in the Policy Development and Research Office the entire time, mostly in the program evaluation division, where I have helped design and manage the department's large research studies.

In that capacity, I really worked at the intersection of housing and health. During my time there HUD’s interest in health and using housing as a platform for health and improving the quality of people's lives has only grown. That's where I've done most of my work, especially at the intersection of health and housing and thinking about how to support older adults to age in their communities. But I have worked across a variety of projects, including most recently on a demonstration to help families with children access higher opportunity areas.

I have a bachelor's of science degree in psychology from Virginia Tech, and I earned my Ph.D. In neuroscience from Georgetown University. In that capacity, both as a research assistant and later as a Ph.D. Candidate, I've worked on a variety of cognitive neuroscience research studies, including some studies with children with autism. I'm really excited and humbled to be joining the committee and thinking about my previous research experience and looking at it through a new lens as part of HUD. Thank you very much.

DR. GORDON: Well, thank you, Dr. Lozier. Of course, we know how important housing is for members in the autism community, especially as they reach adulthood. And so, we appreciate HUD's continued participation. I want to thank Dr. Teresa Souza, the previous IACC member from the department for her past service to the committee. We also want to announce some members who have changed positions since our last meeting. Dr. Susan Rivera is now a Professor of Psychology and the Dean of the College of Behavioral and Social Sciences at the University of Maryland. Congratulations, Dr. Rivera. Dr. Jenny Mai Phan is now a Postdoctoral Fellow in the Center for Autism Spectrum Disorders at Children’s National Hospital right here in Washington D.C. Congratulations to you and actually to both of you on your new positions. If any members of the committee have similar announcements you'd like to share at future IACC meetings, please do alert Susan.

I would like to start off the meeting with a summary of what we're going to be doing today. We're looking forward to a variety of presentations. Some on services and some on the latest science. We're going to start the morning with a recognition of National Disability Employment Awareness Month from the Department of Labor and a presentation on Employment Focused Autism Research. We'll also continue working on one of our key assignments, the IACC Strategic Plan. I want to thank all of you for your work over the summer and for coming to the meeting that we held in July to do some focused work on the plan. There are some public comments about that work as well. We'll have an opportunity to discuss the plan during our work session, as well as during the public comments.

This afternoon we'll also be hearing other public comments and hearing presentations about autism and older adults, including the voices of scientists and individuals with lived experience. I'll turn it over now to SUSAN for opening remarks and for approval of the minutes from our last meeting, which took place in April. SUSAN.

DR. SUSAN DANIELS: Thank you Dr. Gordon. I also want to welcome everyone to this meeting today, and we have some exciting presentations on the agenda and are pleased to recognize National Disability Employment Awareness Month here at this meeting and looking forward to the presentations related to that. I also want to thank everyone who participated in the July Working Group Meeting for the strategic plan. It was a very productive meeting and I really appreciate everyone's engagement and some of the follow-up that you did afterward. We'll be talking about that in our committee business today. We will be talking about the strategic plan later.

If you were unable to attend or would like more information about that meeting, you can go to our website and there's some information there, and the videos, of course, are posted for anyone who's listening. Also, welcome to all of our listening audience today.

So, just a couple of housekeeping reminders, please keep your microphones off unless you're speaking and we ask you that you keep your cameras off during the presentations and breaks. Of course, if you are speaking, you're welcome to turn your camera on. If anyone is feeling Zoom fatigue or stress about being on camera, you don't need to be on camera. You can leave your camera off if you need to. If you are a committee member or federal alternate who would like to contribute a comment in writing during a discussion versus speaking orally and putting up your hand, you can raise your hand and we can call on you. Or you can send your comments to send comments here, which is, in Zoom, you will see that person listed. That is a staff member from our team, Steven

Isaacson, who will see any of the chats that you send through to him, and he will be able to read them out for you if you prefer that method of communicating during the discussion. Steven (send comments here), also can help with any technical issues and pass that on to the rest of the team that can help you if you're having any problems. I'd like the team also to know right now there are some people that were having trouble with the Zoom link. Please be aware of any kind of messages coming in from people that need help with Zoom.

Unless there are any questions about that, I will proceed with the approval of the minutes from the April 2022 meeting. The draft minutes are posted on our website and you had a little bit of a chance to look at them. I wanted to know if there are any comments, is there any discussion about the minutes that we posted.

We haven't heard anything in writing in terms of the minutes. But if there isn't any discussion of the minutes, can I get a motion on the floor to accept the minutes?

MS. JALYNN R. PRINCE: I move to accept the minutes.

DR. DANIELS: Thank you. A second?

MS. MYRICK: This is Yetta Myrick. I'll second.

DR. DANIELS: Thank you. All in favor of this, please raise your hand in the Zoom feature so our team can see. Okay. Thank you. You can put your hands down.

Is there anyone opposed? I think Jalynn, you had your hands still up. Is there anyone that is opposed to accepting these minutes as they were prepared?

Alison Marvin, are you opposed or are you for the oppose? No. I don't see anybody opposed. Is there anyone that just wants to abstain?

I believe then unanimously, we're accepting the minutes. It looks like the majority of the committee is in favor of them. Thank you very much. We accept the minutes and we will post the final version after this meeting. But the draft, which is basically the same as the final version, is already posted for anyone who wants to review what happened at the last meeting. Thank you so much and I'm turning it back over to Josh.

(Minutes Approved.)

DR. GORDON: Well, thank you, SUSAN. Thanks to the committee for accomplishing that one little piece of business we have to do before we get into some of the more entertaining and informative parts of our day. To start, I'm really pleased to welcome Ms. Anupa Geevarghese, the Chief of Staff for the Office of Disability Employment Policy at the U.S. Department of Labor. Ms. Geevarghese will be sharing a few words with us and recognition of National Disability Employment Awareness Month.

You're muted still. There you go.

MS. GEEVARGHESE: Thank you, Dr. Gordon and Dr. Daniels, and members of the Interagency Autism Coordinating Committee for inviting me to speak today. Good morning. My name is Anupa Iyer Geevarghese and I am the Chief of Staff with the Office of Disability Employment Policy. I am thrilled to be here on behalf of Assistant Secretary for Labor Disability Employment Policy, Taryn Williams, and to speak with all of you about National Disability Employment Awareness Month.

The Office of Disability Employment Policy, or ODEP, is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities. Our goals at ODEP are to improve access and opportunity and advance workforce inclusion for diverse people with disabilities through policy change, outreach, and technical assistance. We do this by partnering with a wide range of stakeholders, including the IACC. It is my great pleasure to speak about National Disability Employment Awareness Month and how we commemorate NDEAM through virtual and in-person events throughout the month of October.

We have actively celebrated the inclusion of people with disabilities in the workforce in October since Congress recognized the first week of October as National Employ the Physically Handicapped Week in 1945. This celebration expanded to promote the employment of all people in 1962. In 1988, it transformed into the month long celebration we are familiar with today. This year's NDEAM theme, which is behind me, is Disability: Part of the equity equation. It fits perfectly with the IACC's emphasis on supporting diversity, equity, inclusion, and accessibility, or DEIA, in its strategic plan and in improving quality of life.

This administration has demonstrated commitment to increasing accessibility for diverse job seekers and workers. When President Biden issued his executive order on diversity, equity, inclusion, and accessibility in the federal workforce, it was the first time disability was included in our broader DEIA efforts for the federal workforce. We have also, at the Department of Labor, prioritized our commitment to DEIA through our Good Jobs Initiative and our projects at ODEP, such as the Partnership on Inclusive Apprenticeship, or PIA.

Supporting neurodiversity at work is crucial to our goal to promote solutions for the equity equation and ensure diverse people with disabilities can fully access gainful employment opportunities and career pathways. Earlier this month, ODEP hosted an NDEAM Employer Chat on Workplace, Mental Health, and Wellbeing, which featured remarks by Labor Secretary, Marty Walsh, Thought Leaders from Industry, Advocacy, and Labor Movements, and Assistant Secretary Taryn Williams. We recognize that people who are neurodivergent, including youth and adults on the autism spectrum, can face major barriers to attain and maintain jobs that fit their interests, strengths, skills, and talents.

Many autistic people remain unemployed or underemployed and lack access to the needed support systems to help ensure workplace success. That's why recently, ODEP's Employer Assistance and Resource Network on Disability Inclusion, or EARN, or Technical Assistant Center for Employers, launched its redesigned guide to neurodiversity in the workplace. This toolkit includes information about organizational and employee benefits for neurodiversity at work, and approaches and practices for management, peer training, and mentoring. It also spotlights hiring and recruitment programs for neurodiversity at work in the federal government and across the industry. In addition, the Job Accommodation Network funded by ODEP also features information and resources on how to support workers with disabilities, including people who are neurodivergent.

Specialists at JAN are available to provide free, confidential, and expert guidance. As well, JAN has a fantastic A to Z guide on accommodations for people with disabilities. This morning, we're excited to share that you'll be hearing a presentation by Mathematica about its autism focused work, including an ODEP funded project on Research Support Services for Employment of Young Adults on the Autism Spectrum called REYAAS. We are thrilled by the ongoing work of the REYAAS project team to learn about how to improve access to job opportunities and careers for diverse youth and young adults on the autism spectrum. Assistant Secretary Williams and I encourage all of you to help us put the A for accessibility into DEIA. And help make disability a key component of the equity equation by hosting NDEAM events during the remainder of October and, of course, celebrating throughout the year.

We cannot have full inclusion in the workplace, unless we have accessibility. That's why we must highlight the need for workers with disabilities to access inclusive workplaces and receive workplace accommodations that we know can help drive jobs success.

Please make sure to visit our ODEP webpage for NDEAM to download the NDEAM posters in English and Spanish. Watch a short but fabulous video on NDEAM and find other NDEAM resources, such as a social media kit. Thank you for all the work that you do for supporting full inclusive access to employment opportunities for youth and adults with disabilities, including autistic people and happy NDEAM. Thank you.

DR. GORDON: Well, thank you very much for joining us today and for that message. We're going to build on that message now. It's really my pleasure to introduce the next set of presentations, which is going to focus on autism-related research at Mathematica, a company that provides software for mathematical solutions for a range of problems.

Our first speaker to introduce the

presentation will be Scott Robertson, Dr. Scott Robertson. A Senior Policy Advisor in the Office of Disability Employment Policy at the Department of Labor. He is an alternate member of the IACC and also an Autistic Self-Advocate.

Dr. Robertson will be providing the introduction for the presentation from our guest speakers from Mathematica, Dr. Ankita Patnaik, who is a Senior Researcher at Mathematica. Dr. Paul Shattuck, who is an expert in autism and adulthood, and who many of you may have known from his previous position at Drexel University as Director of their Life Course Outcomes Program, and who's now a senior fellow at Mathematica. Welcome to you all. Dr. Robertson, please get us started.

DR. SCOTT ROBERTSON: Great. Thank you Dr. Gordon for that great intro. I will just briefly be sharing a little bit more about the backgrounds of our presenters and why the Office of Disability Employment Policy, ODEP, while we have been making a major investment in that project on Research Support Services for Employment of Young Adults on the Autism Spectrum. For those who do not know me, I am a white autistic man with blue eyes, brown hair, and glasses, and I'm wearing a checkered shirt and a dark jacket. As Dr. Gordon mentioned, I am a Senior Policy Advisor in ODEP and a point for much of our work on supporting neurodiversity in the workplace. The ODEP poster for National Disability Employment Awareness Month is behind me as my virtual background today. I have that great honor today to introduce our next presentation from Mathematica, which will be co-presented. Hopefully, I don't do intros that often. I'm hoping that I don't mess up on names here. I've got pronunciation here in my talking points. Even though I work with you all, sometimes it's not my greatest strength in terms of pronouncing things right. I apologize if I make any mistake.

Here is Drs. Ankita Patnaik and Paul

Shattuck. This presentation will discuss the autism research at Mathematica, including, as was mentioned, our ODEP funded project on Research Support Services for Employment of Young Adults in the Autism Spectrum. I would like to share their backgrounds and why again we're making this investment in the REYAAS Project. Dr. Patnaik is a Senior Researcher at Mathematica and the Deputy Project Director for the REYAAS project. She has a Ph.D. in economics from Cornell University and a master's degree in economics from the University of Edinburgh. She has served as the impact study lead for the evaluation ODEPs retaining employment and talent after injuries/illness network, our RETAIN project. Among other roles, she has also served as the Evaluation Lead for the interagency Promoting Readiness of Minors in Supplemental Security Income Evaluation, or PROMISE Project. And DOL is one of the departments that has been a partner on that PROMISE Project.

Dr. Shattuck is a Senior Fellow at

Mathematica and an expert on autism in adulthood, including outcome measures and supports and services for employment and community living. He has a Ph.D. In social welfare from the University of Wisconsin Madison. His research focuses on measuring and improving the performance and equity of systems of care for vulnerable populations. He is a member of Mathematica's Equity Committee of Practice and he is also the former founding leader, as was mentioned earlier, of the AJ Drexel Autism Institute's Life Course Outcomes Program, the National Autism Data Center, and the Transition Pathways Community Partnership Initiative.

The REYAAS Project, which is part of the awesome research that they're going to be focusing on and their presentation coming up in a second, is a contract from ODEP to Mathematica, which was launched in FY 2021 as a collaboration between ODEP and Mathematica, and a historic investment for us as an agency at the request of Congress as indicated by prior priorities in appropriations language. This historic $2.1 million three-year project reflects a pioneering investment by ODEP to expand our knowledge about improving access to employment opportunities for diverse autistic youth and young adults.

It represents one of our largest projects ever for the focus on supporting neurodiversity at work in the 21-year history of the agency. Its findings offer a crucial opportunity to gain knowledge that can help shape our work to advance policies and practices in this space, to expand employment access for all autistic youth and young adults. Fostering the REYAAS Project at ODEP has emphasized our interest in learning about barriers, challenges, approaches, and strategies for employment success and career pathways.

We have prioritized learning about key gaps and disparities about youth and young adults on the autism spectrum, whose backgrounds can reflect diversity of race, ethnicity, gender, sexual orientation, socioeconomic status, and other aspects of diversity, equity, inclusion, and accessibility. Varied communication styles and needs, including any use of augmentative, alternative communication, or AAC systems and devices. Diversity of access and support needs, including for both employment supports and community and independent living, that may vary widely from extensive to less extensive and more moderate support for success in employment opportunities and community living. Crucially, these priorities for the investment in the REYAAS Project all align with our ongoing work at ODEP to drive support again for diversity, equity, inclusion, and accessibility, or DEIA work.

I would now like to turn the microphone over to my esteemed colleagues at Mathematica so they can share more about the research on autism, including the REYAAS Project. Thank you.

DR. PAUL SHATTUCK: There it goes. It's

working. Thank you so much for that kind introduction. It is a thrill to be here. I got to tell you, I'm looking at the roster of participants and this, it's like a who’s who of people who are dedicated and dedicated to making a difference in the world and dedicated to making a difference in the lives of autistic people and their families and communities. I'm thrilled to be here. It's an honor. I've presented to this body before. I want to do a special shout out. I see on the roster here, Marsha Mailick and other colleagues from the AUCD network, where I really got my start and my training 20 plus years ago. Marsha's mentorship and the mentorship I got from the AUCD network really prepared me for a lifetime of service in this arena. I'm so grateful to be able to be here and sharing our work with you all. Today, we're going to talk a little bit about who's Mathematica. I'll tell you a little bit about our background as a company, why I left academia to join Mathematica.

We're going to talk about the IACC's strategic goals and how we crosswalk some of the work that we're doing. Our growing portfolio of autism research to the strategic goals of IACC. Then I'm going to hand it over to my colleague Ankita, who's going to do a spotlight presentation on our ODEP funded project. Then we'll wrap up with a quick look ahead about where we're going next and have time for questions, because I'm here to hear from you all. Let's roll. Next slide, please. Thank you.

I'm not going to read this slide, but I'll highlight some of the takeaways. I left Academia a couple years ago to join Mathematica, which is a policy research company. Sorry, Dr. Gordon. There is another company called Mathematica that does mathematical software modeling, but that's a different company. We're a policy research company.

DR. GORDON: Sorry.

DR. SHATTUCK: Oh, that's okay. No, it's a common. It's a common mix up. We are an employee-owned company and so it's a really passionate community of very dedicated scientists who believe in building evidence to inform public policy so that public policies in the areas of education, human services, public health, are grounded in the best available evidence. It's an exciting team and it's a really exciting place to work. I decided to make the switch out of academia because I really wanted to direct my career in a way that would be emphasizing much larger scale programmatic impact. Mathematica as a company is often the go-to contractor of choice for government agencies that want to do extremely large scale national evaluation studies of big national programs, establishing national research priorities in essential areas. We had a lot of work in our portfolio during the public health emergency related to contact tracing and leading edge work on COVID and how it was making its way through vulnerable safety net populations like the Medicaid population. It's an exciting place to work and we're all about making an impact on public policy and improving the lives of citizens through rigorous research.

We're part of an ecosystem of private companies that do this kind of research. I think our employee ownership is a signature feature that distinguishes us. Another distinguishing feature that attracted me to Mathematica is that, for many years, it has had a disability unit. There, we have a couple dozen or more research scientists at Mathematica that focus exclusively on disability research and disability policy and work that informs new disability policies, as well as evaluates large scale national programs. We do a lot of work with the Social Security Administration, with NIDILRR, and other agencies that focus on disability, and so to the opportunity to join our dream team of really smart people who are passionate about improving public services and public programs for people with disabilities was a chance that I jumped at. Next slide, please.

I'm going to connect, as you all know, because [laughs] you created the strategic plan. The strategic plan is divided into these different focal areas organized by questions. A lot of our work serve clusters under Question 6, which is, how can we meet the needs of people with ASD as they progress into and through adulthood? Much of our work can also be clustered under Question 5, which is, what kinds of services and supports are needed to maximize quality of life for people on the autism spectrum? Some of our recent autism research, we had a couple other projects. These are the big flagship ones that are in play right now. The REYAAS Project funded by ODEP, which we'll be getting into in a moment.

The Promoting Readiness of Minors with Autism Spectrum Disorder is something I'll briefly go over. It's a Social Security

Administration funded project that was pretty exciting. Our NextGen Project, which is focused on enhanced employment strategies, is in play right now. We have several sites around the country. It's a large scale demonstration and evaluation research project that includes a site that's focused on autism. Then our HRSA Autism Transitions Research Project, which we just got refunded for another five-year cycle. That was a project that I was PI on, when I was at Drexel. I remain in close contact and work under a subcontract with my former colleagues at Drexel. We submitted a renewal recompete, which I'm thrilled to say got a perfect score. We got refunded for another five years of HRSA work focused on autism transition. I'll talk very briefly about that. Next slide, please.

The PROMISE evaluation was a really exciting opportunity that was made possible by a contract with Autism Speaks. We had a very large scale study that was funded originally by the Social Security Administration to evaluate this SSA Initiative called the PROMISE Initiative. It just happened to include a bunch of autistic people in the data, but the SSA contract did not pay us to drill down and examine the unique experience of people on the autism spectrum. But we had the data. Autism Speaks, in their wisdom, was willing to invest in time it would take to do the analyses and write up a report, which is available on our website. In this demonstration project, transition services were provided to over 12,000 adolescents with disabilities who were receiving SSI, Supplemental Security Income. About 13 percent of that number were autistic. We drilled into the data to look at the unique experience of that subset of people. What we found was [clears throat] that the promise participation in the Promise program -- sorry, it's a triple P. It's a tongue twister. Participation in the PROMISE Program nearly doubled the share of autistic youth who held paid jobs during the following 18 months after the intervention. We're in the midst of a five-year impact follow-up study. We're excited to see if those effects hold over time, because we know right here in this room, we know that the challenges, they're two really quite distinct challenges. Getting a job and keeping a job are two different things, and many autistic people struggled with both. Any line of work on employment in autism really needs to be longitudinal in its design.

I'm so grateful again to MARSHA and my colleagues in the AUCD network, who schooled me on the importance of longitudinal cohort research methods because autism is a journey. It's not a state. People on the autism spectrum like everyone else grow, develop, learn, change, and evolve through their life courses. Research on things like employment really need to be longitudinal in nature in order to capture the unfolding trajectory and journey of how these things play out over time. Next slide, please.

Our NextGen Project is funded by the Administration for Children and Families.

It's a tough one to characterize because the NextGen by design, the NextGen initiative, it manifests somewhat the model benefits a little bit differently site by site. But, for example, we have a Bridges from School to Work Program that provides intensive employment related supports to students who are in high school special ed, who have intellectual and developmental disabilities that creates these supportive services as youth are transitioning out of high school.

We do have one site that's based in Philadelphia that includes a large contingent of autistic youth in the study. That's underway right now, and we'll be excited to share findings from that study as they emerge in the coming years. There's an implementation assessment, a cost study, as well as an impact assessment. In our experience doing large scale evaluations, it's important to understand all these features of an intervention. Not just like got the punchline of like, was there an effect size on the target population? But what were the implementation issues? If you wanted to scale this and roll out more widely, what were the challenges with implementation that would have to be addressed by others who would hope to replicate that work? What are the ways we might overcome those implementation challenges? How much does it cost?

I think something that is often, I would say, underdressed and underconceptualized in a lot of intervention research is, how much will this cost and who's going to pay for it and who's in the long run? How will we sustain the financing of new interventions that are developed with research funds? We tend to obsess on that question here at Mathematica and it's something we're really good at. It's another reason why it was exciting to join the team here. We have a number of leading economists in the disability area and the human services area who are just experts at thinking about these issues of cost, financial sustainability, and financial feasibility. Then, of course, impact analysis. Did the program have an effect? Did it work? Did it have the intended effect? How big was the effect size? Of course, these questions are always of interest as well. Next slide, please.

The HRSA Autism Transitions Research Project is a multifaceted project that's funded through the Maternal and Child Health Bureau. The key feature really revolves around the National Autism Data Center that I built when I was at Drexel with my colleagues, Jessica Rast and Anne Roux and Kristy Anderson. In the first five years of that funded project, it was a juggernaut. We produced a lot of work. We've got over 35 publications and a bunch more in the pipeline. We had a very strong emphasis on training the next generation of applied public health researchers. We had 75 unique authors across those publications because we were really always trying to include trainees and doctoral students.

Again, that was something I learned at the Waisman Center as a trainee, was the importance of involving the next generation in leadership roles and conducting research, design, analysis and publication, and grant writing, to build that pipeline of talent to move forward in the future. We covered a lot of different topics in the first five years, ranging from understanding the nature of service ecosystems and the nature of collaboration among service providers. Looking at health outcomes, equity issues, we had a number of papers focused on employment. Some policy papers focused on the impact of the rollout of the WIRA in 2016.

Mental health. Mental health is still an understudied area. It's one of those topics that we all know makes a difference for autistic adults and all these domains of friendship and community living and employment. But it's still a fairly underconceptualized and understudied realm of adult experience on the spectrum. Then I think one of the things I'm most proud about is, I had some colleagues, some trainees, who really ran with the ball and pioneered a series of publications on financial hardship and social safety net participation.

Again, it's an area of inquiry that hasn't received a lot of attention in the world of autism. But we found that almost half of autistic teens in the United States live in extremely poor, low-income households. Just over one in four autistic teens are living in households at or below the poverty level, which is the rate that's much higher than the average population. Anyway, I'm not going to get into that, but I would love to talk to folks about that because that is my soapbox.

We do acknowledge here at Mathematica

that the experience of having a disability often intersects in this multiplicative way with other dimensions of disadvantage, including poverty and exclusion based on other identities. We have a second year of five-year funding that just began, and we're excited to pioneer some really new and exciting lines of research, including developing transition intervention for Latinx and Hispanic youth and partnership with our wonderful colleague in Arizona.

I'd like to move on now to the next slide and introduce my colleague, Ankita Patnaik, who will do a presentation about our ODEP work. Before Ankita takes the mic, I just want to say thank you to the Department of Labor. I want to say what a thrill it is to see the pool of federal agencies that are investing in pioneering autism research. That pool is diversifying. We've got SSA. We've got ODEP. This investment, in particular, it's a pioneering investment to have a federal agency that's outside the usual realm of research subjects to come in and invest in the topic of employment in autism. It's a big move and it's a very large investment and it's a remarkable project. I just want to thank the leadership and the vision of our colleagues at ODEP for taking this bold step to support this kind of research. ANKITA, take it away.

DR. ANKITA PATNAIK: Thanks very much, Paul. Hi, everyone. I'd like to start off by just seconding everything Paul said. We're so grateful to ODEP for this incredible opportunity and this pioneering investment on this topic. As Scott mentioned, the REYAAS Project began about one year ago, and we have three more years to go. I'm very excited to be sharing some findings today from what we've learned during the first year of project activities, as well as providing an overview of the goals of the project and previewing some of what we have planned and what is in the works for the years to come. With that, I will kick off an introduction to this project, which as you've heard a few people say, is nicknamed the REYAAS Project that stands for Research Support Services for Employment of Young Adults on the Autism Spectrum. The project is funded by the U.S. Department of Labor. I'd like to also give a shout-out to PAUL. He's the principal investigator on this project. I am the project director and it's been a really wonderful partnership with PAUL and of course, an incredible learning opportunity for me as well. Next slide, please.

All right. The REYAAS Project is really well connected to Question 6 in the IACC Strategic Plan, which is about supporting the needs of people on the autism spectrum as they progress into adulthood. The goals of this project are some big ones. It really seeks to understand the barriers and facilitators that are in play as young adults on the autism spectrum are transitioning from school to work. The objective is really to identify specific programs, policies, approaches, or practices that have been shown to work in facilitating employment for this population. We also want to take stock of what the research literature has to say. What do we know from rigorous evidence has worked so far and what are the gaps in our knowledge and in our evidence? As a result of that taking stock and identification of gaps, we are working with ODEP to suggest new evidence building activities and opportunities to produce more knowledge, more rigorous evidence, on what can work to support young adults on the autism spectrum who are seeking employment. Next slide, please. To achieve these goals, REYAAS has several different project activities. The first set of activities is really focused on knowledge development.

As I mentioned, we conducted two large literature reviews, which I will summarize in a few minutes, in order to understand what the research literature has to say on programs that exist, that aim to support employment outcomes for young autistic adults, as well as what we know about the effectiveness of these programs. We also very excitingly held listening sessions with key players in this space. Most important of which, of course, are young adults on the autism spectrum themselves. We held public listening sessions that invited young adults and their family members to come talk to us and tell us about their employment experiences, what their goals are, what their perceived challenges and ideas are for how we can support their transition from school to work. We also hold continuous discussions with a technical working group, which comprises external experts outside of Mathematica, who may have expertise and advocacy in this space, research in this space, or our federal policy makers. We are conducting analyses of existing data, so what administrative and survey data do exist on this topic, we have created an inventory of these data sources and we have selected a data source to dive into to get at some really interesting research questions. I will cover that in a moment. In partnership with ODEP, we are also developing options and recommendations for evaluation designs. This is an activity where we are suggesting new evidence building activities that would occur outside of the REYAAS Project. This is for the future including the possibility of demonstration projects. An optional task under REYAAS is to conduct surveys of young adults and stakeholders in the space, which include employers and advocates, for example. The goal of that activity would be to create a whole new data source that contains the necessary information to really dig into this topic.

This would be a survey data set if the task is exercised. This would be a survey data set that would not only be analyzed by Mathematica itself, but would be a contribution to the research field, as it would likely be available to other researchers in some form as well. Finally, of course, we don't want to be conducting our research in isolation. It's only useful if it's spreading the word and informing both research and policy priorities, and so disseminating the findings and the insights that we glean from our knowledge building and evidence building activities, is a very important part of this project as well. Next slide, please.

As I mentioned, we conducted a literature search that had two goals. The first was to identify and summarize the range of programs, models, and strategies, that are being used to support the employment for young people with developmental disabilities, including young autistic people. The second goal was to examine the evidence on these programs. From goal 1, we know what exists out there, what is being done out there. But the second goal is to really understand whether these programs and practices are effective in helping young autistic people get employment and keep employment. Next slide, please. We conducted a literature search that looked at published research literature, as well as pre literature by related organizations. We identified a wide range of about 140 programs in the United States that have the goal of supporting employment outcomes of young adults with deveopmental disabilities, including young autistic adults. More than half of these 140 or so programs exclusively serve young adults on the autism spectrum.

In this graph, you see an illustration of the different types of strategies that are being used by these programs to support employment. Many of these programs include components, such as soft skills training. as one of the most common strategies that's being used. Coaching or mentoring, job search assistance, job development, and job training, those are three of the most commonly used strategies in the programs that we've found. But of course, many of the programs combine multiple components. Some of these programs focus on transition planning support for high school students as well. I want to focus on one type of strategy in particular, and that is work experience.

More generally, from the research literature, we have found that work experience is considered an evidence-based practice to support the transition from school to work for young people with disabilities. Of the 140 or so programs that we found, about four in every 10 of those programs included work experience as a component.

As I mentioned, many of these approaches combined several strategies. For example, programs might combine work experience with another support, such as soft skills, such as providing young people with soft skills experience, soft skills training before offering them a work experience opportunity. We found that more than half of the programs generally provided work experiences, but only about a quarter of the programs that only serve young autistic adults provided work experiences. We did find that very few of the programs focused on mental health supports on occupational training, or on services that addressed the employer side of things. Programs that aimed to help employer's ability to hire and support young autistic people or young people with intellectual or developmental disabilities while they were on the job.

We also found that many of the programs are pilot programs. They are resource-intensive which makes it challenging to replicate them more broadly, or scale them. Others faced challenges recruiting youth while they were in high school or establishing relationships with schools or employers that might be able to help either with recruitment or job placements. Next slide, please. Of those 140 or so programs, 62 studies existed that provided evidence on whether or not these programs, strategies, practices, and strategies were or were not effective. 17 of those 62 effectiveness studies focused specifically on employment outcomes. We found that in general we don’t know a lot about the effectiveness of these strategies. So of the many programs that we had found, there were only six rigorous studies that could provide strong evidence on whether or not these programs and strategies were effectively helping young adults improve their employment outcomes. We defined rigorous evaluations as either randomized controlled trials or quasi experimental designs. I'll quickly recap what those mean. A randomized controlled trial is generally where you enroll a large number of young adults and you randomly assign some of them to a treatment group, wherein they get the intervention, which means they can participate in the program or the strategy or the approach. The others are randomly assigned to a control group, where they typically cannot access the program or at least cannot access the program for a certain period of time, such as a waitlist.

In a quasi-experimental design, there's no random assignment of people. However, you do compare people who are similar in their baseline characteristics before they get an intervention, and only some subset of the participants in the study get the intervention. When you compare their outcomes, you can reasonably attribute any differences in their outcomes to being the causal result of the intervention that they received.

We found three randomized control trials that had been conducted of a program known as Project SEARCH plus ASD Supports. I imagine that many of the people on this call are familiar with that model. It is a variation of the Project SEARCH model that has been adapted specifically for young people on the autism spectrum. It's a transition-based employment model for high school students. Those showed promising results with more people who participated in Project SEARCH, having employment at the end of the observation period than the control group that was not participating in Project SEARCH plus ASD.

We also identified two randomized control trials of a virtual interview training program, which showed that the participants were more likely to secure competitive integrated employment at higher rates, compared to the control group. Lastly, we found one quasi experimental study. The program that was being examined was adding supported employment services to vocational rehabilitation clients’ experiences. We found that it did increase the share of clients who attained competitive integrated employment. Next slide, please.

As I mentioned, we conducted these listening sessions as part of our knowledge development activities. The listening sessions were held with a range of key players in this space. As I mentioned, we held listening sessions with young adults on the autism spectrum as well as their family members. We held about four of these sessions in Spring 2022. All across the sessions, about 100 young adults on the autism spectrum joined us and shared their viewpoints. Participation was, of course, voluntary. It was optionally anonymous. Folks were free to join us on video, if they wished, on audio only. They could participate just by chat on our Zoom box. They were also free to just submit written comments via email.

We heard some really interesting perspectives from the young adults on the autism spectrum. It was very valuable to hear from them in their own voices. I would like to share just a couple of the things that we heard from them today. One young adult said, "I feel like I face additional challenges related to my position in my society, because not everybody knows how to communicate with me and I cannot get what I need."

Another young adult said, "I've worked

with some programs that have really helped me gain courage while in the job market." Another said, "People with autism are also able to make good managers and leaders, as long as you accept yourself, surround yourself with a good supportive system, and keep going towards your dreams." Finally, a fourth quote I'd like to share. One young adult told us, "I enjoy working with others who are neurodivergent, because I would never be as confident or successful if it wasn't for older neurodivergent workers who took me under their wing and showed me it was possible." I’ll note that while these quotes are from the young adults on the autism spectrum, we also had listening sessions with professionals who work with them or who work on this topic.

We held five sessions around the same time. In spring 2022, we spoke with advocates, with federal and state policy makers, with service providers, educators, and researchers. We tried to get a broad swath of people from across the United States. I will mention that these listening sessions were incredibly informative and I think so great to have the participation of others than just researchers on this topic to inform the rest of our project activities. I will note that it's still a small number of people. In total, we had about less than 200 people participating in these listening sessions. Naturally, we identify and what we heard might not be representative of all young adults on the autism spectrum, nor all the stakeholders in this space. Next slide, please. Looking across all of the input that we received from young adults, as well as stakeholders, we identified a couple of themes in what we heard. We identified some things that were mentioned as barriers to employment and some things that were mentioned as facilitators to employment. They're on the screen now, but I will go through them as well. Young adults often mention challenges in job search and finding a good work environment. They also mention biases in typical recruitment and interview processes.

For example, some mentioned that a typical interview process might, for example, reward candidates for being very expressive for answering questions on this spot and might have behavioral interviewing processes that might disadvantage young adults on the autism spectrum who are very qualified for the job. They encouraged more inclusive recruitment hiring and work environments that would be more focused on the ability to complete the task at hand rather than behavioral interviewing, for example. Stakeholders, as well as young adults, mentioned a need for greater and more enhanced supports and services. As just one example, addressing transportation barriers that people might have in getting to and from a service provider or getting to and from work. They also mentioned a need for more self-advocacy and career advancement training. Not only focused on how to get a job, but how to progress in one's career as well. Very resonant with what we found in the literature review, many stakeholders mentioned challenges with generalizing and scaling services beyond a single community-based pilot program. We also heard many positives about facilitators to employment. Young adults and their family members often talked about encouragement and advice from their support network that might include family, friends, staff from job readiness programs, and how helpful that encouragement and advice was to help them keep going on their employment journey.

Paid internships, career mentoring programs, and customized employment were all perceived as very helpful by both young adults and stakeholders in this space. I mentioned already the cultural shifts and training for employers in order to help build and maintain more inclusive work environments and hiring practices. There are facilitators to employment, that in terms of more collaboration and the funding for the needed supports, one suggestion was partnering with neurodivergent consultants or career coaches with disabilities, which really resonates with the quote that I mentioned earlier about having the role models and mentorship from other neurodivergent senior folks. Coordination with more large and established programs was also mentioned as a facilitator to employment. Next slide, please.

Let's switch now to talking about data. One of the exercises that I personally found to be very useful as part of the REYAAS Project was conducting this scan and inventory of existing data. ODEP wanted to know what data sources exist to support research on this topic. The motivation for this is self-evident in some ways. Quality data are crucial for us to rigorously understand what the needs, barriers, and facilitators for employment are for young autistic people, and to build more evidence on what can help support these outcomes. To support this goal, we scanned existing survey and administrative data sources to identify a subset of sources that met certain eligibility criteria. The data source had to include young adults in the age range that we're focused on, so 16-28, as this is the crucial time of transitioning to employment. It had to contain information that would allow us to identify individuals on the autism spectrum, and it had to contain employment related measures. Next slide, please.

We identified 11 such data sources. This data inventory is online, and I will post a link to it in the chat in a minute. As I mentioned, 11 different data sources and they have each different strengths and limitations. In our data inventory document, we provide more details on things like the universe of people who are captured in this data set, the sample sizes that you can expect, how you can access these data, et cetera. I won't go into the details of each and every data source, but I will provide an overview of what we've learned, looking across these 11 data sources.

One thing we noticed was that, unfortunately, many of these data sources have small sample sizes of people on the autism spectrum. That's because there was no single data source that focused entirely on young adults in the autism spectrum. It was always a subset of the folks who are captured in the dataset. There were a few exceptions, of course. They tended to be larger and administrative data sets. As just one example, Social Security Administration’s benefit data would contain information on everyone who receives Supplemental Security Income, SSI. Or Social Security Disability Insurance, SSDI. But, of course, people who receive such benefits are a subset of all young adults on the autism spectrum.

These data sets are typically not representative of all autistic people. As just one example, if you had access to the SSI benefits file. SSI is a means tested benefit that is focused on people with low incomes, and so you would not be capturing the full socioeconomic distribution of young autistic people. I'll also note that access to many of these data sets is restricted. Several of them were administrative data sets from government agencies that you would need special privileges to be able to access and other data sets at a minimum would require an application and a vetting procedure in order to get to. Most of these data sets also contained limited employment information. They would often have an indicator for whether or not someone was employed. They might contain information on earnings or hours worked. But they rarely contained more nuanced information about the employment experience.

As an example, they rarely contained information on things like the occupation in which someone worked, the industry in which they worked, job quality measures, for example. Do they have access to health insurance through their employer? Do they have access to paid sick leave? Those kinds of information are typically not available. There's also little information on employer accommodations or what support needs are either helping people with employment or are unmet support needs, that people perceive would be able to help them with employment. But these data sets do often contain other information that's relevant to employment. For example, they might contain health measures, which of course, influences employment opportunities and constraints. They also often typically contain demographic information, which would allow researchers to conduct, as an example, a subgroup analysis or a deeper dive into disparities in employment outcomes or experiences.

Having said that, looking across these data sets, there really was no one data source that was even close to ideal for diving into a representative rigorous study of employment experiences and outcomes. There is a need for more large sample representative data on young adults on the autism spectrum that's really focused on employment as a domain. Next slide, please. We did pick from among these 11 data sources, one data set to get access to and to dive into to answer some research questions. That data source was from the Rehabilitation Services Administration. This is the RSA-911 data set that some of you all may be familiar with, essentially contains case service reports on people who are engaged with vocational rehabilitation (VR) agencies.

These are population data. They cover all 78 VR agencies in the United States, and they contain all VR applicants. It's a pretty large sample size of young people on the autism spectrum. For example, between 2017 and 2019, we found about a little over 170,000 young people on the autism spectrum had applied to VR. The data are pretty recent. They're annual files, so they're released every year. Data as recent as, I believe, 2021, are now available.

These data are relatively straightforward to access. You do have to submit an application and get vetted, but more straightforward than some other administrative data sources in our inventory. The sample that we are focused on is young adults who applied for VR services. We are focused, as I mentioned, on the age group of 16-28 at the time that they applied for VR. In order to identify autistic young adults, we focused on the source of primary or secondary impairment that is recorded in VR case records. Next slide, please.

These analyses are currently underway. Unfortunately, I can't share findings, but I will walk us through the research questions that we are examining. The first thing we wanted to understand is the pipeline into VR for young people on the autism spectrum.

We're looking at, what are the common sources of referral to VR for young adults on the autism spectrum?

We wanted to understand, for example, what is the role that schools are playing as opposed to perhaps service providers, family and friends, people applying by themselves, DOL Programs, et cetera. We wanted to understand what other agencies and connections are really important for connecting young people to VR Agencies.

We also wanted to understand who is applying to VR Agencies. What are the characteristics of the young adults on the autism spectrum who apply to VR? At the time that the VR Counselor develops something called an individualized plan for employment, which is something like a service plan. The VR Counselor often notes commonly identified barriers to employment. For example, whether someone is an English language learner, might be something that's recorded in their case file.

We also wanted to understand, what are some of the common barriers to employment that we see for young VR applicants on the autism spectrum? Then we wanted to understand their journey through the VR system. We're interested in the types of VR services that young adults on the autism spectrum are using once they enter the VR agencies. We also wanted to understand what the outcomes of these VR services are. We are looking into the shares of young adults who exit VR with employment and what types of employment outcomes they might have. For example, whether it is competitive integrated employment or supported employment, et cetera.

We wanted to understand variation in these experiences and outcomes. We are going to be looking at how patterns play out in these referrals, characteristics, and outcomes, in terms of variation across states, so geographic variation, as well as comparing young adults on the autism spectrum to other young VR clients, including clients with intellectual disability and all other young VR clients with disability. We also wanted to understand variation within autistic young adults.

We will be looking at patterns as they vary across age. Younger clients, perhaps those who apply when they're 18-20 versus 20-28. Variation in sex, so males versus females and variation by race or ethnicity. Finally, we're conducting some very exploratory analyses to look into how the COVID-19 pandemic might have changed things. We're looking to see whether the patterns in VR applications, the number of youth that go from applying to VR to actually receiving services, and the share that exit with employment, might differ in the period before the pandemic versus during the pandemic in 2020. Next slide, please. As I mentioned, those analyses are currently underway. The report from that analysis will be available in early 2023. I hope you all will look out for that. With that, I will turn things back to PAUL.

DR. SHATTUCK: Thank you, Ankita. We've just got two quick slides left and wrap up. We've touched on a few of these. I don't want to belabor this slide, but two points bear repeating here. In the world of services research and policy research on autism to date, there's very inconsistent and infrequent attention to issues of equity and the life course perspective. Again, this life course perspective, which is so prominent in developmental research and what I trained in at the Waisman Center and what so many of you have pioneered really in your developmental research on autism. But that life course perspective is still not well integrated into applied work on policy and program impact analysis.

That's something that we're eager to champion, is how to really integrate and unify a life course developmental perspective with an intervention and policy research perspective. Then there remains lack of acknowledgement and understanding and really a methodological approach for understanding the complexity of the service ecosystem experience that many autistic people and their families have to navigate. Autism hardly ever comes by itself that most people on the spectrum also have other stuff going on. Mental health issues, physical health issues, learning challenges. Many people, or most people really on the spectrum, are simultaneously trying to navigate engagement with different service ecosystems, different sectors, education, healthcare, mental healthcare, employment, housing, the list goes on. We still don't have a really great methodological toolkit or conceptual framework for making useful and insightful conclusions about the complex nature of that journey. That's another area that we're eager to contribute to in our work here at Mathematica.

Then another gap that we're trying to

step into right now is that the field of autism research has thus far been slow to respond to things like the COVID public health emergency and the growing risks of things like climate change. We have some seed money that we're using to delve into both those topics right now using Medicaid data. We're going to be charting and publishing a report on how the pandemic made its way through the Medicaid population of folks on the autism spectrum with both children and adults in terms of health conditions, health services patterns, that kind of thing. Then we're also beginning to prepare the data for linking to climate risk data like wildfire data and heat wave data to understand how climate change is showing up as a risk for health and development among adults on the spectrum. Next slide, please. Last slide.

Looking ahead, we really want to be pioneering and leading on this integration of things that are often treated separately. Equity, the life course perspective, the social determinants of health perspective, and the applied research and policy and program evaluation perspective. As we move forward with building this program, we're super eager. We're a highly collaborative work setting and we collaborate all the time with academic partners and foundation partners with other companies and government agencies as well. Just know that we're eager to collaborate. We're really passionate about this work and expanding the work here at Mathematica. We have a tremendous infrastructure that often compliments the strengths that many university investigators have with our capacity for large scale research of big questions and big programs that are really across a national and international scale.

Another thing that we're quite passionate about, oftentimes, research on employment and interventions in the autism space focus on developing a new approach or a new program model, which is awesome. We need more of that. That's great. But another complimentary perspective is, how do we take - Because the challenge, when you're developing a new program or a new intervention model, let's say, it works, then you're like, "Oh, gosh, how are we going to scale this? Who's going to pay for it? Where will it be implemented? Who would implement it?" A lot of those scaling questions are often under conceptualized at the outset of intervention research. We're also like trying to tackle this challenge from the other direction, which is saying, well, we have infrastructure that's already at scale. How can we make infrastructure and programs that are already at scale more successful at including and helping autistic people?

For example, we have social safety net programs, which are vital. They're a lifeline for people on the autism spectrum and their families. Employment programs like Job Corps and American Job Centers, which are already at scale, serving tens of thousands of youth, how can we make them more successful at including autistic adults? I'm going to conclude there and thank you all so much for your time this morning, and it's really a treat to be here. I think we have time for a couple of questions.

DR. GORDON: Well, thank you very much, Dr. Shattuck and Dr. Patnaik. We have just a few moments for questions or comments from members of the committee. I'll ask you either to send them to send comments here. I have two hands raised already. Probably that's all we'll get to. But if you'd like to try to talk after that, please raise your hand. We're going to start with Yetta Myrick. Then it'll be Dena Gassner. Yetta.

MS. MYRICK: Thank you for your presentation and all your work. Had so many questions, but you've answered some of them. That's good. I won't waste a lot of time. Could you speak about how diverse the participants were in your listening session? Because you mentioned the equity piece and making sure that these programs are accessible to different groups of people. Could you speak to that? Then also you noted about how you were looking at the VR programs, but I wonder if there is any thought about looking at the pre-employment transition services, which are precursor to VR services, and investigating that to see what access looks like. I was just curious to know if you are planning on investigating that as well. Thank you.

DR. GORDON: Ankita, can you handle these ones?

DR. PATNAIK: Yes. Happy too. Can you all hear me okay? Yes.

MS. MYRICK: Yes.

DR. PATNAIK: Great. Yeah. That's a great question about the listening session participants. We made a very concerted effort to try to cast a wide net to enroll people. Especially for the stakeholder listening sessions, we were very intentional about, for example, capturing people at universities in different parts of the United States, service providers from different states, et cetera. Of course, impossible to be representative, unless you have a very large sample of things.

For the public listening sessions, we also cast a wide net. We essentially put an open call. Used Twitter, social media, Instagram. Also used our networks to try to spread the word using a snowballing approach, et cetera. We did not systematically collect information on race and ethnicity. It was optional because we did not want to make it a requirement that would disincentivize people from participating, for example. I can certainly check with DOL about sharing some of the information that we do have. But I’ll caveat, it didn't capture everybody who participated because we didn't want to scare anyone off from participating by making it a data requirement.

MS. MYRICK: I get that. Thank you. Then to my second question about --

DR. GORDON: Sorry. Yetta, I'm going to ask that we move on to Dena.

MS. MYRICK: Okay.

DR. GORDON: Just so if we have time, we'll circle back to you, right?

MS. MYRICK: Okay. Thank you.

DR. GORDON: Dena.

DENA GASSNER: Hi, folks. Thank you so much for all of your work. If I'm only going to get one question, I'm going to ask one thing. I'm going to ask, first, can we get all your citations. But secondly, I'm going to say that, while I appreciate all of this, I am gravely concerned that we have an entire community of workforce-ready individuals who have experienced repeated employment failures due to not even having a diagnosis available to them that we are not talking about today. We're talking about young adults, and I have one of those. I feel that Voc Rehab is really not prepared to help middle functioning people find employment.

Everything is either task-driven or very labor-driven work. There's nothing in the middle. There's no phlebotomy jobs, if you will. They don't have the ability to make that happen where we've been, and we've been in five different states. But I'm very concerned that we're not investigating people between the ages of 30 and 60 who would really like to be in the workplace and have just never had a real meaningful opportunity. What are we going to do about them, if you don't mind? Thank you.

DR. SHATTUCK: Well, in 10 words or less [laughs] that's a big question, Dena. Thank you. As always, I love your provocative thought process and advocacy for asking the big questions. I can't really address that question in the minute that I've got here. But I would love to take this conversation offline with you and get your thoughts on like how we can infuse some of that thinking into our work here at Mathematica.

MS. GASSNER: Much appreciate it. Thank you, Paul.

DR. SHATTUCK: Sure.

DR. GORDON: Thanks. Then Steven has a comment that was put into the text. Then we'll end this portion of the meeting. Go ahead, Steven.

MR. STEVEN ISAACSON: Hi there. This is Steven. I have a comment from Lindsey Nebeker. She says, thank you for your presentation. In regards to the young adults on the autism spectrum who were captured in the data inventory you collected, are you able to provide more information on the demographics of support needs? Are you able to provide an approximate percentage of participants who are non-speaking, require a support coach or job coach, or participants with high support needs? Are there any strategies you have in place to capture more representation of autistic young adults with complex support needs in your research efforts in relation to employment barriers, recruitment, and outcomes?

DR. PATNAIK: That's a really good

question. I can take that, Paul. Yeah. I would be delighted to share the data inventory with all of you. I'll put it in the chat in a few minutes. There is not a lot of information out there on the support needs of young autistic adults. As I mentioned, none of the data sources are focused on autism. The types of questions that they ask on a survey, for example, aren't really focused on autism. The administrative data sets don't capture information, for example, that could identify someone who is minimally verbal or nonverbal either. That is definitely a gap in the data that exists.

I'll note here, I mentioned at the top of my presentation that there are surveys that Mathematica might be conducting of young adults on the autism spectrum. That is very much on our radar as an element that we should be capturing. It's very hard to address any question. Just given the nature of autism, it would be a disservice to collect new information without really capturing the spectrum of support needs that people have. Unfortunately, that doesn't exist in the existing data systematically. But should we be collecting new data under surveys, that is definitely something we'll be paying attention to.

DR. GORDON: Thank you very much, Drs. Patnaik and Shattuck, for your presentations today for the ongoing research that's so important. You heard how there's a hunger not just in terms of what you're already doing, but in expanding research into the roles and mechanisms of improving employment in individuals with autism. Thanks for coming to us and telling us what you are doing. That gives us food for thought as we move forward. I apologize to Yetta and other members of the committee who might have liked to add additional questions, but we are running a bit over.

We're going to take a break now. We're going to take a 10-minute break. We'll be back at 11:35, and for the next segment of our meeting today. Committee members are welcome to turn off their videos. Please stay on the Zoom so that we don't have any trouble getting back in for technical reasons. We'll see you all in 10 minutes.

[Whereupon, the Subcommittee members took a brief break starting 11:25 a.m. and reconvening at 11:35 a.m.]

DR. GORDON: Good morning again. Welcome back. It is 11:35, and we're going to get started. Susan, you're going to give us the National Autism Coordinator update. As I mentioned earlier, Dr. Daniels is the Acting HHS National Autism Coordinator. Susan, take us away.

DR. DANIELS: Thank you. Yes, I will be taking you through an update about activities going on around the federal government and across the broader community just to get us all on the same page. I'm going to share a few non-governmental updates, although I will have to say that some of a couple of these are funded by federal sources, and I will share that with you.

First, I wanted to mention that there's been a launch of a new podcast called The Black Feathers Podcast. This has been funded by ACL through the UCEDD Program and the State of the States in Intellectual and Developmental Disabilities Projects of National Significance. This podcast has co-host, Crystal Hernandez, who is a mother of a child on the autism spectrum and a person who practices as a psychologist, and Shauna Humphreys.

They discuss disability related topics of interest to tribal communities through data, storytelling, and innovative content. This podcast embraces diversity, equity, and honors within tribal nations. We would encourage you to check it out or pass it along to people who may be interested. Also wanted to mention that the Autism Science Foundation has now launched a Novel Participate in Research Website Directory to help people in the autism community identify studies that they might like to participate in. We've provided here the information about that. It's on their website and there's a link in this slide set that will be posted after the meeting.

I also wanted to bring your attention to a meeting that happened over the summer that was sponsored by Autism Speaks. Their Thought Leadership Summit on Autism and Aging, which relates to some of the content we're going to talk about in the afternoon.

In June, Autism Speaks hosted this summit, bringing together families, autistic adults, researchers, and policy makers, to discuss issues facing autistic adults as they age. This was an interesting meeting. We have a photo here of Chris Smith, our Congressman, who spoke at the meeting. We'd encourage you to check it out. The link is provided here and it's on their website too, if you'd like to watch that meeting.

Just yesterday, the Stanford Neurodiversity Summit ended, but I wanted to bring that to your attention to those who might be interested in this Neurodiversity Summit. It was available for a nominal fee. I know that they're going to be posting the videos online. I'm not sure if you have to pay the nominal fee to see the videos or if they'll be posted for free, but the event details are on this link. If you go to their website, you can find it. But many of you may be interested in that as well.

I wanted to mention that upcoming is the AUCD 2022 Conference: Health Equity Serving the Whole Person. This is going to feature some of the research that's been funded by ACL, HRSA, and NIH. Several different UCEDDs, LEND programs, IDDRCs, and the Developmental Behavioral Pediatrics Program. Please check it out if you are interested in the conference schedule. Registration details are available on this link that's provided. Now, I'm going to share some federal updates.

First, just recapping what we heard this morning from Ms. Geevarghese about the

National Disability Employment Awareness Month, and the White House's celebration through the presidential proclamation, which is linked here. I wanted to let you know that our office, the Office of Autism Research Coordination and on the IACC website, has a page for NDEAM, where we've listed a lot of different events and news items from around country about NDEAM. And so you can go there and you probably can find videos as well for things that have already happened. The Department of Labor's NDEAM page is also linked here. We'd encourage you to check that out to see what's been going on with that over this past month.

I also wanted to bring us all onto the same page about diversity, equity, inclusion, and accessibility. You've already heard a little bit about that this morning from ODEP, but I've had questions about why we're talking so much about inclusion in the IACC. In case some of you that don't work in the federal government aren't aware, there has been a lot of work going on federal wide on this concept of diversity, equity, inclusion and accessibility, or DEIA. This is based on two key executive orders, which I've linked here.

The Advancing Racial Equity and Support for Underserved Communities Throughout the Federal Government and Diversity, Equity, Inclusion and Accessibility in the Federal Workforce. These two executive orders combined have helped us create an ambitious whole of government equity agenda that includes the federal workforce, as well as all federal programs.

This has resulted in DEIA efforts across every federal department and agency and every federal official that's sitting in the Zoom meeting today is somehow connected to DEIA efforts going on across the entire federal government. These efforts are enabling opportunities to address full inclusion and access to people with disabilities among other groups that are underserved. It's resulted in multiple working groups, committees, initiatives, reports, and so they're coming out at a fairly fast clip.

I will try to, in these updates from time to time, share some of the important reports that are coming out that do include information about people with disabilities, but it's also creating new opportunities for disability, disability employment, and neurodiversity initiatives, as well as consideration of issues of intersectionality with race, gender, and other categories.

Recently, April 2022, because we last met then, there was a report that was put out by the Equitable Data Working Group based on the Executive Order 13985. This report talks about using data that the federal government is collecting to help serve people from underserved groups and how we can collect better data and enhance our data resources. This report includes information about data on people with disabilities. The link is provided here if you're interested in checking out that report.

Last year, I didn't point this report in this media in the IACC meeting, but there was another report that came out. The Government-Wide Strategic Plan to Advance Diversity Equity Inclusion and Accessibility, which also mentions people with disabilities. I'd encourage you to check that out. It talks more about the strategy for the entire federal government as the nation's largest employer to enhance its inclusion of underserved groups in the federal workforce and how to better accommodate and strengthen the work that we're doing together.

With that, I'll move on to the next item, which is a report that came out recently on improving data infrastructure for patient-centered outcomes for people with ID/DD. This was developed by the Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services. This report describes key insights from informant interviews and ASPE-hosted listening sessions on short-term opportunities for improving patient-centered outcomes, research, data infrastructure, and the needs of individuals with intellectual and developmental disabilities. I've provided the link where you can download that report if you're interested in that. We will hear a little bit more from ALICE KAU later in the Round Robin. But NIH made a large award of $100 million. Not to one place, but for several awards, for nine different awards, under the Autism Centers of Excellence Program. We've linked here to the press release about that. You will hear more from NICHD. This program is supported by NICHD, NIMH, NIEHS, NIDCD, and NINDS that are all on this committee.

Also, with the Agency for Healthcare Research and Quality, they're seeking public input about person-centered care for people at risk for or living with multiple chronic conditions. Comments are due by November 15th. Those of you who would be interested in that, there is more information available online. We have a link for that. This will inform their work as an agency and their research agenda.

The Interagency Committee on Disability Research also has had a number of different activities recently, including the release of a new toolkit, getting the most out of stakeholder engagement, which is a toolkit to better understand and measure engagement with people across the community. The link is there for that. They also have held a number of Lunch and Learn webinars and one that is linked here, understanding and responding to cultural and linguistic differences in the conduct of disability research with Prof. TAWARA GOODE, is one that I actually had the privilege of moderating and was an excellent webinar. I'd encourage anyone who's interested in intersectionality between disabilities and other categories to watch that webinar.

The RAISE Family Caregiver's Advisory

Council is of interest to people on this committee, especially with concern to family caregivers of people with disabilities. They recently have published their 2022 National Strategy to support family caregivers, and they've put the completed national strategy up online for people to access and to also provide public comment through November 30th. I'd really encourage people from this committee who are interested in caregiver issues to look at this and submit their public comments on this report. The comments will be used to continue with their report is going to be a living document. They'll continue updating it, and they're also connecting with the Support Grandparents Raising Grandchildren Council on their efforts.

The Federal Partners in Transition is another federal work group that is managed by the Department of Labor. This is focused on youth with disabilities. They are doing a number of things, including continuing to work on their strategic plan. They just held My Future Matters Symposium. This was in-person. I don't believe that there is a recording of it, but we can always check in with Department of Labor to see if there is any information about it. But that was a recent event that they held and they are continuing to work actively on their strategic plan. The President's Committee for People with Intellectual Disabilities, or PCPID, held their first meeting in the summer in July and discussed home and community-based services, employment, education, housing, and direct support professional workforce. The meeting materials are provided on their website for people who want to follow that, and thank you for bearing with me with all of these.

I just want you all to be aware of the breadth of all the different efforts going on across the government because we are trying to stay coordinated and not be duplicative. The National Council on Disability, which is an independent federal agency focused on disability, they just tell their quarterly business meeting and they didn't have anything that was highly relevant to our committee right now, but we like to keep you posted on that. Same with some of these other committees. The ISMICC, they have a meeting coming up later this week, and their agenda is up. The Disability Advisory Committee of the Federal Communications Commission is also going to be held shortly on November 1st. The National Advisory Committee on Individuals with Disabilities and Disasters, which I know that, Scott Robertson mentioned last time. I wanted to make sure that you got an update on them. They had a meeting on August 4th, and we will continue to keep tabs on them and make sure that we're coordinating on any information about people with disabilities and disasters. With that, I am finished with the update from the National Autism Coordinator as the Acting National Autism Coordinator. Are there any questions before we move on to the next section of our meeting?

Not hearing any. Hopefully, that was clear and the slides will be available. I hope that that gives you a sense of all the different efforts that are going on and we're trying to make sure that we are keeping tabs on things that are really important to our committee and the work that we're doing on our strategic plan. Then I'll go ahead and move into the committee business for today. I'm going to give you an update on the IACC Portfolio Analysis, the IACC Summary of Advances projects, and then we'll move into a discussion of the IACC Strategic Plan. First off, an update on the IACC Portfolio Analysis Report, which you all know, is a report that provides comprehensive information about autism research funding from across federal agencies and private research organizations in the U.S. We also track progress on the strategic plan objectives or recommendations in our strategic plan. We also provide analysis of funding trends over time, and we've been tracking this information for many years. We do some comparison and provide trends. We also provide progress toward the budget recommendation and the strategic plan. We are currently in the process of the final stages of preparing the 2019 and 2020 IACC Portfolio Analysis Report. Our plan will be to present this to you in January, so you can see the results of this report. There are some really interesting findings that are a little different from previous years, and we are looking forward to sharing that with you at the January meeting. We have also launched the data call for the 2021 IACC Portfolio Analysis Report and appreciate different federal agencies and private organizations that have shared their data with us. We will continue to collect that information and work on the next report. We always have them in progress.

Next, let's talk about the IACC Summary of Advances. Since we last met, we published the IACC Summary of Advances for 2020. You all contributed your nominations and voted on that. Then we prepared the report and it was issued in June of 2022. This provides lay friendly summaries of 20 of the most significant advances in ASD biomedical and services research that you all selected by vote. The final report is available online. For the first time, based on feedback from the committee, our team prepared an easy read version of the Summary of Advances. We plan to do that going forward for our major documents. You can access this online and we encourage you to look at it. Congratulations to all the researchers whose research is featured in the report, including some members of our committee.

After this, we're still catching up a little bit on the Summary of Advances. There are a couple of years that we are not quite caught up on. We have 2021 and 2022. Let me update you on where we are with 2021. The steps of the process on this slide, we've gone through the first three. We've nominated the articles, discussed them at the committee meeting, and also we did an online discussion, which we have shared that information on our website so that it's transparent to people, which we just did so that we could try to catch up. The IACC members have now voted on the top 20 articles. Our office is currently in the process of preparing summaries and the draft publication. We are working on that and we will give you a preview of the draft later this fall and be preparing the final publication for early 2023. Hopefully maybe at the January meeting, we're able to share the final publication or soon thereafter.

So in front of us right now is to work on the 2022. The work on 2021 for the committee is mostly done at this point. We're moving on to 2022, trying to catch up to the present moment. I just sent out a data call to everyone on this committee this week as your first data call for 2022, and would ask that committee members consider research articles that have been published in 2022, that you think are significant and you'd like to nominate for consideration. You can basically send those on a rolling basis between now and January 6th. We will send you a couple of reminders to prompt you to think about research articles you've read that you think that are worthy of nomination. We will plan to discuss them at our January meeting and then allow you to vote and publish the final report in the spring. At that point, we will be caught up.

As I said, our action items are, I'll be sending you a preview of the 2021 IACC Summary of Advances to look at. If you do have any comments or corrections, we can take those into account before we publish the final report and the easy read version. Then for the time being between now and early January, please submit your nominations for 2022. Are there any questions about the summary of advances?

Dena?

MS. GASSNER: Just an observation. I know I might sound like a broken record, but I came across a dissertation by a woman named KATIE SAVIN, who examined what it is like for disabled people to live on social security. Her findings found things that we, at the grassroots level, well know about using sex work, using bartering, working under the table, living far below the poverty line, as some of the outcomes that people are living with in regard to their low income on Social Security. I know that we are very much supportive of more quantitative research, but I just have to say those findings are instrumentally valuable. I would just like to advocate for us to at least open 1-3 slots specifically for this kind of groundbreaking qualitative research. I know the samples are small, but I think that they should be informing further quantitative big data research. That's my pitch for the day. Thanks for listening.

DR. DANIELS: Thank you. Qualitative research is welcome. We do try to limit it to published research in journals. But if this research is going to be published in a journal upcoming, which oftentimes people with dissertations do publish in a journal as a part of their work, we can consider it for this. If that dissertation is published at this point, you can send it forward to us for consideration for mention in the strategic plan, because that's a little bit of a different document and we can include different kinds of citations there.

DR. GASSNER: I just throw it out for its value and as an example. I'm not suggesting we should have dissertations represented here. But I'm just throwing it out as how critically valuable the information she gleaned was in terms of informing big data sets. Thank you.

DR. DANIELS: Thank you. Yes. Qualitative research is certainly acceptable and welcomed. Please don't hesitate to send studies that are qualitative in nature.

Then I will move on to the Strategic Plan Discussion to give us some time to talk about this and bring you up to date to where we are on the IACC Strategic Plan process. I'm just going to recap the steps. I know that it's been lengthy and we've been working on it for over a year and just want everyone to, again be on the same page about where we are. Last October through November, our office collected input on the strategic plan from the general public in a request for information. Results of that RFI were presented at the January, 2022 IACC Meeting.

In November through March -- well, November, 2021 to March, 2022, we also collected input on the strategic plan from IACC members through a survey. The results of that survey were shared at the April meeting and are posted online. We also, next in April to June, prepared the first draft of the strategic plan, which was shared with the committee over the summer. We held a meeting in July, where many, many members of the committee were able to make it to that working group meeting and discuss your input on the first draft of the IACC Strategic Plan. That was a very helpful and productive meeting, where we got a lot of input and we really appreciate everyone's active participation in that meeting. After that meeting, the next step we took is, July through September. IACC members responded to another survey that collected input on other aspects of the strategic plan that hadn't already been discussed, as well as left room for other comments to be shared. Those survey results are posted online for this meeting. However, we've already incorporated those to our best ability in the current draft.

We have, on our team, prepared a revised draft of the strategic plan. With this, we did have our team do the heavy lifting of writing, taking into account all of your comments, comments we've gotten from the public, the RFI, to try to prepare a draft that reflects a collective view from all of the information that we've been able to gather. This has been posted up on our website prior to this meeting. Anyone who's interested, you can go to the Meeting page and you'll see a listing of all the chapters of the strategic plan that we have available now for review. IACC members, I know that you received this. It's a very lengthy document and I don't expect that people have read it verbatim as yet. We wanted you to have it before the meeting so that we could talk today, but you will have additional time to look at it and provide us with input. We will provide you with another form, so we will create another survey document. The reason that we do this to collect data is that, we don't want to lose emails. Like, if you just emailed it to me, if I'm getting emails from 40 different people, I don't want anything getting lost.

It also allows us to bend some of the comments to which part of the strategic plan they belong to. It's easier for our whole team to be able to collect it because it ends up in a spreadsheet that makes it easy for us to make sure that the right comments are going to the right place in the strategic plan. Bear with another survey. However, this one will be fairly simple. It will just allow you to provide input on the different chapters of the strategic plan. With that, in December, our team will plan to provide you with a revised version of the strategic plan after we collect your input on this version. We will provide you with a new version before the January, 2023 meeting, which is happening on January 18th. We hope that that will be the final plan that we will be able to approve.

Any questions about the process? We've made a lot of progress and I know that it has been lengthy. However, we do have a lot of input that we're trying to put together to make sure this plan is comprehensive and up-to-date to where we are today.

To give you an update on the contents of the IACC Strategic Plan, there's some different themes and issues that we've emphasized in the strategic plan, including major research services and policy issues. We've also included the increased need for inclusion in research, including community-based participatory research, which we've heard from members of the committee and the community about. We also have taken a deliberate approach to address the whole spectrum and the whole lifespan, and including those with high support needs. We have been very committed to equity and reducing stigma, disparities, and discrimination, which we have heard about from this committee as being a very high priority. I just mentioned to you the DEIA efforts across the federal government.

These are in step with that set of priorities, and we are making every effort to try to raise understanding and awareness that the committee does stand together in a commitment to equity. Also, updating you on the research portfolio and budget recommendations. You will see that in the draft that we have now, we do have some information about the research portfolio analysis that we're going to be sharing with you in January. The new budget recommendation that I'll share with you today that you all contributed to and major federal activities and initiatives and interagency coordination to give a picture of what's going on.

(1:49:36)

You've received the core chapters of the plan that have been updated or created, incorporating your feedback, including Chapter 1, or question 1, which is on Screening and Diagnosis. Chapter 2, which is on Biology. We did survey you on the titles for this chapter, and there really was just no agreement on anything new, so we will be sticking with biology. Chapter 3, Genetic and

Environmental Factors. Chapter 4 is Interventions. Chapter 5 is Services and Supports. Chapter 6 is the Lifespan. Chapter 7, Infrastructure and Surveillance. We have the cross-cutting topics of Sex and Gender and Promoting Equity and Reducing Disparities. Finally, there's section on the impact of COVID-19. We also have some other sections that have been developed, including the mission and vision statement, which have been revised, as well as a revised set of core values that I'll share with you today.

The budget recommendation, which is required under the Autism CARES Act, which you all contributed to a new revision of that. The statement on duplication of effort, which is also required by law, and a conclusion.

Before I move on to anything else, any questions about those sections? Oh, Jalynn. If you have something written, Jalynn, you can send it to Send Comments here.

MS. PRINCE: Sorry, [inaudible].

DR. DANIELS: No problem.

MS. PRINCE: I had something come on the radar and I wonder if we need to address this, and it is fairly major, so rather than a comment early or later on.

DR. DANIELS: Okay.

MS. PRINCE: It is about mental health and disabilities, and I'm wondering if we need to look at something in our strategic plan, because I was involved in a conference that is financed by some big dollars with mental health. There were many other subgroups that were being mentioned, but disabilities and especially autism, weren't even on the radar. I've been invited there. I ended up, by default, being a voice for disabilities in general and autism specifically. These happen to be national organizations, people that are working on defining things for the nation. I'm wondering if we need to look at something in the Strategic Plan that is addressing the mental health issues that go along with our population and what is or isn't being addressed and what might need to be. It may not need to be a large component, but I think we need to mention things. Because if we're expecting others in the mental health arena to be addressing some of these things, to include our population, that we should have included within our Strategic Plan. It isn't something that I see listed, per se, in what we've been doing.

DR. DANIELS: Well, thank you so much for bringing that up. Even offline, Dr. Gordon and I have talked about that. Mental health certainly is a theme that has come up in several different parts of the Strategic Plan, including Chapters 2 and 4 and Chapters 5 and 6. Mental health come up in all of those areas, and I think this afternoon in our aging discussion, you're going to be hearing about mental health as well. This is indeed a very high priority. Josh may want to say something about this as Director of the National Institute of Mental Health.

DR GORDON: Yeah. Jalynn, I appreciate you bringing it up. I also appreciate you speaking up at that meeting that you were at. What I would suggest is that you look at those sections in the draft Strategic Plan that you all have as part of the materials for the meeting, that Susan just mentioned. Perhaps, Susan we can have someone from the staff actually point JALYNN to the places where it's mentioned. Then with that in mind, decide whether or not, it needs additional highlighting and make some suggestions as to where that might be done.

DR DANIELS: We also might be able to bring that out a little bit in the introduction. I would say that it is something that has been a strong theme.

DR. GORDON: Right. I'm actually going to be taking a hard look at the introduction and so I'll certainly take that point as I read that introduction and make sure that we call that out. We've heard over and over again, that mental health challenges are a major component that individuals and communities with autism need help with, whether it be anxiety or depression, or other manifestations. We want to make sure that that's featured in a way that makes sure that it is appropriate to the level of concern.

MS. PRINCE: Excellent. I think we need to also look at families in conjunction with this, because many of the mental health problems is for the caregivers and by the siblings. It makes me wonder and I appreciate so very much perhaps mention at the beginning, but should it be its own topic in our report, so people who are interested in this can see that it is a subject in and of itself, rather than going into a lot of individual places to try to find out where that information resides?

DR. DANIELS: Thank you. We will take those comments into consideration and you will all have an opportunity to comment on this new draft. So please feel free to share your comments on that. Jennifer.

DR. JENNIFER JOHNSON: Hi. Yeah, Jennifer Johnson with the Administration for Community Living. I just wanted to share to the point about the needs around individuals with co-occurring mental health disabilities and other types of disabilities. We have been doing a line of work in this area, recognizing that this is one of the most unserved and underserved populations of people. We have a couple projects that we're supporting right now. We just launched a national center on co-occurring mental health disabilities and ID/DD. That was awarded to the University Of Cincinnati University Center for Excellence in Developmental Disabilities, and they're working with a number of partners on that project, and they're just getting underway.

We're also supporting five state teams. The teams include staff from the DD agencies and the state mental health agencies, to try to break down the silos that exist in states to better serve this population. We hear a lot about that being a barrier to services and supports. Those state teams are working to break those down. Just wanted to share a little bit about what we're doing in this space.

DR. DANIELS: We appreciate that, Jennifer. Thank you so much. Dena, do you have a comment?

MS. GASSNER: Yes. I'll be submitting comments, but I just wanted to piggyback onto this. I'm wondering if we need to capture some of the information that's more disseminated in a more central way, because I think we need to talk about rapid and repeated misdiagnosis of autistic people with mental health conditions. Although they can co-occur, many, many people get medical maltreatment under false diagnoses because of the lack of training for diagnosticians in mental health. Also, the public comments had many, many statements around medication hypersensitivity or ineffectiveness for this population and the need for more research around how autistic people process medications. I'm in favor of it at least grabbing everything that's scattered and compacting it into one section.

DR. DANIELS: Thank you for sharing that and we will look forward to seeing comments from you and others on that topic.

DR. GORDON: Dena, while we have you here, what's your vision for what that topic would be? I can see actually that falling into one of the existing priority areas, whether it be considered under lifespan issues or actually under biology. But I'm wondering what your thoughts are about where that might fit in as a unified section. Those different pieces that you just mentioned. You don't have to have an answer now, but think about that as you have a comment, unless you have an answer now.

MS. GASSNER: Well, I would say the research supports that this is the rule rather than the exception for autistic women or people who were assigned female at birth.

I think that's a huge barrier to them accessing proper services. Personally, I spent five torturous years on lithium for a condition I never had. I can tell you that, that medical maltreatment is really bad. I also think under mental health, we need to look at poverty and the trauma of living in a chronic state of trauma of poverty. We see that in other literature, but not as it applies to the autism community. That could be a call to action in terms of researching the trauma associated with low income.

DR. GORDON: Yeah, I think it'll be important to me on the face of it. Dena, you brought up several different ideas that fall into different parts of the Plan. Indeed I think many of them are covered in the Plan. But as you point out, many of them are not. It'd be useful for you to think about that as you look over the Plan documents. Again, just like I suggested with Dena, these -- sorry. No, with Jalynn, that you consider how best to integrate it into the structure. I think one challenge at this late date is if we start mucking with the structure too much, we will end up delaying the report anymore. I'm thinking about how these comments can fit in with the existing structure will be helpful.

MS. GASSNER: I'll be focused. Thanks.

DR. GORDON: Thank you.

DR. DANIELS: Thank you. Mitchell, do you have a comment on behalf of SAMHSA?

DR. MITCHELL BERGER: Yes. I was just going to say we supported, and I believe I shared with IACC staff two articles in psychiatric services. One on persons with intellectual and developmental disabilities in the mental health system, policy, and systems considerations, and one on clinical considerations. SAMHSA, like ACL, has been doing work trying to support work in this area.

DR. DANIELS: Yes. Thank you for sharing those, and we'll flag those for staff to look at them and see how they fit in. So thank you for that. Ivanova.

MS. IVANOVA SMITH: This is Ivanova Smith. I wanted to emphasize the importance of making sure that treatment for mental health disabilities and autism that intersect, that there's a treatment that are trauma-informed and that would not cause more trauma in a person. Looking at how do we make psychiatric treatment for mental health disabilities less traumatizing and not use things like institutionalization, but find ways to find treatments that are comforting and positive for the person and does not restrict autonomy. Thank you.

DR. DANIELS: Thank you, Ivanova. Julie Taylor.

DR. JULIE TAYLOR: Hi, everybody. Just a quick comment. I agree that mental health issues are super important for us to be really, I think, pulling out of the report. But I also am really cognizant of your suggestion, Josh, that I don't know that we want to sort of muck things up too much at this stage. I'm wondering if a good alternative or maybe compromise is to think about mental health as a crosscutting theme that we could highlight where it falls in the different sections that are already there.

And maybe while we’re all looking through this draft of the document, for those of us that think that that might be a good way to go about it, we can keep an eye out for that and see if that feels like that might be a good fit to pull out mental health without going through the process of making it its own question at this point.

DR. GORDON: Yeah. Julie, I think that's an interesting suggestion. It certainly would be maybe helpful if we need to really tie all those bits together. Certainly, it is a crosscutting theme from a structural perspective. We do want to know the genetic, biological, and environmental factors that lead to it. We want to know what services are necessary to help, to diminish the impact of mental health challenges, individuals with autism, and et cetera. You can see how that might work very well. We can take that. That's a very good suggestion.

DR. DANIELS: I agree. I think that is a potentially good suggestion. With our crosscutting theme, something that I want to bring to your attention as a committee is, part of the reason that we have been trying to stick with a structure is because we've been tracking research over time according to that structure, and we don't want to change the structure and then lose our tracking that we've been doing for years and years. But when we add crosscutting themes, that gives us another tag to track with. For example, if you wanted us to pull all the research information on mental health into an analysis, and we can do it without the crosscutting theme. But if we officially do it as a crosscutting theme, then we would just be automatically tagging all the research that is mental health in one place. That is a good suggestion we can certainly consider it if something the committee would like to do.

DR. DANIELS: Was there another question? I think I saw a hand and then it disappeared.

MS. SAM CRANE: Hi. This is Sam. I actually put in the chat, but I had raised my hand to say exactly the same thing that Jennifer did. I think it might make sense to put it as a crosscutting theme, because it does touch on biology, treatments, screenings, lifespan, services and supports. Just so many different questions. But putting it as a theme makes a lot of sense.

DR. DANIELS: Thank you. I'm hearing quite a bit of support for that. Is there anyone on the committee who's not in favor of making that a crosscutting theme, because it's something we could work on in the next version? Is that Helen saying no or is that Helen having a question?

DR. HELEN TAGER-FLUSBERG: Helen having a question.

DR. DANIELS: Yes.

DR. FLUSBERG: It's very quick.

DR. DANIELS: Go ahead. Yes.

DR. FLUSBERG: I think having it as a crosscutting theme makes a great deal of sense. But then at the same time, I would say talking about the variation in intellectual functioning is another critical crosscutting theme. That's really on a par because it also covers the full range of topics.

DR. DANIELS: Thank you for that suggestion. It's certainly possible. I guess we don't want to get to the point where we have so many different ones that things get lost. But maybe we'll have a discussion about that and try to figure out what we can do. I agree though that that is another theme that does trickle through many parts of the Strategic Plan, and we have tried to address, but welcome your comments when you read the draft. Jalynn.

MS. PRINCE: The crosscutting theme seems like a very interesting way of approaching it. I would like to understand what that might look like if someone happened to be looking at this Plan to see what is happening, what the attitudes are, is it something that is highlighted in a particular color as one goes through all of these things? Any of the mentions can be cited, or how do we get into it? Because sometimes looking at these reports, they're fairly weighty. I've got some of the chapters in front of me right now and going through all of those things to find out where there are mental health mentions or some of the other types of things, could be more labor than people have time to devote and to trying to get into information.

DR. DANIELS: Right. That is the challenge. We're trying to be comprehensive. We've got a report that's already about, I know it's over 100 pages. Which is why I knew that not everyone was going to have time to read that in its entirety before this meeting. You will see that with disparity.

DR. GORDON: Why don't you put up that

table of contents, if you will again? You had it already. That'll help. I think, Jalynn understand how it's called out to certain degree.

DR. DANIELS: We already have a crosscutting theme. A new one that's on promoting equity and reducing disparities. We already had one on sex and gender. If we were to create one on mental health, we could. But as you see, we already have a lot of chapters. I would say we might not want to make a whole lot of new chapters as it will get harder and harder to read, as you said. However, if there's something really important that, I think, one of the deciding factors is, is this something that we want to track separately for some reason? With mental health, I could see us wanting to track that information and have it in one place. With intellectual disability, it might be a little subtle, for it's probably a part of, say, in research, a lot of research. I don't know if it would really make a huge distinction. If we tried to pull that separately, we might not be able to separate it out.

DR. GORDON: I think also one place to look for the consideration of the spectrum of intellectual functioning will be in the introduction where we talk about autism as a spectrum. That might be a place that we could beef up the notion that we need to be thinking about different levels of intellectual function as we think about these different chapters.

DR. DANIELS: Thank you. Steven, did you have a comment that you wanted to share on behalf of someone?

MR. ISAACSON: Yes. I had one comment and one question. Jenny Mai Phan wanted to express interest in including psycho-pharmacology in the mental health crosscutting theme. Then Dr. Susan Rivera wanted to know exactly what the crosscutting theme would be.

DR. DANIELS: With crosscutting themes, like we've said on this slide that I have shown right here, we do have sex and gender and promoting equity and reducing disparities. Part of the goal of that is possibly pulling together information that might be scattered across the chapters into one place, but it also, we in the office are using those as guides for us to be able to tag research projects and be able to pull them into a specific analysis. With psycho-pharmacology, I don't know that that is something that would be crosscutting across all the chapters. We do discuss that in the Plan. I would suggest potentially looking at Question 4 and seeing if we've treated it adequately there. Then LINDSEY, do you have a question?

MS. NEBEKER: Yes, I do. I was just trying to think, and since we're discussing on mental health and figuring out how to prevent, putting in too many crosscutting topics, I'm trying to think if putting either if it's a crosscutting topic or putting a subsection somewhere about health and wellness and putting it, mental health, under that umbrella of health and wellness, or if that might be too broad. But I wanted to just put that thought out there.

DR. DANIELS: Thank you. Health and wellness is mentioned throughout the plan. Again, that's one where it would be pretty hard to separate that from pretty much any of the research that's funded. All of it is pretty much of something related to health and wellness or understanding why people are not healthy and well. But it is certainly mentioned. Just look at what we have when you have a chance to review and let us know if there's something different that you see a place that you think it needs other mentions. Dena, do you have a comment?

MS. GASSNER: I have a comment for Hari. He's having trouble getting in to leave comments. I'm just going to read this. "We need better development of meds to help with mental health needs, SIBs, and obsessive compulsive behaviors and so on. Instead, all we have is big pharma recycling and rebranding drugs made in the 1950s. Minor changes in chemical structure allow for repatenting and maintaining exorbitantly high prices and profits. I heard Dr. Antonio Hardan of Stanford mention that these drugs don't work the way they say they should in autistics, as in the general population. Why are we still overmedicated with these same drugs? Have we thought about whether SIB could be psychological stress and indicative of suicide ideation? Maybe you don't have the physical ability to carry out suicide, which requires lots of executive functioning and planning, so you do what is available to you.”

DR. DANIELS: Thank you. SIB is on the list of one of the topics to just re-review for our team as we go through the plan. We have a list and we're taking notes through this, and we will be going back and looking through the chapters to try to make sure that we've done our best and incorporate things.

Of course, we'll be taking your feedback for additional comments. If it's okay with the time that we have left, I'd like to just share with you the mission and vision statement and some of these other things that have been revised. The mission and vision statement that we have after revision is “the purpose of the IACC Strategic Plan for Autism Research Services and Policy is to focus, coordinate, and accelerate innovative research and foster the development of high quality services and supports. The plan will emphasize the critical importance of partnerships among government and community partners to address the urgent needs or urgent questions and needs of all autistic people across the spectrum and across the lifespan. Ultimately, the plan will catalyze federal and private activities that will improve health, wellbeing, acceptance, and inclusion for all people on the autism spectrum and their families.”

That is where we landed with all the

input that you provided at our last meeting. We've also done some revision to the core values. We had the same set of core values from 2009. After looking at it with the input that you provided, made some edits and updates to this to focus on some of the things that you all have shared with us in the meetings. We now have additional core values. We have one on impact, one on community focus, one on equity and inclusion, one on excellence, one on responsiveness, and one on the spirit of collaboration that we have updated.

In the interest of time, I'm not going to read them all to you, but they are here in the slides. I don't know if they're on the web right now. But if they are not, we can make sure that we provide them and they will be a part of the next draft. But we really appreciate the input that we had and hope that this better reflects our current thinking. It was good for us to have an update on these.

I also wanted to report out to you on the budget recommendation. In the survey that you received, you shared with us what your priorities were for the budget recommendation we had you vote. We took the top three issues that you voted on to be items to highlight. It doesn't mean that the budget is not going to focus on all the other things that are in the Strategic Plan. But the result of your vote was that the committee decided that they would like to focus on lifespan issues, evidence-based interventions and services, and research on disparities and development of culturally competent tools and services as three highlights within the budget recommendation.

You also did decide at a previous meeting to extend this goal to reach funding level of 685 million by 2025. The previous goal was to reach that point by 2020. We didn't make it quite there. We have extended that to 2025 based on your input on that. That is the budget recommendation. It has a narrative and text that you can read in what has been provided. We also included a statement on duplication of effort, which is something Congress requires us to do to ensure that the federal agencies and people working on autism are not duplicating effort, and particularly for federal agencies not wasting taxpayer funds on things that are duplicative. This narrative that we provided explains that the goal of the committee is to recommend research that is not duplicative, and also that we support the idea of verifying research results, having multiple studies on an issue from different angles, and that we don't consider this duplicative.

That's just a little bit further on that. That's what I wanted to share with you. We have a couple of additional minutes to share any other comments that we want to share here. I will give you some action items. Do we have any additional comments?

Why don't I just run through what the next items will be? We're going to be providing you with a survey that you will get. You have these draft chapters. We will make sure everything is there. You will have a certain amount of time to provide us with your feedback. We are not providing word documents for line edits from 40 people, because that would not be manageable. We're just going to give you a survey document where you can just write your comments in and then they will be binned for us and we'll incorporate those into the new draft. Before the next meeting, there will be a new draft for you to review and we hope that it's ready to approve in January.

The next meeting is going to be on January 18th. We have not yet decided if it's going to be virtual or hybrid. We will keep our eye on what is going on in our environment at the time. If it is a hybrid meeting, if we still have restrictions on space, it may not be open for the public to attend in-person. It may only be open for members to attend in person, but we will keep you updated based on the latest on that. The website will have meeting updates. If there are some other questions, I see a couple of hands raised. I just wanted to make sure I got through the rest of these slides. Jalynn, do you have a comment?

MS. PRINCE: Yes, I have a question. With the budget, at one particular point a few years ago, there was a proportion that had been dedicated toward adult autism. Then I guess the rest of the bucket is a poor way of stating it. With this budget, what portion of that is directed toward adults or is that even being separated out any longer?

DR. DANIELS: That's the lifespan issues part of it. To clarify what the Budget Recommendation is, it's a recommendation from the committee about where agencies might want to focus if they wanted to focus on things that are important to the committee. Although the entire Strategic Plan and all of its recommendations are advisory to the Secretary of Health and Human Services and to Federal Agencies. That is covered here. But this does not mean that there is a set budget, like some central federal budget that's being divided up into pieces. Every agency gets its own budget and makes their own funding.

DR. GORDON: I think, Susan, the question that Jalynn was trying to ask was, is there a recommendation for a certain subset of the 685 million by 2025, that we recommend spending on research and services. I think this is research actually, sorry. Research and adults with autism.

DR. DANIELS: The budget recommendation previously has not recommended a specific dollar amount. I think that would be a little bit challenging given how appropriations are made to federal agencies to specify and then try to add that up. But we are tracking on the 685 million total. That includes non-federal organizations as well.

MS. PRINCE: A few years ago, it was like two percent of the autism funding happened to go to adults with autism. Then it increased to four percent. That's what I'm asking about - what proportion of that or maybe that isn't even the way that things are looked at now, but we gave testimony for that a few years ago.

DR. GORDON: Jalynn, that's a data question as opposed to a recommendation. Yes, we can track. It can be challenging, but IACC staff do track some of the details about how this money is spent in different areas. What we're talking about here is a recommendation for future expenditures on autism research, which is what Congress has asked us for, and we have not, in the past, tried to specify how much goes for which kinds of topics.

DR. DANIELS: We will share with you when we do the portfolio analysis update in January, what the update is on lifespan issues. I can say as a preview, we've noted an increase in our analysis, but we will share that with you in detail in January. Any other questions before we break for lunch?

MS. GASSNER: I just want to put a pitch in for an in-person meeting. I think our body is really struggling to coalesce through the meeting, through Zoom. I think we've done the very best we could with our circumstances. But I just want to put a pitch in for that. I think we really need that off the record bonding time to bring the group together.

DR. GORDON: Thank you, Dena. We are in full planning mode to be able to have an in-person component for the meeting. It's certainly my intention to hold the meeting in-person. But no one can know what will be happening with regard to the pandemic.

MS. GASSNER: Understandable. Yeah. Thank you.

DR. GORDON: For those of you might feel otherwise from DENA and be concerned about the prospects of traveling, et cetera, we will have a hybrid option. As we've had in the past, it'll be much better than it used to be because of our experience here. But I appreciate the comment, DENA and any others who have opinions about it are welcome to express it to myself or to SUSAN. With that, thank you very, very much for your hard work and attention to these business matters and the rest. We will be returning sharply at 1:30. We're a few minutes late going into our break, but we're going to start up the afternoon on time. As you'll know from your agenda, the first item on the agenda back is the public comment session. We'll see you at 1:30.

DR. DANIELS: Thank you.

DR. GORDON: Again, sorry. If you can please leave the Zoom open. It's just easier than having to worry about whether you're not going to have technical issues coming back in. But stop your videos and mute your microphones.

[Whereupon, the Subcommittee recessed for lunch at 12:30 p.m. and resumed at 1:30 p.m.]

DR. GORDON: Well, welcome back everyone. Thank you very much. Hope you had a good useful break and are ready for the busy afternoon. We have planned for us all. The next segment of our meeting is the public comment session. To lead that session, I'm going to turn it back over to Dr. Daniels. Susan.

DR. DANIELS: Thank you. So we are going to be talking about public comments and hearing public comments in this next session. First, we'll be hearing from our oral public commenters, and I'd like to remind everyone on the committee that we are here to listen to people that are going to be sharing things from different perspectives and that we want to just be thoughtful in our listening and consideration of points that are being made by our public commenters. We appreciate all the public commenters also having the courage to come and share your points of view with this committee.

We have Shannon Des Roches Rosa, who will be our first presenter. Then that she will be followed by Judith Ursitti, Amy Lutz, Amy Montimurro, Rieko Shepherd, and Elliot Gavin Keenan in that order. I will hand it over to Shannon Des Roches Rosa to start us off with a public comment. Remember everyone we're sticking to about three minutes per comment. We won't be responding to them until after we've gone through all of the oral and written comments. Take it away, Shannon.

MS. SHANNON DES ROCHES ROSA: Thank you so much, Dr. Daniels. I'm speaking to you as the parent as an autistic adult who requires full-time support and supervision. Also a Senior Editor of Thinking Persons Guide to Autism, an Autism Research and Advocacy Community, where I constantly hear from parents, autistic people, professionals, and researchers about their priorities for autistic people to live safe, healthy, fulfilled lives. Community priorities include research on how autistic people may process medications differently.

The medical community seems largely unaware that autistic people often have paradoxical or atypical reactions to commonly prescribed medications, such as not reacting to or being overstimulated by sedating drugs. In worst case scenarios, this lack of knowledge has been fatal. We also need research on why sedation for medical care is an access need. Both speaking and non-speaking autistics often require partial or full sedation to be able to tolerate medical procedures, such as dental exams and MRIs, yet the sedation is rarely covered by insurance. Such research could improve healthcare access as well as outcomes. We also need research on competing sensory access needs.

Autistic sensory systems don't only differ from non-autistic people. They often differ from each other. We need research illustrating why it is inappropriate to put autistic people together in classrooms or other settings without fully evaluating and accommodating their individualized sensory profiles. We also sorely need research on improving access to autism diagnoses across age, gender, class, and racial gaps. While I know this is improving, too many autistic people are being misdiagnosed, categorized as having behavioral disorders, resorting to self-diagnosis, or being overlooked altogether. They are suffering as a result leading to avoidable anxiety, depression, isolation, poverty and suicidality. Finally, we need research on transitioning out of the school system and into adulthood, especially for autistic people with the highest support needs.

The cliff is a real thing for students like my son, who is currently facing a complete lack of appropriate local adult programs. At the same time, there is also a direct support worker shortage, so my son does not have the staffing he needs and deserves and has been allocated. If families like mine, which have the language, class, and cognitive advantages that make it easier to navigate often, labyrinthine and impenetrable, public disability support systems and still can't find any support, then families who don't have our advantages are certainly worse off and need our support.

A final note. I am glad about the IACCs current membership inclusive as it is not only of autistic adults, but of autistics who use AAC to communicate, who have intellectual disability, who are parents, who have family members with intensive support needs similar to my own son, and/or who are people of color. It is hard to have faith in an advisory body that does not resemble the population for whom it is responsible. Also, as someone whose autistic son has limited language, it is important for me to know that autistic IACC members, people who understand my son's life in an experience in ways that I as a non-autistic person never can, are looking out for his interest as a human being. Thank you.

DR. DANIELS: Thank you, Ms. Des Roches Rosa. We will move on to the next comment, but I appreciate your comments. Thank you for sharing that with us. Next, we have Judith Ursitti.

MS. URSITTI: Hello, there. I have a bit of a cold, but I promise I'm COVID negative. If I start coughing, just please jump in and take over. My name's JUDITH URSITTI and I'm Vice President of Government Affairs for the Council of Autism Service Providers. If you haven't heard of CASP, I hope you will soon. We are a non-profit trade association, made up of hundreds of autism service providers of all sorts. Schools, multi-specialty clinics, ABA clinics, adult service providers, all make up our membership. They provide autism services across the lifespan to autistic people all over the United States.

I'm speaking to you today because I want to make sure as you're working on this strategic plan for the IACC, that you keep some things in mind. One is protecting the quality of the services that are provided in the Strategic Plan and doing so through a couple of things. One is prioritization of generally accepted standards of care. The courts in the United States and examples with versus United Behavioral Health, as well, as our federal and state governments, have passed mental health parity legislation, pointing to generally accepted standards of care.

It's important to note that there are, as an example, generally accepted standards of care for the provision of applied behavior analysis. The practice guidelines for ABA are actually available on our website and have been implemented by some health plans. The California Department of Insurance has recently recognized them. Has generally accepted standards of care there under their SBA 55 requirement. As you look at the Intervention section of the Strategic Plan, I ask that you keep that in mind. Additionally, CASP recently launched an accreditation program, the Autism Commission on Quality, to further ensure protections and member organizations and non-member organizations can seek to be accredited. Again, it's just another effort to ensure that the services that are being provided to autistic individuals across the lifespan are appropriate. They have dignity, respect. They're based on evidence-based practice. I want to thank you all for your work today. There's a little bit more information in the comment that I wrote. I promise it's not too much longer. But with that, I just thank you for your consideration as you work on the Strategic Plan to do your very best for autistic people all over the country moving forward, including my son, Jack. Thank you.

DR. DANIELS: Thank you so much, Ms. Ursitti for sharing those comments. We do have the full length comment in the written portion of our packet so people will want to review that. Thank you.

MS. URSITTI: Now I can cough. I'm so glad.

DR. DANIELS: Great. Glad that worked out well for you. Thank you so much. Next, we have Dr. Amy Lutz who would like to share on behalf of National Council of Severe Autism.

DR. AMY LUTZ: Thank you, Dr. Daniels, and thank you to everyone in the committee for the opportunity to speak. The National Council on Severe Autism is extremely alarmed at recent efforts to cleanse the IACC, its strategic plan and autism research more broadly of basic, accurate, and meaningful language like behavior, risk for autism, and quality of life. The clear trend here is to mandate language that treats autism as a neutral condition or difference. But Congress did not pass the CARES Act and allocate hundreds of millions of dollars to research because autism is a neutral condition. That an autistic child cannot learn to speak or develop abstract thought is not neutral.

The abnormal neurogenesis, neural migration, synaptogenesis, and neural connectivity evident in autism are not neutral. That an autistic individual engages in self-injury or perpetually elopes or destroys property is not neutral. That countless siblings live in fear of being attacked by their autistic brother or sister is not neutral. That an autistic individual faces life-threatening seizures, pica, or gastrointestinal distress is not neutral. That an autistic child suffers unrelenting insomnia causing family-wide sleep deprivation is not neutral. That parents must sacrifice careers, incomes, and their own independent lives to permanently care for seriously disabled autistic children and adults is not neutral. That autistic children lack basic safety awareness to the extent they may rigidly refuse to exit a burning house is certainly not neutral.

That growing numbers of autistic adults lack basic cognitive functions to live independently is not neutral. That we suffer a terrible shortage of inpatient placements, crisis care centers, child and adult psychiatrists, medical personnel trained in autism, and residential support centers to treat the surging population disabled by autism is not neutral. The steady growth of autism prevalence now closing in on 3 percent of U.S. children and 5 percent in some areas is a national crisis and not remotely neutral. There is nothing inclusive about neutral or strength-based language that specifically excludes or denies realities of autism, particularly severe or profound autism. This is a high-stakes debate. We must ensure all federal efforts relating to autism are based on reality, not fantasy. If we must be neutral about autism, we cannot emphasize the most urgent priorities facing our community.

We urge the IACC and its strategic plan to fully include all realities of autism, including especially its most severe manifestations, and to focus on true community priorities using language that accurately and meaningfully captures our community's desperate needs. Thank you so much.

DR. DANIELS: Thank you Dr. Lutz. We appreciate you sharing your perspectives and comments with the committee. Next, I'd to call on Amy Montimurro from Abilis to share her comments.

MS. AMY MONTIMURRO: Thank you for allowing our comments today. Abilis is a Connecticut nonprofit supporting over 800 individuals with disabilities and their families, 45 percent of the adults who we support have autism. We launched our supported typing program, now known as STeP, after incredible outcomes from a small sample in February of 2019. A STeP participant whose life has been transformed because of our program typed the following, "I am free now of the frustration of not being able to tell you my thoughts and that has made a huge difference. People see me differently and I think differently. I now have hope for freedom in my life that I have never had before. Please give me and others like me the chance to be the people that we really are." Abilis strives to build a community of typers and well-trained facilitators using best practices to ensure words being typed are the person's own authentic voice. For three individuals who are part of our 2019 sample, independent typing is now an emerging skill. In March of 2020 with the onset of COVID, our STeP program moved to an online coaching, training, social groups and workshops. This unexpected shift allowed us to reach way beyond our catchment area. We have worked with typers and facilitators from 18 states and five countries. During the past two years through Zoom, we have trained over 175 facilitators, which includes parents and staff members of organizations like Abilis from around the country. In some states, there has been government funding for initial assessments, ongoing coaching, social group fees. Some states reimburse services provided by our program through self-determination.

Our clients and their families often describe the significant life changes that occur when someone learns to type to communicate. However, many school districts deny access to these typing methods even after parents and therapists have demonstrated successful communication when their autistic child is paired with a trained communication partner. Policy statements from some professionals or some professional organizations, it stifles educational opportunities for many. Their arguments rely on dated, limited, flawed research to deny services. Communicators feel unseen, disrespected, and incredibly frustrated. We ask that the IACC recognize that some forms of AAC such as FC, RPM, and S2C are currently being utilized and are worthy of further scientific inquiry. We suggest the following research opportunities.

How can we better identify individuals who benefit from FC, RPM, and S2C? How do individuals with a communication partner learn independence? And how can we measure the cognitive and social-emotional growth of typers and the impact on independent life skills? Thank you very much.

DR. DANIELS: Thank you Ms. Montimurro for sharing those comments with us. We appreciate it. Next, I'd like to call on Rieko Shepherd to share comments on behalf of the Autism Women and Nonbinary Network.

Ms. RIEKO SHEPHERD: Thank you. And I just want to make a quick note that I represent the Autistic Women and Nonbinary Network. If you're looking for us, the A should stand for autistic. AWN together with the Autistic People of Color Fund appreciate the opportunity to submit commentary to the IACC today. AWN is a national nonprofit that supports women, girls, trans-feminine and trans-masculine non-binary people and Trans people of all genders. Together, AWN and the fund direct policy research and community advocacy to advance the health and independence of all disabled people. All autistic people are at a higher risk of unemployment, poor health, and other adverse outcomes than their non-autistic counterparts.

However, they face further oppression on account of racism, anti-queer discrimination, and anti-immigrant prejudice. When research studies do not include or focus on diverse populations, this lack of information can be misinterpreted as indicating a lower prevalence of autism, which in turn can lead to underfunding services that could best support and respond to the specific needs of these marginalized communities.

We urge the IACC to prioritize the following research topics and also ensure that this research is informed and led by autistic principal and co-principal investigators. The first topic is exploring the impact of racism and anti-immigrant discrimination on the mental health of autistic people. Systemic racism and anti-immigrant discrimination contribute to increased rates and severity of psychological distress, but we need more empirical research to provide those appropriate supports.

Two, the prevalence of school exclusions and court involvement for autistic students of color. Most research studies focus on students with disabilities as a whole, but autistic students of color may need tailored strategies to protect them from criminalization, suspension, and expulsion.

Three, health disparities focused on autistic people of color, LGBTQ+ autistic people and autistic immigrants and refugees with a goal of developing guidelines and standards in cultural competency and communication access.

Four, prevalence of housing instability for autistic people with additional demographic analysis across race, LGBTQ+ status and immigrant and or refugee status.

Five, employment rates for autistic people with additional demographic analysis across race, LGBTQ+ status, and immigrant and or refugee status with a goal of developing strategies for increasing competitive integrated employment.

Six, The effects of linguistic and cultural barriers on autistic immigrants and refugees, adjusting to life in the United States.

Seven, research exploring negative repercussions or permanent punishments for formerly incarcerated autistic people, including but not limited to housing and educational options or health outcomes with additional demographic analysis across race, LGBTQ+ status, and immigrant and refugee status.

Finally eight, access to alternative and augmentative communication disaggregated by the same demographic criteria I previously listed. Thank you.

DR. DANIELS: Thank you so much Ms. Shepherd for sharing those comments. We appreciate you being here. Finally, I'd like to hear from Elliot Gavin Keenan.

MR. ELLIOT GAVIN KEENAN: Hi. Thank you

very much for hearing my comment today. My name is Elliot Gavin Keenan. I'm a doctoral candidate at UCLA and a visiting scholar at Stony Brook University. I study autism and I am also autistic. I was diagnosed at the age of six. My parents were told that I was "high functioning." I want to talk about this concept today. What does it mean to be high or low functioning or alternatively to have severe autism? For me, what my parents were told when I was six was in important and meaningful ways a lie. I have bipolar I disorder. When I was nine years old, I fell into a dark depression that lasted for several years. This was due to the genes that I was born with. Many of those genes are the same genes that have been identified as causing autism. My normal is far from the normal day-to-day life most parents envision for their children. Over the past several years, I have been hospitalized 20 times in a locked inpatient psychiatric unit.

Whenever people post guidelines on what

constitutes high or low functioning, I can't help but compare myself to whatever arbitrary metric is being touted today to capture what is really an ineffable sort of quality. Living independently, we tried it and failed. My parents now keep me in their home. Personal safety or need for supervision, I'm chronically suicidal and have a history of medically serious drug overdose. Hygiene, showering once a week isn't that bad for me. I won't brush my teeth unless someone physically forces me, drags me to the sink. It may seem odd to include bipolarity in our assessment of functioning as it relates to autism, but that's just the thing. We've been bundling intellectual disability together with autism like a buy-one-get-one gift for years. True, not every condition that a person can experience is comorbid with autism at the population level, but many are. I'm talking about almost every psychiatric disorder, epilepsy, GI problems, and more.

If these conditions impact level of

functioning, is that not the severity of autism? By dissociating the constituent parts of one greater entity from each other, we can fit them into neat little boxes and minimize the importance of some. I humbly ask the IACC to consider, in the context of modern controversy, the role comorbid conditions play in the severity or support needs of autism and how functioning categories may be misleading. People don't follow straight lines. A lot of rhetoric these days plays on the perceived impossibility of a high-functioning adult regressing into low functioning. But these labels aren't individuals.

They're states of experience that we may live in or pass through on our journeys. Finally, we need to study comorbid conditions in autism across all levels of functioning.

DR. DANIELS: Thank you so much, Mr. Keenan, for your comments as well and thank you to all of you. All of the comments that you've shared are related to different parts of our strategic plan. As you may have heard, if you listened to our session earlier, our committee is working very hard on that strategic plan, and I know that they will take your comments into consideration. Next, I'd like to move to the written comments, just to give you a sense of what we received. The full packet is online, on our website, and our members as well as the members of the public can access these comments to read them in full. We're not able to obviously hear all of them in this meeting as there are many. But we had 43 comments that relate to research and service needs, resources and policy implications and all of the people that provided these comments are listed here.

We had 15 comments on research services and supports for adults on the autism spectrum. Five comments on augmentative and alternative communication. Six comments on inclusion of autistic perspectives in research. Nine comments on co-occurring mental health conditions and negative life experiences. Eleven comments on addressing the needs of autistic individuals with high support needs. Five comments on concern about medical practices. Three comments on increasing autism acceptance and reducing stigma. Five comments on the role of the IACC and the federal government. Four on employment. Four comments on potential causes of autism and one comment on wandering and safety. You can read all of those in full and I know that the committee received these in advance and many of you have had time to read through these comments.

Next, oh, there should be a discussion slide there, but we have time for the committee to discuss these comments. Dr. Gordon, I don't know if you'd like to start with some comments for the discussion.

DR. GORDON: Well, first of all, I want to thank the oral and written commenters for giving us a lot of food for thought. I think, Susan, you laid out our task quite nicely and which is to consider the comments that we've heard today and think about whether as we revise that strategic plan, we want to include in it if it's not adequately included, or stress differently different elements of consideration based upon those comments.

As I should say, as always, as we've done for several years now, basically, since I took over, we've devoted a period of time for the committee to discuss any of the issues that were raised during the comments and including things that you agree with or things that you may not agree with. The floor is open to members of the committee for questions and comments. Dena, go right ahead. Others, I should say, while Dena gets ready and unmutes herself, should feel free to raise their hands to get in the queue if you have something to offer. I would ask those of you who are speaking, again, if you feel comfortable to turn on your videos so that you can speak.

Also, reminder that if you would prefer

to do so, you can send the comments through the chat function to the send comments here individual and they will be read. But if you would raise your hand so that we can keep it in the right order, that would be helpful even if you submitted your comment in writing.

MS. GASSNER: I'm sorry, but our cameras are being blocked.

DR. GORDON: Oh, they are. Well, we'll see what we can do about that. If the hosts can unblock the cameras from the IACC members, that would be helpful.

MS. GASSNER: Thank you.

DR. GORDON: Go right ahead.

MS. GASSNER: I didn't have so much of the comment is I wanted to just champion a couple of the comments we got. I am extremely excited about the sheer amount of feedback we're getting. I think this is unprecedented. I did want to point out that we spent a lot of time this morning talking about employment, but the reality of it is the vast majority of people living with autism are not going to be able to work full-time. All the comments that came in around having a more meaningful life experience after 18 across the autism spectrum was certainly very important. I think we are not giving that enough attention. I did want to thank Rieko Shepherd and Finn Gardner for their comments about immigrant needs, school to prison pipeline. I think we can talk about that more in another time. Homelessness and overall healthcare access. I like Shannon's comments about anesthesia. I know we think about anesthesia frequently when we talk about issues related to dental care, but we don't talk about it for reproductive healthcare. I think that could be very, very helpful in boosting the numbers of autistic women who will actively participate in reproductive healthcare access. I wanted to just point out to people that in the Round Robin the Agency for Healthcare Research and Quality is seeking commentary on multiple chronic conditions, that multiplicity piece. Those of you who wrote in about the multiple dimensions of co-occurring conditions may want to comment there.

I do want to say if Viola Sanchez is listening, if she'll reach out to the committee, I'd love to talk to her about her social security appeal. Then lastly, I just want to say that I'm so excited about how our language is evolving. We started out with terms in our history like idiot, and moron, and mentally retarded, and now we're leaning toward more compassionate and dignified language that's more respectful of the human condition across the spectrum. Given that we know that every single feature of autism presents across the board in terms of the autism spectrum, I'm just really happy that we are representing and supporting the needs of the entirety of the autism spectrum. Every time we bring up gastro issues, mental health, reproductive healthcare, difficulties with people being employed.

The point that Paul made about a fourth of teenagers living in homes below the poverty line reflects the lack of services that force women and other providers out of the workforce. I'm really happy to be part of this community and I hope we can continue to work collaboratively to resolve some of these issues.

DR. DANIELS: Thank you, Dena.

DR. GORDON: I see Jalynn has her hands up next. Go ahead, Jalynn. Then just so you know I see, Morneike, Scott, and Ivanova afterwards. Go ahead, Jalynn.

MS. PRINCE: Excellent, Thank you. I really appreciated Amy's comments. This is an area that we have become more and more familiar with all along the way. Sometimes referred to as extreme autism and we've been made very much aware of very few places or locations where families can turn for this type of help. Just last night I was reminded by a sister-in-law of a woman who had been very capable, who was on the spectrum, who had worked in a coffee shop and had a very productive life.

A couple of things happened within her family and she regressed and is 45 now, and is in a medical care situation because the family can't have her at home because they can't regulate all the meds that she needs. But the program that she's in is very inappropriate for her because if they administer the drugs and maybe have physical exercise once a week, that is sufficient. But it's not sufficient enough for her mentally to get back to where she was to be productive and to work. I'm not seeing places, and I'm not understanding that there are many places that people can go to have this remediation perhaps, maybe it would be more long-term. But no one wants to see institutions, but I don't think anyone wants to see neglect either, or to see human potential not realized.

How do we come to that? I think it's a healthy debate that we need to have, and it ranges from there to low support needs. But low support needs doesn't mean no support needs. We've got a lot of balancing to do there and I would love to see that type of conversation coming in. How do we encourage what is it that is needing to be done? Because there are hundreds of families that are pleading, crying, needing to move on with their lives, with their children's lives, with their grandchildren's lives, and they're unable to do so. Thank you.

DR. DANIELS: Thank you, Jalynn. Next, we have Morenike. Do you have a comment for us?

MR. ISAACSON: Hi, there. Morenike asked me to read their comment for them.

DR. DANIELS: Thank you.

MR. ISAACSON: I lack the vocabulary necessary to adequately convey how emotionally draining it is to have to fend off the mischaracterizations and distortions that the members of the National Council for Severe Autism, Amy Lutz, Jill Escher, Allison

Singer, and others, every time there is an IACC meeting as well as social media gaslighting. Histrionics and false news aside, let's not pretend that this is a war between autistic IACC members and everyone else.

We wish for all people on the spectrum to be discussed, addressed, and described in a respectful, non-stigmatizing manner and to have the personalized support and resources that are needed regardless of their level of functioning. Let's dissect just one of the terms that has been described as basic, accurate, and meaningful language that is allegedly necessary and preferable over neutral language. How about risk for autism? Why would it be more respectful to use likelihood of autism rather than risk? The first known use of the word risk was in the 1600s. It was synonymous with hazard and was intended to refer to something being a source of harm. Risk according to Cambridge means the possibility of something bad happening, something bad that might happen, to do something although there is a chance of a bad result, causing something to be in a dangerous situation, danger or the possibility of danger, defeat, or loss, or to get into a situation that might have a bad result.

The Society for Risk Analysis says that risk involves uncertainty about the effects, implications of an activity with respect to something that humans value such as health, wellbeing, wealth, property, or the environment. Often focusing on negative undesirable consequences. Oxford University describes risk as the possibility of loss, injury, or other adverse or unwelcomed circumstances. It wasn't that long ago that the basic, accurate, and meaningful term for children like mine was the R word. It wasn't that long ago that the basic, accurate, and meaningful term for people who look like me was the N word. What about basic, accurate, and meaningful terminology such as colonizers deciding Zimbabwe should be called Rhodesia or Mumbai should be called Bombay. The accurate terminology for people who are redheads, freckles, and Olympic athletes, according to your logic, is mutant.

Red hair in humans is due to certain loss of function mutations of one of the peptide products of the POMC gene, the melanocortin 1 receptor. Freckles are associated with the variant of a gene called MC1R. Endurance athletes generally have a mutation in the ACTN3 gene.

You don't know, what I or any of the autistic members of the IACC know or have been through or what our families have been through - pica, enlopement, incontinence, aggression, communication challenges, group homes. You think that just because we choose not to disrespect our loved ones and cry woe is me that you are the only people who have experienced such things? It would be hilarious if it wasn't so myopic, privileged, and inaccurate.

DR. DANIELS: Thank you much, Steven, for reading those comments on behalf of Morenike. Thank you much for sharing those Morenike. Scott, do you have a comment?

DR. ROBERTSON: Thank you, Dr. Daniels. I want to say first that I appreciate the comments on employment, quality of life, health wellness, and, for instance, on homelessness. We had a prior workshop on the last iteration of the IACC on housing, homelessness related issues. I don't know if that's something that could be looked at, what was done before and maybe for future resources or future meetings. Because I know that we've seen increasing research studies in that focus, especially from internationally in the U.K., for instance, United Kingdom on homelessness and the impact. Because you need housing to be able to have employment, to have community living opportunities, to thrive in life and have a high quality of life.

It's one of our focuses, for instance,

on the employment related supports team that I'm on at ODEP. Well, I appreciate a lot of these comments in terms of showing a lot of the challenges folks have and successes and it's helped inform what we're doing with activities for the IACC and the strategic plan. I do have some concerns about some of the rhetoric in some of the comments as far as the plan the committee's use in the plan of inclusive language.

I'd like to emphasize there are two reasons that just from my perspective at least, that should undergird our use of inclusive language. One of which is an evidence-based practice from the research literature. We have data that shows that it is beneficial to folks to use inclusive, unbiased, respectful, strength-based language. That it's very empowering for folks and to use stigmatizing language can cause harm to folks.

We have that from personal perspectives of folks with disabilities, including autistic people and other studies that have looked at language rhetoric and both in written symbols, visual symbols. It's for similar reasons. For instance, there are visual symbols, including for the puzzle piece where there are pieces of folks' heads missing and things like that, that have caused harm for people, including non-autistic people. When they see stigmatizing visual symbols and hear stigmatizing language, it makes them think differently about autistic people too. Makes them think in terms of that we're not fully human, that we should not be fully included.

I think there are reasons from the research literature that support our work in this area as far as to have more modernization, I would say, of inclusive, unbiased language that is strength-based and respectful and still supportive of the barriers, focusing on the barriers and challenges that folks with differences in access and support needs may have in life.

Then briefly, I just wanted to also tie it back to our focus on diversity, equity, inclusion, accessibility here in the federal government is that we have agency priorities for DEIA and that includes our language used too in terms of what we do with the plan, what we're doing at agencies and departments across the federal government to support empowerment and full access to folks from diverse and underrepresented backgrounds.

Language is very meaningful and the content that we develop is meaningful. How we characterize folks we should think really carefully and strategically, and aligning with the evolution on what we know now from autism that we didn't know 15 or 20 years ago. That we know especially more from autistic people ourselves that have a valued perspective in terms of the rhetoric, the language, and the content that we should do. I think we've gone in a strong direction in terms of the inclusive language, the support for DEIA in the strategic plan. I think it's just the priorities in the federal government and the evidence-based practices for inclusive language is something that we should remember is a reasoning for the use of language in the manner it is in the draft plan. Thank you.

DR. DANIELS: Thank you, Scott. I would like to let, I've got five hands up, every person have a comment. If you can keep your comments a little shorter, that might help us get through it. I think we have enough time in the schedule overall to be able to do that. Ivanova, if you could go ahead.

[Inaudible Comments]

DR. DANIELS: Your audio is really poor Ivanova. We're not understanding.

DR. GORDON: I think it may be a problem with your Internet connection.

MS. SMITH: I just want to thank you [inaudible] kick in. Can you hear me?

DR. DANIELS: Yes.

MS. SMITH: Again, I'll repeat myself. This is Ivanova Smith and my comment is I want to thank those who gave comments about how it's important that autistic people have for access to the community. I think that's really important. I'm thankful that there are more autistic commenters and more people speaking about [inaudible]. We want to make sure that we're all in the community and our universal design principles is how we'll get there. I feel as we have the mindset with the curb cut effect, where we have accessibility that's accessible in a way that it makes everything better for it makes it easier for everyone to have access. Thank you.

DR. DANIELS: Thank you, IVANOVA. Josh, did you have a comment?

DR. GORDON: No. I was just going to thank --

DR. DANIELS: Thank you. Next, Sam Crane, do you have a comment?

MS. SAM CRANE: Hi, everyone. I had just two quick comments. One is I really appreciated Dr. Keenan's comments. I think that it's important for us to recognize that just because someone is standing, or sitting, or whatever in front of this committee today, we really don't know what that person's life is and what their functional support needs are. Then just to respond very quickly to JALYNN'S comment. This is a really common issue. I know maybe 20 people who match this description that she's describing of someone who has very significant medication management needs and cannot have their medication managed without significant supports.

That's one reason why advocates have been agitating pretty strenuously for paid in-home supports that come into a person's house and help someone with medication and with other activities of daily living by keeping that person in their home, in the community. They do retain the ability to have stimulation, to see friends, to go to activities, to take walks. At some point when they're ready, they can regain employment. It's much more difficult to obtain employment if you're at a medical facility just in terms of transportation, the discrimination that you face if that's your address. That is something that has been addressed in the community for many years now.

DR. DANIELS: Thank you, SAM, for sharing that. We appreciate that. Aisha Dickerson, do you have a comment?

DR. AISHA DICKERSON: One is a suggestion and one is a question. I did see the comment from Jenny Mccreedy on the public comment about airtime of IACC members. I have to say, I agree that there does tend to be a cluster of people who monopolize a lot of the comment time. I had a suggestion, and it's just something that I do in my group meetings. Is there a way that we can limit the amount of time that people have dedicated to comments the same way we limit the amount of time dedicated to public comment? That's a suggestion option.

That's one. Then two, I had a question specific to Morenike's comment on the use of risk versus likelihood, because this is something we've been discussing a lot within the autism research community. Risk is a term that we often use for statistics like risk ratio, relative risk, which is different from a likelihood ratio. I wanted to ask Morenike and anyone else on the call who might have some suggestions, what would be a better terminology for statistical evaluation of likelihood of an autism diagnosis in research? That's all.

DR. DANIELS: Thank you for that comment. We might have to have that discussion offline because of the time that we have here, but we certainly can take into consideration if the committee would provide any comments that you have based on that question about ways that we can describe likelihood, or risk, or other related concepts. You can put those in your strategic plan comments.

DR. GORDON: Actually, I think it's important to recognize that the terminology we use in a strategic plan is not meant to be the terminology that one would use in a scientific report. But I think, Aisha, you're appropriately raising a question, okay, I want to learn from this. If we're not supposed to use risk, which is a very commonly used term from a statistical perspective, what word might be used other than likelihood because that has its own scientific meaning that's different as well? I appreciate you raising that, and as SUSAN suggests, that's something we can follow up with offline.

DR. DANIELS: Thank you. Alycia Halladay.

DR. GORDON: there you go.

DR. ALYCIA HALLADAY: Am I back on?

DR. GORDON: I can hear you.

DR. HALLADAY: Great. Thank you. I want to thank you for letting me address some of the comments that have been made, both in the public comment as well as a response to public comment in the last 30 minutes. I think there's essentially been a mischaracterization, a misunderstanding of probably how the majority of people perceive what's accurate or what's acceptable terminology to refer to autism. It's clearly a complex issue.

Actually, Dr. Gordon, I want to acknowledge you for thinking about this and publishing about this when it comes to mental health and substance abuse. You're actually an excellent person to help guide us. Now we spend a lot of time talking about this, but it's really not as dichotomous as has been portrayed in recent attempts to dictate language. One actual example is what Dr. Dickerson just mentioned, which is the use of risk when you're talking about statistics versus the risk when you're talking about a probability.

Again, there's been diversity, again, just in the last 30 minutes. To add to that, some people prefer person first language and others prefer identity-first language. Some people even on this call have called conditions co-occurring and others have called them comorbid. These are just examples of many. There is a great diversity. Who is surprised by that? There's a great diversity in preference because we come from diverse backgrounds, we have different cultural backgrounds. We live in different countries. Some of the countries we live in provide services, and this is even including the United States based on sometimes some of the certain language that's used that's essential to receive those services. Of course, terms are based on context.

We just heard Scott talk about how there's data around use of language and how it can be stigmatizing and I’d like to ask SCOTT to send me that data, or at least the manuscript. Please don't send me the raw data. But I couldn't help thinking when I heard this stigmatizing to who and who decides? There's certainly a diversity of preferences and the community has not discerned what is scientifically appropriate versus what is appropriate in more lay language or board discussion settings. I think part of the problem is that many recent publications have left no room for the diverse opinion in the use of words, including things like person first versus identity-first language or other terms that I'm hearing here is even have diverse preferences.

These publications draw lines about words that they can be used or not. Not that they can be used in certain contexts. They can either be used or not. Unfortunately, this perspective can be shortsighted. I hope the IACC or someone else, since I don't think this is really the purview of the IACC, use a more data-driven approach of collecting preferences among different groups of people so that we can ensure that the most scientifically accurate, but also respectful language is used to characterize the person, the situation, and then, of course, the context.

I think everyone here is totally in

favor of using respectful and accurate language that respects the diversity of opinion. However, the current guidance that's been published is pretty dogmatic, and I don't think that it accurately reflects the feelings of the broader community. I think we need a larger conversation, maybe not at the IACC meeting, about this. But in the meantime, I think we should embrace different perspectives and different ideals about what is acceptable terminology.

DR. DANIELS: Thank you for that summary, Alycia. We appreciate hearing from you on that. We have Alison Marvin, and then it sounds like Steven has some comments to share on behalf of somebody that has some written feedback. Alison.

DR. ALISON MARVIN: Hi, this is Alison Marvin from the Social Security Administration. I wanted to first acknowledge the comment from Laurie Torres about the difficulties she's been having with social security. I also wanted to address Viola

Sanchez's comments that SSA has no heart and done with helping her grandson. He turned 18 and he lost his benefits. But I just wanted to just make a reminder that SSA, Social Security Administration, administers the law. That's what the agency does. It does not set policy.

If you would like the law to be changed, please contact the lawmakers. You might be interested to see that SSA regularly submits legislative proposals. If you look at ssa.gov/legislation, under the first link, legislative proposals, you'll see we regularly try to get the law changed. For example, last year's FY 2021, we had a proposal to improve SSI youth work incentives by disregarding all earned income and eliminating income reporting requirements through age 20, providing a higher disregard of earnings with a gradual phase down for SSI recipients between ages 21 and 25, and eliminating school enrollment reporting requirements. We also requested a budget to improve access to vocational rehabilitation services. That's what we had in FY 2021. FY 2022 is not up there yet, but the proposal for SSA to the legislators was more generous than that. Please contact your Congress people and if you can get the law changed, that's great. But currently we are limited by administering what the current legal status is. Thank you.

DR. DANIELS: Thank you, Alison. Next, Steven, do you have some comments to share on behalf of committee members?

MR. ISAACSON: Yes. I'm just sharing another comment from Morenike who said that they agree it's best to have a discussion around language offline. They said, "Please note that the narratives that were referenced in the public comments were about words used by families, not about statistical analysis and accuracy in scientific literature."

DR. DANIELS: Thank you much for that clarification. We're close on time. We're only three minutes over on the schedule.

Should we reconvene right at 2:30 or do we want to give a few extra minutes so people can have their 10 minute break?

DR. GORDON: I'd say we give a few extra minutes. Let's give them 10 minutes. But before we close, I just wanted to say something in closing. I really appreciate the back and forth. I appreciate that the tenor of the conversation was for the most part, respectful. We touched on some issues that are very sensitive, particularly around language. It's important for us to agree on language as a committee for the report. If in reviewing the report you have specific suggestions regarding our use of language that you feel you want to change in light of the conversation we had today, I encourage you to do so. That goes, of course, as others have already mentioned, that many of the comments will be incorporated in one way, shape, or form as we finalize the strategic plan moving forward.

We'll reconvene at 2:35. We'll be five

minutes behind schedule, so we'll try to make it up at some point. But I think people need some time to decompress. Thank you, everyone.

DR. DANIELS: Thank you, everyone.

(Whereupon, the Subcommittee members took a brief break starting at 2:25 p.m. and resumed at 2:35 p.m.)

DR. GORDON: Welcome back to our next segment of the IACC meeting where we're going to turn our attention to an issue that we haven't yet really spent a lot of time talking about, which is autism in older adulthood. Of course, we have been focusing more and more on lifespan issues. But one aspect of the lifespan, older age, is one that I think it's worth for us to consider. We're going to do that for much of the rest of the afternoon.

We're going to start with a lived experience panel and then hear about a brief overview of research on autism in older age from two scientists, one of them a member of the IACC. We're going to go right ahead and launch into this panel. Of course, by way of introduction, we know that adults have very different needs from children. Caregivers of adults have different needs from caregivers of children as well. While the IACC has really done an excellent job to bring focus to transition-age youth and young adults and making progress on adults in general, today we're really going to focus on older adults in their '60s or later.

We're going to start with a panel of five people who will share their lived experiences, either as autistic adults or caregivers for autistic adults. We're very happy to welcome back Mr. John Robison. Mr. Robison has been a former member of the IACC and is a neurodiversity scholar in residence, the College of William & Mary, and an autistic adult.

We also welcome Dr. Yulanda Harris, a certified neurodiversity professional and CEO of Trainingphase, and also an autistic adult. Our third panelist is Ms. Ruth Jones, who is the sibling of an autistic older adult, her brother PETER. Our fourth panelist, Ms. Lisa Morgan, is the founder and co-chair of the Autism and Suicide Committee of the American Association of Suicidology and an autistic adult.

The fifth panelist is Sue Swezey, a mother of an older adult son, sent in written testimony to be shared by Dr. Oni Celestin from the OARC staff. Thank you all for joining us today and for the willingness to share your stories. I'm going to ask John Robison to lead the panel presentation or should say to lead it off. John, take it over.

MR. JOHN ROBISON: Can you all see and hear me now?

DR. GORDON: We can indeed.

MR. ROBISON: First of all, those of you who know me from my time on the IACC, you know I generally just speak off the cuff, but today I have written this out that I can post a transcript online after the presentation, if anyone wishes to have further discussion. I've been involved with autism advocacy for 25 years now. Throughout that time, particularly during my 15 years of government service, I mostly advocated for autistic people younger than I. But at age 65, I'm here to ask, what about the older autistic population? We have unanswered questions and we need support.

I'd like to share some of the things I've experienced. All autistic people have some degree of blindness to the unspoken messages of others as part of the diagnostic criteria. What about blindness to ourselves, to our own bodies? That's less studied, but equally real. I don't have a good sense, for example, of when I'm hurt. I don't know when I'm too cold until I see frostbite. I don't know often when to stop or back down. I don't know really when to read my own body. People say things about sensing things in their bodies and those words are alien to me. When

I was 50, that didn't seem to matter very much. But if I miss medications now, because I'm not mindful of that, I may die. If I overstress myself now, I can suffer injuries that I can't recover from.

Every year the stakes for failing to recognize my body's cues grow higher. Isolation is a recognized problem for autistic people and it's worse in old age. How many people like me, therefore, die alone because they're out of touch with their bodies and their needs, no one is taking care of them, and they make a mistake? No one knows. Growing older I feel that I've gotten more autistic. The same can be said for many of my autistic friends. We are more inclined toward being alone. We are more isolated. Perhaps we are isolating ourselves. Ticks and mannerisms that were long lost seem to be resurfacing in me.

I'm less mindful of the need to look at other people and I would say my social skills have slept. That's contrary to my observations from a decade ago and the findings of a variety of studies, which found that people with good cognitive ability tend to see their disabilities diminish with age. That was certainly true for me up to a point. Ten years ago, I observed how much more successful I was in social situations than, say, at age 20. I saw how much benefit I'd gained from learning what my autistic strengths are and how to use them to best advantage, something that comes with life experience.

Those things are still true today, but they're less meaningful. I'm not as inclined to be social. I'm more at home being alone. My autistic technical abilities brought me success in many domains, engineering, music, photography, writing. But I doubt I could replicate those successes with my current cognitive abilities. I'm not as flexible, I'm not as patient, not as full of new ideas. I feel like I'm not as sharp. Now, all those same feelings might well be expressed by any aging person. We hear of senior moments, slowing down. I experience that - are autistic people different in that regard? I don't think anyone knows. But as an autistic person, I find those changes in me, which has happened since 60, troubling.

An old friend with autism had another part of the answer. He said to me, "You know when I hit 55, it felt like my ADHD-fueled energy just ran out." I never really thought of it that way, but that's very much how it feels for me. Ten years ago, and those of you who served with me on the committee before, you may remember this, I served on this committee. I served on INSAR’S board. I held two teaching appointments. I did 25 speaking engagements on site around the world every year and I still had time to run my automobile business in Massachusetts. Looking back, it was surely -- let's see. I see it says the host has stopped the video feed. Are we still connected?

DR. GORDON: You're still connected.

You're fine.

DR. DANIELS: Your video is fine. It looks good.

MR. ROBISON: Now the video has started. All right. Anyway, looking back, I can see that that was a great example of ADHD-fueled energy empowering me. It certainly kept me going and in my early 60s, it just went away. In terms of accomplishment or my ability to accomplish things, to me that feels like a great loss.

I can't do all the things I used to take for granted being able to do. If I look at the diverse range of things I did in 2017, five years ago, and the range of things I can do today, it is much more limited. That is not by choice. I just can't do it all anymore. My ability to juggle disparate, cognitive intensive tasks and get them all done was considerably better than average and that's no longer true. Given that that was an autistic ability, it is not a neurotypical ability. It's certainly fair to ask, is that a penalty I pay as an autistic person getting older? Ten years ago I was confident and full of energy. Now I am anxious, worried, and constantly tired. There's no question that my anxiety has increased these past few years. Is that autism? Is it natural aging? Is it even a side effect of COVID? There've been many articles about that. I don't know. But before COVID I knew a number of older autistics who became more anxious as they aged.

At the INSAR conferences where I saw older autistic folks from around the world, I had many friends that I saw become paralyzed by anxiety as they got older. I feel that that is a serious and overlooked problem in autistic people with otherwise good cognitive function. I feel that it worsens with age if those examples are a guide. I will also say that for people who say, well, JOHN, your life experience is just you and all autistic people are different. Now, I've heard all that before. As you know, I've probably talked to more autistic people in my life than most clinicians have at this point and I have certainly had thousands and thousands of people write me over having similar experiences as I've characterized in my books and writing. I think that these kinds of things may be much more common than we know and they are under the radar because there aren't that many autistic adults of my age speaking out.

Anyway, I've just enumerated some ways in which it feels like I'm diminished with age. Luckily, I'm surrounded by people who care about me and look out for me. Without that, in isolation, I could well imagine that I would come to the rational decision that suicide is my best option as there's nothing but pain to look forward to. As someone who's lived with depression and anxiety all my life and who's been in that place more than once, I really urge you to take that seriously. If a person like me seemingly well connected, articulate, and capable, can feel that that's a reasonable option, how many of my fellow autistics who don't have some of the advantages that I've had choose that way out? In my last time on INSAR’S board, we worked on a policy brief on suicide.

I think that's a big concern. The problem to solve is a societal one, not an individual issue. In earlier IACC meetings, we discussed the emerging realization that intellectually disabled and non-speaking autistic people may have as much or more suicidal ideation as non-intellectually disabled autistics. It's a lifelong risk for us no matter where we fall on the spectrum.

A recent labor department study found 7 percent of Americans were self-employed. A Dartmouth study of desire said 70 percent want to be. It's a little misleading in my case and in the case of many autistics. I've been self-employed most of my life because I had no choice. I didn't have the social skills to navigate work life in large organizations. That's a side of life statistics don't capture, but we can see it another way. The prevalence of autism and neurodevelopmental disorders among the homeless and incarcerated is well above the prevalence in the general population. Outside of that, [inaudible] and other follow-on studies showed that older autistics as a group, end up worse off than the general population by various measures of attainment. Given the contributions we make to the world, I think that is really wrong.

At 55, I felt like I could keep working forever. At 65, I feel like I have no choice but to work forever. Those are really different perspectives. I and most older autistics have absolutely no government, academic, or corporate retirement plan. In saying that, I'm not counting social security and disability. I'm talking about retirement funding that provides a decent standard of living in retirement as most working professionals in America can expect. The only retirement I have is what I make by investing and building assets. It's easy for any of you to say, well, that's just the same as me, but it's not.

Those of you with government, tenured academic, or corporate jobs get your retirement security by being part of a social system where you're employed. As long as you remain in that system for the duration, it will take care of you. I know of no statistics on this, but I suspect the number of autistic adults who successfully run that social skills gauntlet for the 30 some years to qualify for pension is very small. Reflecting on that, though, the issue is more than money.

Now, don't get me wrong, money for retirement security is important. That's something that I couldn't see when I was younger. The social network afforded by employment is even more important. Work is the place where so many people make friends, find life partners, discover new interests, and join a social web that nurtures and protects them in times of stress. In that respect, the workplace is more than just a job. Years ago when I tried to fit into a large company without success, I sneered at people standing around the photocopiers gossiping, and I thought, why weren't they working? They were just wasting time. But I now see that that gossip actually nurtured those people and was a valuable social support, which I never received because of my autistic disconnection.

It's fair to say, did they exclude me or did I exclude myself? I probably did exclude myself. But it doesn't change a fact that it's a very real problem that worsens with age. To help autistic people fit into workplaces and become more socially connected, I would suggest this thing that I think every autistic person listening will agree with. Fix the ugliness in our schools. That's a tall order, but that ugliness not only leaves millions like me with psychic injuries and the resultant disabilities that last the lifetime. It's the breeding ground for today's crop of school shooters and others who pose a far greater threat to society than people like me.

Our mistreatment as schoolchildren throws up lifelong barriers to our success at work and our associated social success. That stigma of childhood rejection follows us into adulthood where it joins with our autistic social disabilities to cause endless missteps in our efforts for social engagement. I suspect that when you get to my age, a lifetime of those missteps combined with our inherent autistic social disability really makes it harder and harder and harder until we give up on connection. That may be why some of us are more isolated at 65 than at 55.

Some of us withdraw, some of us turn to drink, some do connect. That we're lucky when we do. Many of us succeed at some level, but we live with more sadness, anxiety, and isolation than anyone would want. That is truly suffering. I don't know of any autistic person who wants that. There's nothing to celebrate about that side of autism. There's a whole generation of 40 plus autistic people who grew up with no diagnosis. Many of us are just going along aware that we're different, and feeling that we are less with no understanding of neurological difference. How would we see things differently? That's how I lived most of my life. Having talked with many such undiagnosed people, I believe the last thing they want is for someone to say, "Hey, you're acting autistic. You must have undiagnosed autism."

When presented with a paradigm shift like that, they reject it because of autism stigma. That was certainly my first reaction. In my case, the therapist handed me TONY ATTWOOD'S old book, Asperger's Syndrome, and he said, "No, really, it's not what you think. Read about it." He had taken the trouble to highlight passages that did match me. But even for me, and you know me as a champion of autistic people and autistic abilities, that was a very hard thing for me to overcome. I saw it as a disease with no cure, the reason I was a failure, and I would never get better. It was crushing at first. That's not how discovery has to be for us. That's where neurodiversity comes in, especially for us older autistics.

If we're presented with a neurodiversity paradigm instead of a medical diagnosis, there's a chance for a far better outcome to those conversations. Hearing that we have a different kind of brain is fundamentally different than hearing that we are disordered. We are stronger in some ways and weaker in others. We can start a conversation about balance, not deficits. We can start with diversity and not disorder. I really see this happen in some workplaces with many neurodivergent people.

I can give you one example. Some of you know that I'm the neurodiversity advisor at the Lawrence Livermore National Lab under the department of energy. The lab is one of the world's premier scientific institutions. Engineers and scientists work on some of the most difficult scientific and technical challenges known to us. Success there often requires extraordinary cognitive gifts and often those gifts are accompanied by diminished abilities and other domains. Many brilliant scientists and engineers have terrible trouble with human relationships, whether that's relating to the finance or human resources department at the lab or relating to their families or friends outside of work.

As an autistic person, I see clearly that neurodiversity is at the root of that, but I wouldn't say it's autism. If I were to say to somebody like that, somebody my age, you act autistic, a scientist at the lab would reject that because autism is a medical term for disability. Any conversation about autism starts by deficit. Deficits imply failure and most people working at a place like Livermore would not be characterized as failures, no matter how they see themselves inside.

Even if they do see themselves inside as having autistic traits, the next thing, and we've discussed this in IACC meetings in years past, is that if you're autistic, you aren’t qualified for military service. You might be a security risk. You're a higher insurance risk. There are many other good reasons to reject that. If on the other hand, we explain how their neurotype that makes them so successful has hampered them in social settings, we have the basis of a conversation that leads to understanding and making their lives better. I have seen at the lab how enlightenment has been as transformational for some of them as it ultimately was for me. You saw how it has worked for me over the years. Who might initiate these conversations?

I think neurodiversity at work programs are going to move in that direction. One thing that's important that Livermore is doing in their neurodiversity is directing their focus onto neurodivergent people who already work at the lab. I think that's where companies will get real benefit, making a few thousand existing workers happier and more productive through understanding their different brains. You really win big, much more so than a small number of neurodiversity at work interns, which is the current prevailing model, which I feel is failing. Companies that believe in this should see that the people they can help are right there on the job, not on the street waiting to be recruited.

Outside the workplace, once you're dealing with people who've aged out of public school supports, I really think that the medical and counseling professionals need training in understanding and presenting the neurodiversity paradigm. Because once the era of free support in public school ends, there's a tendency to reject something we don't want. Autism is not a thing that older people want to embrace with enthusiasm, but neurodiversity difference and empowerment are. I believe that that's a very, very important thing we can do to support older adults and it will help everyone. A final thought on neurodiversity in this space.

All of you know me as an autistic person and you know me as an expert on autism, I've served on steering committees to define autism and so on. But my multitasking, that's all always been ADHD. My reading difficulties, which you don't see, but I have, have always been dyslexia, just like my son who was diagnosed with dyslexia. My tremors sometimes that you see, maybe they're hints of epilepsy, maybe it's a little bit of Tourette's. Saying that I have a number of comorbid conditions, its insulting and it has no meaning. But saying, I'm neurodivergent, that's a thing that I can embrace. In saying that to you I would say that there's millions of people who would see it the same way as me.

Now, having said that, I respect that there are people who came before us in my time on IACC and said, "I hate my autism. I hate it. I'm not neuro divergent. I'm autistic." I respect that people can have other opinions than me. But I would suggest to you, with all due respect, that the neurodiversity power paradigm is very powerful and a great many people feel as I do, based on my experience talking to people. Before I ask for questions or comments, I'd like to offer these thoughts also. I served two terms on this committee and a number of years on government committees before that and I'm proud of most of what I said or did.

There's one thing that I regret. I regret the times that I criticized, or mocked people who attacked me, or said things I thought were ridiculous. To those of you I hurt with my words at those times, I apologize. Serving on IACC comes with a duty to advocate for all autistic people, no matter who they are, how they feel about autism, themselves. You, as IACC members or the committee, your job in representing the autism community before the federal government is to do your best for all autistics without favoritism. Every person who comes before the committee went to trouble to do so and they deserve our attention and respect. In the last years of my service on the IACC, I really came to believe those words apply most of all to the people who oppose us, who dislike us, who hold views we think are wrong or even dangerous. We are their representatives too, before the government.

I think that's really a sacred duty that we have to represent everyone fairly and at the same time to be guided by the best of today's scientific knowledge. It's up to you on today's IACC to carry this advocacy forward and urge you to do so with kindness, respect, and wisdom. Thank you.

DR. GORDON: I think we will hold

questions to the end of the session with the voice of the lived experience. We'll move on to our next speaker who is Yulanda Harris. Dr. Harris.

DR. YULANDA HARRIS: Good morning. Can everyone hear me okay?

DR. GORDON: Yes, we can.

DR. HARRIS: Thank you. First of all, I just want to acknowledge Dr. Daniels for inviting me to be a part of this panel, as well as Camille Proctor, who is the founder and director of the Color of Autism that referred me to Dr. Daniels. Just to share a little bit about me and my personal experience as an older adult. My company, Trainingphase, what I do is I work with businesses to create a more neurodiverse-friendly environment.

That's just a quick overview of what I do along with working in a non-profit sector as the Chief Organizational Development Officer, where I do leadership, professional development, coaching with the staff. Just to describe a little bit about my diagnosis compared to what I experienced earlier in life, I was 58 years old when I was formally made aware of my autism by receiving a diagnosis of Asperger's Syndrome which is a form of being on the autism spectrum disorder. The way my therapist had described it to me, or the psychiatrist had described it to me he said that, Yulanda you have mild autism. He went into much more detail explaining what autism spectrum disorder is.

I do want to really acknowledge my therapist, this was back home in Michigan, Dr. Duren Gutierrez from Easter Seals of Michigan which is where I spent a lot of my time going to therapy with him because growing up didn't really know what was going on even in my early adulthood as well. The way it was explained, and this is where I really want to just follow up with what ELLIOT was saying in the other segment, the earlier segment about high functioning autism, and knowing that based on research that I have done, it's not an official medical term or a diagnosis. That's why someone like myself do not using that term high functioning autism because it's an informal term that's used in a neurotypical setting that people will use when they talk about individuals like myself on the autism spectrum disorder, who can speak, read, write.

We're talking basic life skills like when we talk about eating, and getting dressed, things like that. We live independently. People who are high functioning, which is that term again, we still have a very hard time and challenging time when it comes to social interaction as well as communication. I'm now going to speak basically on behalf of myself where I now have learned to advocate for myself in addition to others with ASD. When it comes to any type of social interaction, I don't necessarily read or pick up on those social cues.

I have found especially as I have become older, and I know this is the part about being an older adult, this segment here, which I'm really going to touch a lot on over the years, and by me now being 62 years old and to be considered as an older adult, I still struggle with that in terms of aging. The issues and the challenges that I seem to have faced at this stage in my life is that one, with the understanding of knowing that autism is a lifelong neurological and developmental condition, you're going to find and we are finding that there are an increasing number of older adults who are now being formally diagnosed later in life.

Growing up I did exhibit and even now which is more prevalent where I exhibit a lot of the emotional traits where I was mistaken when I was much younger as being shy, being too sensitive, or right now in terms of dealing with past trauma. What I would have to do in terms of masking any type of autism symptoms in order to really appear neurotypical or just to fit in. By doing that, it became increasingly stressful. The stress, as you all know, when we go through any type of stressful situations, which is what Dr. Duren had really coached me on through the process in terms of staying away or to not be in a lot of stressful situations, that has really taken a toll in terms of mentally and physically when we talk about health problems over time in older adults.

That really explains as I reflect, as I think back, as I process that during that time as I was going through my stages in life, you can say that I now understand why I was misdiagnosed as being bipolar, misdiagnosed as having borderline personality disorder along with other mental health issues. We talk about severe depression and so on. The challenges I think now that I am really facing as an older adult is when it comes to communication. The communication level of being too direct, being very literal, and sometimes being misunderstood. I am very much aware of that.

Is it easy to control? At times, yes. It's manageable and I want to say control, but able to manage it knowing that this is a lifelong trait that I have. I think the ability to manage it now, not so much mask the behavior because as I go through and I mask or the term that's being used that I hear it now often, especially at work is I think we say code-switching. Code-switching for a neurotypical, especially as an African American woman or a person of color we have to code switch.

Well, yes, we can do that in the workplace. It's easy for a neurotypical individual to code-switch and then go back to being ourselves. But for someone, especially as an autistic adult, it is painful. This is something that I have tried to express over and over where I simply growing up and realizing now during my childhood, into my early adulthood, even now, it's very, very in intense and it can be very painful at times to when it's time to rip off that mask in terms of camouflaging. Those are the challenges that I have as an older adult.

Other challenges that I have when it comes to reading people, not being able to determine if this person is being sarcastic or if this person is just kidding. Where they have to tell me, "Oh, hey, I was just kidding." Things like that. I think one of the biggest challenges when it comes to older adults, as family members, friends, coworkers, colleagues, partners, to really be aware when it comes to our challenges of being able to discern trust, being able to establish those boundaries and safety of any type of relationships. One of the things when it comes to being older and at my age and realizing now being more aware that I'm not getting any younger.

I am getting older, is that we have to be very much aware of older adults who are being less mobile. We're talking the shrinking of the social circle that we have and the impact on the older person's social communication skills which, again, could mask any underlining autism traits. We are more susceptible when it comes to certain mental health problems particularly when we talk about loneliness and depression. This can have a huge, huge impact on our self-esteem and our behavior where it causes us even more daily to avoid any type of social situations. Because I am aware of all of that, I do what I can when it comes to my self-care, being an advocate for myself to not only manage certain types of behaviors, but to still see what I can do where I can, not necessarily, I don't want to use that term in terms of fit in. But to help others to understand, to be more accepting of individuals who are autistic.

I do know based on research that I have done that there are experts that say they're confident that autism doesn't get worse with age. But Dr. Robison just really hit on a point, I was taking notes, where he said that the older that we become more autistic traits begin to surface. This is what I have noticed when it comes to me. When that happens, even though I know there's still not a lot of what we don't know about any experiences when it comes to older autistic people, because it can be difficult to diagnose. It could be very difficult to diagnose, especially in older adults because a lot of the symptoms or the traits can actually mirror other age related conditions.

I can go on and on and talk more and more about this and I know we're limited on time. I just wanted to keep it brief and short and just share my experience and whatever advice I can give to family, friends, partners of older adults such as myself is to definitely educate yourself on how to be an advocate. Have patience. Have patience because especially during the meltdowns, which I still get, I still get those and it happens depending on the social setting, anything that can trigger that. Just to have that patience and to definitely keep a watchful eye especially for those of us who live independently.

I live independently and to keep that watchful eye and family support, friend support, partner support, that is so, so key. I just want to share just one of the things, examples of ways that I do get support from family. I just moved to a new city here, a new state where I'm originally from Michigan. I live in another state now and I do have family here. But one example is that my niece, if she doesn't hear from me within 48 hours, she won't just call me, she will FaceTime me and say, "Hey, I haven't heard from you. I want to see your face." She wants to see if I'm okay.

DR. GORDON: Thank you, Dr. Harris, in the interest of time to make sure we give all the panelists.

DR. HARRIS: Absolutely. That was my closing statement.

DR. GORDON: Thank you very much. We appreciate it.

DR. HARRIS: Thank you.

DR. GORDON: We'll move on next to Ruth Jones. Ms. Jones.

MS. RUTH JONES: Good afternoon. Here on the slide, let me see. Let me make sure. I have a little slide show here. My name again is Ruth Jones. I am the sister and legal guardian for my brother Peter Jones that you see on the screen here. I just thought I'd share these few family photos of him. He, of course, that's his youngest picture there in the middle. He's with my older sister Fern and I'm the younger sister on the right. We are the two family members that knew PETER the best and has stayed very close to his circumstances. I also included picture of PETER in the middle. I always thought he was my best looking brother with the rest of my brothers and then Peter on the end, where is a current picture of Peter. You can remove the slides now or leave them in the background, however. But first of all, let me start by also thanking Dr. Daniels for inviting me here today to share about Peter as well as was recommended by Jemma Grindstaff who is PETER's director at the Carolina Living and Learning Center, CLLC.

He is currently a resident there and has been a resident there for almost 31 years. Before I get into talking about PETER's current issues, let me give a quick background. Peter was diagnosed with mental retardation in early 1960s, which was discovered around the time he went to kindergarten. It was apparent that he would not be able to be educated in the traditional public school situation. Then he was the youngest of my parents' seven children. They went to work really hard to find out what else was wrong with their child because when he was put into classes for MR students, he didn't show the slow development issues. He wasn't Down syndrome. He had a lack of eye contact, the rocking, the communication issues. He just was notably different.

At that time, autism was not a household word as people know about autism now. I know it was first classified in 1940s, however, it just wasn't a well-known phenomena at that time. Fortunately, we lived in Raleigh, North Carolina, which is only 30 miles from UNC-Chapel Hill, where in 1972, Dr. Sharpler had brought a program called TEACCH to UNC and TEACCH stands for Treatment and Education of Autistic and Communication related to Handicap Children. Well, Peter was evaluated by TEACCH, and then my parents began to feel much more hopeful about what could be done for their son, the provisions for then -- him. Also in the early 1970s, the Society for Autism, Autism Society of North Carolina began and my parents became very active members of that. My mother used to say that -- I remember her saying that she and my father had been to more meetings and crossed more counties in North Carolina for this one child than all seven of us put together. Then

PETER was able to go to public school in the 1980s, to a special needs school. There in this school, he was in classes for the autism and he graduated in the early 1980s. At that time when we we're getting into the '80s, we're talking about Rain Man, the show, comes out, the movie comes out, and people are being more exposed to autism, the society is, and more provisions are popping up.

Regardless of that, Peter was at home by now living with my parents and the rest of the family. He was going to a workshop and he enjoyed the workshop very much. But my parents knew they were in their late '50s and '60s at this time, that they would age out of being able to care for Peter. My parents along with other pioneer parents worked very hard in North Carolina, worked diligently to see group homes like the one Peter lives in now come into fruition.

Peter is currently 62 years old and he lives in a group home where we work with the professional staff there to make sure all of

PETER's needs, intellectual developmental needs, behavior programming, vocational programs, adaptive skills, psychological, emotional, social, nutritional, and physical health concerns are met. PETER is on the spectrum, but PETER, unlike our other guests so far, intellectually cannot speak for himself. He can say some phrases. He has learned some phrases. He can tell you, Peter wants something. He can communicate some concerns, but he does not have language and you could not have a conversation with him. Therefore, his family has to represent him.

Today, when we talk about his challenges, he's 62 years old. He's had some traditional health challenges that come with aging. For instance, joint health, which a lot of us in our family have. But because of his arthritis and his knees, but because of his language barrier, it's hard for Peter to tell you that he's in pain - he has a high pain threshold. We've worked with the facility and they've come up with a lot of very good visual props that Peter uses that he can indicate when he's feeling pain.

This is very helpful. On the other hand, Peter has had several physical issues that are more related to his autism. Part of PETER's issue is that PETER seeks pressure, and he pushes and strains when going to the bathroom. That's created a problem. One time, he was grinding and sucking his teeth. That created a lot of dental issues. But going back to the issue with his straining and pushing, he had to have major surgery some years ago because of a prolapsed rectum.

They had to put some netting in there to bring the floor back up because of his autistic behavior, some of the things he was doing. When you have a person that can't express pain, knowing how to communicate with him was very important. Not only did they do the visual program, but they've gone through a reward system to honor Peter for good behavior and encouraging him not to push and strain.

He consistently has toileting issues though that when it comes to him spending time with family or friends, there are challenges when you're dealing with a 62-year-old autistic man who still wears protective underwear to help to maintain healthy hygiene, and so on. Along with physical health issues, anxiety, as John was speaking of. I can't agree more than I do believe anxiety increases with age. Peter has been at this facility for 31 years, and I am the third guardian. I am the first guardian to ever put Peter on medication.

My father before me, and my sister, and my family generally, objected to PETER receiving medication to control anxiety and some of his issues. But it was shared with me that they were creating more stress for him. They could tell with his repetitive actions and questions and so on. Therefore, they also used the sensory diet, which my sister helped bring to the facility as well. I'm sure some of you've heard of the sensory diet. It's a group of activities that are specially scheduled into his day to assist with attention, arousal, and adaptive responses. He also uses things like weighted blankets, pressure garments, tight underwear, tight t-shirts, things to help him to deal with the pressure needs he has. Another issue I have is succession and guardianship.

Well, let me add one other thing too. His anxiety issues. PETER is a very emotionally sensitive person without language. We had an incident many years ago where he would shout out very angry about a cousin whenever we were together with family, and we didn't know what he was talking about. Later on the cousin shared that he had pinched Peter. Peter carried this grudge for 10, 15 years until that cousin made up with PETER. He was fine then. But he wasn't able to say that to any of us. He couldn't explain that to us. Those are some of the concerns we have, the communication needs for Peter and his anxiety.

Going on, I only have a couple of others. Succession in guardianship. As I mentioned, my father was his first guardian, and he was his guardian until about 2002 when his health started to decline. My sister then became his guardian and was his guardian until her untimely death in 2017. I've been the guardian since. We have tried to involve family in PETER's individual programming meetings they have at the CLLC for him. We're trying to keep the second generation, our nieces and nephews. I don't have any children myself. But we are trying to keep them involved in Peter's needs and Peter's concerns because an untimely death could happen to me or any of us. PETER has lost not only my father and my sister, but he lost another brother last year who was part of his care team. And there are a couple of residents at the facility that he has lost. Grief becomes another issue. How do we deal with grief?

We've had a script as a family that

we've used to try to help Peter rationalize his loss. We say, "Daddy has gone to heaven." Or, "Florence has gone to heaven." And Peter will come back and he'll say, "Peter, go to heaven." Or "Ruthie go to heaven." He knows once you go, you don't come back. Our mother is 96 years old, and I am concerned at how he will handle her imminent death.

The other issue I have as far as a guardian myself, and this is where the federal organizations can be helpful, I am one of the few guardians at his facility that manage his funds, his social security funds as well as any funds he receives from working at the facility. I have to account for every dime I spend and return this into the clerk of court, and I have an attorney that helps me with this. But in working with the Department of Social Services, I find that most of how they want me to justify his income is only related to unmet medical needs, almost exclusively. Then I'm told by the courts, as a guardian, I must be bonded.

I'm to take the bond out of his social security money. I'm to take the fees for his accounting out of his social security funds. Unfortunately, these two government entities do not bridge. They do not know what the other does. They don't necessarily agree with what the other does.

I'm in a current situation where I am trying to get this sorted out, trying to get some understanding. I know it's something that my sister struggled with as well. Just what is the guardian supposed to do? I'm the state guardian as well as the guardian of the person. The last thing that concerns me, and this is my last comment, has to do with cognitive decline and dementia. My mother has dementia and I have a couple of brothers that are also showing signs of early dementia. The director at CLLC actually this afternoon, and for all this week is in a conference called Dementia Capable Care for Adults with IDD. This is about adults that have autism. They're already on the spectrum with cognitive challenges. For instance, those like my brother has a lot of cognitive challenges. Then you put dementia on top of that. That sounds like a true accident waiting to happen.

Or what do you do with that? How do we serve this population when this is going on? And I think we need to have more research about that and continue to research that subject. I thank you for the time to share with you about my brother, PETER. I'm sorry I had no pictures of my wonderful parents, but I hope that what I've shared will be something that will be helpful to all. Thank you.

DR. GORDON: Well, thank you very much, Ms. Jones. We really appreciate you coming here and talking about your family and your brother. Next up we have Lisa Morgan who's going to talk to us about her own experiences. Ms. Morgan.

MS. LISA MORGAN: Thank you. I also want

to thank Susan Daniels for inviting me to be a part of this panel today. I was diagnosed with Asperger's Syndrome at 48 years old. I just want to say I completely agree with the other panelists that my anxiety is getting worse as I get older. I'm going to be discussing my lived experience through what I have experienced and learned since my husband died by suicide in 2015. There's a need for crisis supports for older autistic adults.

My experience, my story, is going to be within the following information, and it's the way I've chosen to share it. Research has shown suicide to be a leading cause of death for autistic people without intellectual disabilities across their lifespan. A study done by STUART et al in 2022 with middle-aged older autistic adults found a five to six-fold increase in the possibility of self-harming behaviors and suicidality than in the general population of the same age group, even when controlled for symptoms of depression.

This finding indicates older autistic adults may be at a particularly high risk of self-harm and suicidal behaviors. The unique risk factors most commonly researched and supported for autistic people are even more challenging for older autistic adults. Masking, for instance, while a social strategy to fit in and have success with social interactions and communication, is a unique risk factor of suicide for autistic people. People diagnosed with autism at an older age have been most likely masking for decades. Research has shown masking to have a negative effect on mental health as well. This is due to the actual act of masking. As autistic people suppress any sensory stimulation in the environment, while they change their natural way of being to look and act non-autistic, put the correct emotion on their faces, and keep up with whatever social event they're participating in. It's exhausting.

Autistic people usually need to withdraw and regulate for self-care after a social event, school day, or work due to how exhausting masking can be. As well, we are not getting the benefit of companionship and relationship while masking because we're not being able to be our true selves, which in the end, while we may have participated successfully in a social event, no one got to actually meet us. The choice to be known for who you are as an autistic person and take the chance of being rejected or at the very least, not accepted, or mask, and not be known for who you are as a person. Number of unmet support needs is also a unique risk factor of suicide for autistic people.

Undiagnosed or newly diagnosed older autistic adults may have difficulty obtaining or accessing support services that can help them with housing, employment, physical, medical healthcare including therapy or other forms of mental healthcare. There was a national study done in Denmark in 2016 that found that 90 percent of the autistic people in the study had co-occurring mental health condition with anxiety being the most prevalent.

Some of the reasons for the difficulty is challenges with executive functioning skills, daily living skills, and the social skills needed to reach out for support services. Knowing who to call, what to say, or even what might be important to remember can be difficult for older autistic people who've never done anything like that before. Follow-up appointments, complicated directions, and simply using the phone to communicate can be so daunting that older autistic adults simply do not or cannot do it. Older autistic people can also find benefits in establishing a safety net of support people. But due to social communication difficulties and the isolation that can come as people get older and more restricted to home, it can be very difficult to develop a support network. Social isolation or thwarted belonging are also unique risk factors of suicide for autistic people.

According to CDC data, some 40 percent of older autistic adults spend little or no time with friends. I've seen that firsthand as a facilitator of a support group for older autistic women. The support group is the only social event some of the women can attend, and we meet once a month for an hour and a half. Also, many online support groups fill up quickly, and there's really a need for more online support. Other unique risk factors of suicide for autistic people are being diagnosed later in life, being an autistic female. Some of the reasons for these risk factors are due to a lifetime of negative social experiences, not belonging, being ostracized, knowing they're different but not knowing why, loneliness, daily struggles to just eat, resulting in unresolved trauma, PTSD, and autism burnout. Autism burnout is a syndrone of constant exhaustion, loss of skills, and reduced tolerance to stimuli that can last up to three months or more. It's due to the demands of life chronically outweighing the ability to cope and lack of support.

Results from a study done by Raymaker et al in 2020 concluded that masking, as well as experiencing discrimination and stigma related to autism can lead to autism burnout, which can lead to suicidal thoughts and behaviors. A way to help reduce unique risk factors of suicide for older autistic people and all autistic people is cultural competence and humility while supporting them. Also understanding that autism has its own strengths and challenges can help with communicating and supporting autistic people.

Some of the strengths of autistic people can be used to help during a crisis, such as being rule-based or adherence to routines.

These strengths can be helpful when the use of a safety plan is crucial to staying safe. Honesty is a strength useful when assessing for suicidal thoughts or intent.

The need for fairness can be helpful in reframing a suicidal crisis, for example, using a safety plan would be fair to oneself or one's family. Passions can be reasons for living. Being detail-oriented can be useful in knowing when to get support or implement the safety plan. Creativity and problem-solving can be useful for every aspect of staying safe in a suicidal crisis.

There are also resources available to help professionals communicate with autistic people in crisis. The crisis supports for the autism community toolkit developed by the Autism and Suicide Committee of the American Association of Suicidology is being used in crisis centers across the nation to both identify and communicate with autistic people in crisis. The toolkit is also being used by other professionals and even family and friends. Sometimes that's the only thing older autistic people who are adults have is the crisis call lines and text lines. More online support groups, social events, and even education about how to reach out for support needs, build a support network, financial information, daily living skills, communication skills, and many other topics can help older autistic adults help themselves.

For example, the website, autismandgrief.org that RUTH just brought up about her brother not understanding loss, that happens for a lot of autistic people. It's the first tool of its kind and helps autistic people who are grieving and dealing with loss autistically. This can be very helpful for older autistic people who are isolated and have no one to ask questions about grief and loss. We need more tools like this website to support older autistic people in other areas of their life. That's it for me. Thank you.

DR. GORDON: Thank you very much, Ms. Morgan. Finally, IACC staff person ONI Celestin will read comments from Sue Swezey. Oni.

DR. ONI CELESTIN: Good afternoon, everyone. The following testimony was submitted by Ms. Sue Swezey for the consideration of the IACC. "I appreciate the chance to comment on the work and goals of the IACC even though I cannot attend the meeting. As the parent of a 59-year-old autistic son, I have experienced the entire range of autism services or lack of them from their beginnings in the 1960s. While progress has been made, there are still terrifying gaps in the future for adults on the spectrum and for their families. Very few parents find it easy to locate residential placement for their adult children. In fact, the process is often harrowing and fruitless with few appropriate services available and with long delays and waiting lists.

While there seemed to be an increasing number of acceptable group homes, there are still horror stories of staff shortages, untrained and unqualified staff, inadequate services and activities, and sometimes abuse.

In addition, quality day programs and activities are hard to find. COVID and new federal regulations have taken a toll. The result for too many parents is that as the clients' age, families may age faster. Some parents may die before their adults are secure, while other parents may need as much or more care than their children. Most drastically affected are the oldest autistic clients and their families.

When my son was born, the autism incidence was four in 10,000, as opposed to today's astonishing one in 44. The Autism Society of America was then known as NSAC, the National Society for Autistic Children because there were so few known adults. Today's adults, 60 and older, are indeed the tip of the iceberg. They are the lead ducks for the incredibly swollen numbers who follow. They set a precedent and considering the present shortage of services, it is not an encouraging one. I am gratified that the IACC is considering autism needs at the federal level. This is an important step forward. I encourage this task force to examine the entire spectrum of autism needs and abilities, and to focus attention on the most severely challenged who have been left behind for so long.

Parenthetically, in today's world, much attention has been paid to autistic individuals who are high achievers. Perhaps some have attended college and have held jobs. Some are extremely bright and very verbal. This segment of the autism population was not included in early autism studies which focused on children with far greater differences. The high achievers may never have encountered any of these individuals. They deserve applause for their accomplishments but are probably not knowledgeable observers of the total autism scene. Best of luck to the IACC. I hope to hear positive results. Please feel free to contact me if I can provide further information. Best regards, Sue Swezey."

DR. GORDON: Thank you, Oni, for reading that, and thank you to Sue for joining us through that written conversation.

We're now going to turn our attention to a brief overview of research on autism in older age. Joining us to give us this brief overview, are Dr. Joe Piven, the Thomas Castelloe distinguished professor of psychiatry and director of the Carolina Institute for Developmental Disabilities, as well as Director of the University Center of Excellence in Developmental Disabilities at the University of North Carolina in Chapel Hill. Of course, Dr. Piven, as you know, is an IACC member himself. Joining Dr. Piven is Dr. Marsha Mailick, the Vaughan Bascom and Elizabeth M. Boggs professor and Vice Chancellor for Research and Graduate Education at the Emeritus Waisman Center at the University of Wisconsin in Madison. They'll be sharing an overview of research on older age and autism. Thank you, Joe, Marsha.

DR. JOE PIVEN: Great. Thank you. Well,

first, I want to thank this committee for including this topic and, of course, for the invitation. I want to acknowledge my experience working with Susan Daniels over the last few months and all the work that she's put in to pull this together. Then, of course, I wanted to thank my colleague, Marsha Mailick, for joining me today. Next slide, please.

Over the last 30 years, the fields of geriatric medicine and geriatric psychiatry have established that the science and practice underlying the care of older individuals require specialized research and training that differs substantially from that of younger populations. Yet, while research, training and services for autism have substantially increased over the same period, there's been a near absence of research on autism in older age. Originally described as a disorder of infants, so-called infantile autism by Leo Kanner, our conception of autism has expanded as those children first diagnosed in the '40s, '50s and '60 have aged into their sixth, seventh, and eighth decades of life. A 2010 article that I reference here on this slide in the Atlantic Magazine, telling the story of Donald T, the first child described in Kanner’s Seminole paper, who was then at age 77 at the time this article came out, was really the first to elevate this topic in the media.

The prevalence of autism in school-age children is currently approximately one in 50. But there's good evidence of similar rates in adults. But it's becoming increasingly clear that there's a dramatic under recognition of older autistic adults who were not first identified as children and are frequently misdiagnosed with other psychiatric conditions.

With the well-known aging of Western societies, this problem of a relatively absent knowledge base will only get bigger as those now identified at younger ages move into this period of their lives. Next slide, please. I'm going to begin this brief presentation with an example from my research where in 2015, we unexpectedly observed that older adults with autism who were examined directly with a neurological exam had high rates of Parkinson's disease in two independent small, and I want to underscore that they were small samples, one in North Carolina and one in Perth, Australia, 20 percent of our sample had Parkinson's syndrome, a rate that is 200 times that in the general population.

This finding was consistent with work from Lisa Croen who surveyed a large clinical database in California, and more recently Hilda Geurts, who collected questionnaire data on autistic adults in the Netherlands. These very different approaches all converged on a similar finding. Next slide.

If this finding is replicated, one obvious question is why is this happening? One example that helps us to think about this is Down syndrome, a genetic disorder of early development. People with Down syndrome not only have a problem with early development, but they have high rates of early onset dementia that is due to the same underlying biology that causes Down syndrome, and it's not an understandable consequence of having a disorder of development, or cognition, or lifestyle, or access to care.

Recently, a group at Drexel led by Giacomo Vivanti and Lindsay Shea reported high rates of dementia in autism using a large Medicaid database suggesting that elevated risk for dementia is also an important consideration in aging autistic adults. Next slide, please. Taking this a step further, while we tend to think about the biological roots of autism as being in early childhood, there is emerging data to suggest that brain changes may not be limited to childhood, but that specific brain changes, that is specific to autism and specific to particular ages, occur across adulthood in autistic individuals.

This work by Brandon Zielinski and Janet Lainhart at the University of Wisconsin is consistent with findings by Blair Braden at the University of Arizona in showing that autism-specific changes in brain development may continue beyond childhood. Next slide. The study by Lisa Croen that I mentioned earlier that suggested high rates of Parkinson's in autistic adults went a step further in their review of the medical records of a large healthcare system. In addition to high rates of Parkinson's disease, they also found that there was an increase in autistic adults in many medical and psychiatric conditions including hypertension, obesity, diabetes, and sleep problems, a finding that has now been replicated and extended by others. Next slide.

The question then becomes, why is this happening? Is tempting to ascribe this to a common understandable cause. Autistic people often don't get adequate clinical services.

They often have communication deficits that undoubtedly lead to underreporting of symptoms and less than adequate preventative care. Or maybe this is attributable to lifestyle factors like diet and exercise. All of these are important targets for intervention and policy that remain to be developed for this population.

But the correct answer is that we don't know if those are the explanations. High rates of Parkinson's may be due to underlying biology, just as we see in Down syndrome. Other outcomes may be a combination of factors. Complicating this further is the fact that while we call autism one thing, autism spectrum disorder, we know that it is not one thing and that the causes are heterogeneous.

It's also possible that high rates of Parkinson's may be due to mechanisms that are different from Parkinson's in the non-autistic population. We just frankly do not know. We need to understand all of these things in order to develop appropriate, preventative, and concurrent interventions, and then to train the workforce to provide specialized care. Next slide. So going beyond thoughts about causation, we need to appreciate the experience of having medical and psychiatric problems common in the aging population and someone with autism, as it is very likely to be different than someone without autism. The panel made that point very clearly.

What are the unique interactions between the characteristics of autism and the problems of aging? I was fortunate enough to have these vignettes put together by a colleague of mine who takes care of older adults with autism in Perth, Australia. I wanted to just take a minute to read them. An autistic man had an active and independent life, although he was noted to get upset with any changes in his routine or environment. His routine included morning coffee at a local restaurant. However, with the onset of

Parkinson's disease, severe tremor resulted in his being unable to drink his coffee without spilling it, leading to behavior outbursts, and ultimately, resulting in a substantial disruption of his schedule and notably diminished level of function. Another autistic man with high support needs living in a group home had always been able to feed and dress himself. With the onset of a severe tremor, he became fully dependent on care by others leading to chronic irritability, frustration, and behavioral upsets that required frequent interactions by his physician and group home staff.

Finally, an autistic woman developed akinetic-rigid Parkinson's disease with poor balance, frequent falls and a shuffling gait. As a result of an exaggerated fear of falling, she became reclusive and developed agrophobia, fear of open spaces, and panic attacks, and her level of function diminished considerably. She was misdiagnosed, by a local physician as having a late onset psychosis, later treated with an anxiolytic medication, anti-anxiety medication. She returned to her baseline level of function. Next slide, please.

In 2010, I organized a small two-day conference aimed at beginning to develop an agenda for research on older adults with autism. This conference included two separate groups, a group of autism experts and a group of experts in geriatrics, as there are by and large, no clinicians or researchers who are expert in both. To underscore this point, there are geriatric medicine and geriatric psychiatry programs in every university in the country, but it would be extremely unlikely to find any expertise in research, training, or clinical care specializing in autism in any of these programs. The reverse of this issue is that most clinicians and researchers working on autism typically started with a focus on children and have no expertise in caring for or conducting research on older adults.

We also brought together experts across multiple disciplines, from the biology of aging to long term care, basic scientists to policy makers. When you begin to think about the scope of the problem, you quickly realize this breadth of expertise is required. Next slide. There's not enough time to go into the recommendations that came out of this meeting, but I will end by noting that the group recommended the need for the development of screening, diagnosis, and assessment tools. As the vast majority of our instruments are for children, and in particular, not developed to identify declining cognitive abilities in older age or screen and diagnose autism in 60-year-olds. There's a clear need for a large scale longitudinal study on the order of the current adolescent brain cognitive development or ABCD study.

A longitudinal study of development across adolescents. As you will see in MARSHA's presentation, development in older age in autism is non-linear, and therefore requires study using longitudinal methods. But we also cannot wait for 20 years for those results. We need cross-sectional studies of older adults to characterize their problems and identify solutions sooner. We cannot make assumptions about causes. There is a need to explore the biology of aging as well as the impact of factors such as environment, experience, and lifestyle.

We need to first understand and then develop services, interventions, predictive measures, and preventative interventions, and strategies for long-term care that do not currently exist.

Finally, we need to train the workforce and build capacity in training, research, and clinical care. Next slide. Let me end and pass this microphone to my colleague, Marsha Mailick, who will tell you about her work on a unique longitudinal study of adults with autism and their families. I think it's fair to say that our work and that of a few others is just beginning to scratch the surface to point out where our knowledge is deficient and underscore the urgent need for multi-level research and training to establish what is currently the relatively non-existent clinical and research disciplines focusing on autism in older age. Thank you.

DR. MAILICK: Good afternoon. Can you see me? Can you hear me?

DR. PIVEN: Yeah.

DR. MAILICK: Great. Terrific. Thank you, all, for this focus on aging and autism. Thank you, JOE, for including me and for Susan Daniels as well, for including me. It's been an interest of mine that began many years ago. I'd like to tell you a little bit about our research on adolescents and adults with autism.

A large study that we began 22 years ago. It's still ongoing. I'd like to point out that our major funding has come from the National Institute on Aging, which is an unusual source of funding for people with a focus on people with autism. You see that during the 22 years, we have conducted nine rounds of data collection on a heterogeneous cohort who were as young as 10 when the study began and as old as 52 when the study began. Their average age was just over 20, and you could see their birth years.

This longitudinal research design makes it possible to look forward across the 22 years to track change prospectively in this cohort and also to look backwards to identify predictors of change. I'm going to tell you about predictors of mortality in this cohort. Next slide, please. Here, you can see some characteristics of our cohort when the study began 22 years ago and three-quarters were male, two-thirds were living with their parents, about three-quarters were verbal, 95 percent were diagnosed with autistic disorder, which was the terminology and diagnostic practice at the time. But all would be considered to have autism today, 70 percent had intellectual disability. But I note that the highest IQ in our cohort was 142.

It was quite diverse in terms of cognitive ability. Half had co-occurring mental health diagnoses. You could see that about a third had excellent health, half in good health and remaining in either fair or poor health. Next slide, please. We looked forward over two decades at various indicators of aging to understand how autistic adults might change from adolescents through midlife, and then from midlife into older age. Because we had such a wide age range at the beginning of our study, we were able to ask these questions.

In the interest of time today, I'm just going to talk about one indicator of adult development and aging. That is activities of daily living, ADLs. Now, ADLs are important because they're an indicator of functionality in adulthood. They include the ability to take care of oneself, to prepare meals, to keep your house clean and in order. Money management. ADLs are commonly measured in adults and older people in the general population is a sign of aging and vulnerability.

I'm going to show you differences between people who have autism with and without ID. Then I'm going to ask whether the same trend is evident for people with Down syndrome who we have also studied. Next slide, please. Here, you see activities of daily living measured in individuals with autism. The blue line are individuals in our sample who do not have intellectual disability. The red line are individuals with intellectual disability as well as autism. Their ages are along the horizontal axis. You can see we have people as young as 10 and as old as in their 60s, as I mentioned earlier.

What we see here, which is maybe not so surprising, is that people gain activities of daily living independence as they move through adolescence into the earlier years of adulthood. But around age 35, things change and there's a gradual loss of independence in individuals both without intellectual disability who have autism and those who also have intellectual disability. The non-linear trend is even more pronounced in terms of the gains of ADL independence and the loss among those who do not have intellectual disability.

Now, the next slide shows the same function for individuals with Down syndrome measured on the same scale of activities of daily living along the same age range. What we see is really different. It's not a curvilinear function, it's a linear function. The differences between those with autism and those with Down syndrome raise many, many questions that we don't have time to delve into today. But these questions warrant future research. Take a look at this one. It's pretty surprising. Next slide.

The patterns that we've observed in studies of individuals with Down syndrome and also those with fragile X syndrome in indicators such as ADLs raise a question about whether midlife is a period of risk for autistic adults. I ask this not only because of our own research, but also because other studies of population-based cohorts have found that adults with ASD have a shorter-than-average lifespan by about 20 years. This is really remarkable difference in terms of the risk of aging and the consequences of possibly factors that lead to poor health during older years. One of these studies was conducted in Sweden and another in Marshville, Wisconsin. They used very, very different methods. They both found about a 20-year difference in terms of average lifespan. Next slide, please. Based on those two studies, we decided to use our data to look back during the study period. In 2019, we did an exhaustive search, both in terms of family data, but also publicly available information about death and National Death Index.

26 of the adults in our study died

during the study period, which is a small portion of our cohort. This is a very small sample. But here, you can see the ages at which they die and also the causes of death. I show you the causes of death because every time I report on this, people say, "Well, what did they die of?" So you can see that some of the causes of death were very common in the population. Cardiac, cancer.

Other causes of death were much less common such as medication side effects or seizures. There was a pattern of choking as well as one of the accidents. This is just very descriptive from a very small cohort of individuals who had been followed. Next slide, please. But because we had followed them before their death, we are able to ask the question, what are the risk factors that predicted mortality, that differentiated those who died from those who survived? Not surprisingly, older age and worse health predicted mortality. There is no news there. But sex did not, males and females were similar, and ID status did not predict mortality.

Those with and without intellectual disability were equally likely to have died within our study period. But above and beyond controlling for age, health, sex, and ID status, what we found was that there were two factors that emerged in our statistical analysis. One was independence in ADL skills, activities of daily living skills. The other was impairments in social reciprocity is reflective of early childhood. For every one point lower on our measure of ADL skills, there was a 9 percent increased risk of death during our study period. For every one point higher on impairments of social reciprocity in early childhood, there was a 26 percent increased risk of death during the study period.

We have to ask a question, which is the same question that Joe has raised and many of the speakers, especially during the lived experience panel have raised as well. That is whether these patterns are due to barriers in health care and services, lifestyle factors which exist. There's no doubt about those barriers. Or are some of the factors that emerge inherent to autism. Or some combination of both. These are factors that require a great deal of additional research well beyond our small, single study. Next slide, please. It would be unwise skipping a very important topic if I didn't mention something about parental death study of aging and autism.

I have interviewed and interacted with hundreds of families who have a son or daughter with autism. The most common interaction involves the question, what will happen to him or her after we're gone? And you heard comments about that today. This father said, "In caring for him, family, friends, and institutions have frequently let us down. We're on our own with him. The greatest fear is what happens when we're gone." We determined through our ongoing study, which included the family even after the primary source of family support, who was almost always the mother, passed away. We checked who was the primary source of family support.

Subsequently, in 12 instances, it was a sibling and four a father. But in six of the 22 families in which there was a loss of a mother, there was no family member who was providing any family support for the also aging individual with autism. All of us need family support across the life course, but certainly, in our older years. The fact that six of the 22 had no family member support is a very important concern. We also determined where these adults lived after their mother died, 13 were in group homes, one with a father, two with siblings, four people lived independently. Two of those with support. One listed his residence as a college dorm and we had missing data on one more. Again, a very small snapshot starting from a cohort as large as 406. But I wanted to share that with you today.

Toward the end of my presentation, in the next slide I'd like to say a few words about an agenda for future research on aging and autism, building on JOE's agenda and not repeating it. We obviously need to expand the reach of our research cohorts and include underserved and diverse populations in longitudinal as well as cross-sectional studies of midlife and older autistic adults. We have been remiss in including diverse populations as we have begun to put our toe in the water in this important area of research.

It's really important to study how having autism affects aging. The lived experience panel said it far better than I could ever raise this point. But the stress of having autism, the genetic risk, the limited access to healthcare, the social isolation, the long-term polypharmacy. These are all important factors to measure as we think about research in the future that addresses the lack of research on aging and autism. How autistic individuals cope with aging-related loss and grief is an untapped area of work that also emerged in the lived experience panel, and clearly, we need to include multiple voices as we craft the research agenda going forward.

The one thing I think we can all agree upon is that we've only just begun to understand aging and autism. Also, this life stage is likely to be as complex as autism in earlier life stages, complexities on top of complexities.

For my last slide, I'd like to say a few acknowledgements and thank yous clearly to the several hundred participants in our study and my co-leaders of the research going forward. I'd like to also list the former members of our research group, and you know some of these names. Julie Taylor is one of yours. Paul Shattuck was on the agenda earlier today. All of these individuals made contributions to the research that we have conducted on aging and autism. Also, I'm very grateful to our funding sources, NIA, as well as NICHD, NIMH and Autism Speaks. But NIA was with us from the very beginning because they saw this as a two-generation aging family. As the parents age, the siblings age, and the individuals on the autism spectrum age. We have to think about this together. Thank you, all, very much.

DR. GORDON: Thank you very much. Dr. Mailick, Dr. Piven for giving us this really wonderful overview. We've now heard the voices of lived experience, both of individuals with autism and caregivers and family members of those individuals, as well as some idea of the state of the science on issues and challenges for individuals and families of individuals with autism. Now is an opportunity for us as a committee to ask questions of any of the panelists, those with lived experience or the scientists who presented to you, and to discuss any of the issues that were raised. As usual, please feel free to submit your comments to the send comments co-host, and also to raise your hand if you'd like to bring those comments to light. Please.

DR. GORDON: Dena, go right ahead.

MS. GASSNER: Thank you. I'm sorry, can we take that slide down and put the screen up so we can see people?

DR. GORDON: That would be great. Let's do that.

MS. GASSNER: I just wanted to say, Dr. Mailick, I appreciate your work. I've been following you for so long. But I wanted to ask this question. I have concerns that many of the students who are degree seeking, who may be clawing their way to a bachelor's degree or clawing their way through a high school diploma, are simultaneously being denied access to independent living skill training and support.

We often see these same students go away to college and crash and burn in the first semester or become suicidal because they're not coping. Or in all of these dynamics when the parent is gone and the parent has been doing everything for them, they're not equipped because people just expect them to be able to figure it out. I can tell you from chatting with some of my friends today, all of us have secret things that we can't even convey publicly because people will judge us for it, which are actually gaps in these skill sets. Whether it's being able to call a doctor, know when your meds are going to expire, keep your house clean, feed yourself. Can you comment on what you're observing in your research related to how that's looking?

DR. MAILICK: You raise a very, very good point and thank you for raising it. I think what we have done is divided the population with autism into two groups when they are in high school, those that we hope will go on to college and those who will not. It's often divided by ID, but it shouldn't be. Those who are divided into the second group, who are not expected to go on to college, they get really good training in maintaining or developing their ADL skills.

They often have capacities and experiences that we do not provide to those who are on the academic track. This ends up leading to all the things you just said. You know far better than I do about the range of problems that individuals have who have great strengths, as many on the autism spectrum do, as well as, I have never really thought of them as secret weaknesses, but I could see what you mean by that. I think if we don't divide the world up into so many unrealistic pieces, and we think about the importance of -- again, not to overstate the importance of our study. It's just one study. But that curvilinear relationship between age and ADL skills has gotten me very worried about autism as the individuals move into midlife and older age.

DR. GORDON: Thank you, Dr. Mailick. Thank you, Dena, for the question. I believe Steven has a comment or a question that he'd like to read. Steven.

DR. GORDON: I think you're muted. We can't quite hear you.

MR. ISAACSON: Hello?

DR. GORDON: Oh, now I can hear you. Go right ahead.

MR. ISAACSON: Thanks. This message is from Morenike. "I'm feeling a little sheepish making this remark because of some of what has been shared about there needing to be more equity in terms of IACC members' ability to contribute at meetings. I will try to be concise. First, I want to thank Dr. Harris for sharing your perspective as an adult living at the intersection of disability, race, and gender. So much of what you shared resonated with me and illustrates the reality of many individuals from our community. I also appreciate Ruth Jones' overview of her family's experiences as a Black family in the Southeast during a time that little was known about autism and especially the community-based housing and sensory tools Peter has accessed as a Black older adult on the spectrum with intellectual disability, who is minimally speaking, who struggles with anxiety. The health, hygiene, financial, and trauma-related circumstances you've summarized are of extreme importance and need to be highlighted. My autistic child also had a prolapsed rectum and was unable to communicate discomfort using words.

Furthermore, as I am an autistic adult who has recently been diagnosed with young onset dementia, I appreciate you bringing that up as well. There is currently minimal information and few resources that address these realities. Acquired neurocognitive disabilities such as neurodegenerative diagnoses such as mine need to be more adequately incorporated into neurodiversity, as right now, it is conspicuously absent and highly stigmatized. JOHN and LISA's remarks about suicidality, anxiety, and social isolation and Sue Swezey's comments about inadequate resources for older adults were significant as well. Although I think it's important to note in response to SUE's statement that though not all quite a number of autistic individuals who might be perceived externally as high-achieving are indeed very familiar with autistic people who are non-speaking, and or have intellectual disabilities, and or have higher support needs. Given that many of these individuals are people who some describe as profoundly autistic are often our siblings and our children.

Of note, though, that might not have been the case previously, this is true of nearly every one of the current autistic individuals on this very IACC committee who care about and seek to advocate for the needs of our loved ones and our collective community across the entire autism spectrum. Lastly, thank you to Dr. Piven and Dr. Mailick as well for the important research and the sobering observations you provided."

DR. GORDON: Thank you. Are there other

questions or comments from other members of the IACC? I don't have any hands raised just now. I might offer a question myself, if no one is going -- oh, let's go with Jennifer Johnson first.

DR. JENNIFER JOHNSON: First I just want to thank everyone for the remarks and presentations that they made. It was really helpful to hear from everyone and hear about the work that's being done. We, at the Administration for Community Living, have been doing some work in this area given the need as was well demonstrated in this panel for addressing people with disabilities, including people with autism as they age. We have some projects that we've funded. One last year that we funded to bridge Aging and Disability Services.

Within the Administration for Community Living, we have the Older Americans Act that we administer under the Administration on Aging that provides funding to state units on aging. They also then turn that around and provide funding to area agencies on aging. There is a nationwide network of aging programs. We also provide funding to aging disability resource centers. While they don't necessarily have a lot of expertise and experience in serving autistic individuals, our project that we funded is intended to better build that capacity within the aging network to support people with disabilities, including autistic individuals with a particular focus on support for families as well as they are aging. I appreciated the point that was made in one of the small research studies about the care that's often given by mothers and all their family members, but mothers do certainly bear most of the responsibility for their adult children with disabilities.

As we're thinking about not only a research agenda around aging adults with autism, I hope that we also think about the service agenda that we need for adults with autism. Again, how our aging networks within the Administration for Community Living can be a part of that conversation and the work that we're doing to support building their capacity to serve adults with disabilities.

DR. GORDON: Thank you, Jennifer. I saw Hari had his hand up for a moment, but it's back down again. I don't know if you wanted to make a comment. Go ahead, Steven.

MR. ISAACSON: Hi there. I have a comment from Hari. He says, "There are lifelong people like me who have a leg in both fields, in post-grad, but also still need lifelong supports, especially in ADL. Add to that, we already have movement issues from young age, possibly from greater risk for Parkinsonism and more as we age. How will this be accounted for because it seems like the thinking is one or the other?"

DR. GORDON: I don't know if either of our scientists would like to answer that question regarding individuals who come in to adulthood with preexisting movement conditions.

DR. PIVEN: I'm trying to undo my video here. Well, I'll just talk without the video. I think, again, the answer is we don't know. I think the key point here is that we can't make any assumptions about this. It's all of the above. I think that it's very possible that what we're seeing is something different from what we see in Parkinson's. We have life experiences that contribute. Marsha had a great slide on that. Stress. One of the things she didn't mentioned was sensory problems and the accumulation of that on older age and sensory problems impacting outcomes on cognitive function.

DR. PIVEN: What I can say, I think the main point of our two short talks is to basically just say there's a lot of stuff here that needs to be studied. These studies that have been done are really literally just scratching the surface. They're really just meant to point out that this is more than just my knees are sore because I'm getting old kind of aging. There are many other things going on here. I don't have a real good answer to HARI to address his comment other than to say, we need to answer these questions. We need to do the research.

DR. MAILICK: I could just add one point to that. Joe, you mentioned the need for bringing geriatrics and into our field, providing training and geriatrics to individuals who are concerned about autism. One of the most prevalent theories within geriatrics and geriatric medicine is cumulative advantage and cumulative disadvantage theory. I think the idea of coming into adulthood with movement problems and ADL limitations, it think speaks to the idea of the possibility of cumulative disadvantage, which only gets more challenging over time. We heard about increases in psychiatric symptoms, increases in anxiety, decreases in adaptive coping, shrinking of networks. All of those things together will interact as geriatricians have shown in the general population and even more so within our community of autism.

DR. GORDON: Thank you for that.

DR. GORDON: JULIE, please go ahead.

DR. TAYLOR: This was such an interesting panel. I really appreciated hearing about the lived experiences and also seeing where we're at with the research. Maybe JOE is the person best qualified to talk about this. Something that I've been thinking about a lot when we've been talking about aging issues is how do you find older adults on the autism spectrum? Because if somebody is in their 60s now, that means that they were children 50 years ago when we weren't seeing as many autism diagnoses. I would envision, but I might be wrong about this, that finding samples of older adults who have an autism diagnosis or who maybe even identify as being on the autism spectrum might be tricky, 40 years from now, maybe not so much as we're seeing people getting diagnoses more often.

But I've wondered, and I haven't had a chance to talk with somebody about how that works when you're doing samples and recruiting older adult samples. Can you find autistic older adults? How challenging was that for you, JOE? What are recommendations in terms of even trying to build samples of older adults who would've been less likely to get diagnoses, at least when they were children?

DR. PIVEN: Well, it's a huge problem. I think there are a number of easy to ignore methodologic issues, but this is one of them. There's a huge ascertainment bias in any study that you do at this age. I went looking in North Carolina for folks over 60, and it took me a couple of years really to find a small group of 20. They were by and large the individuals that were in residential facilities and had gotten diagnosed probably for other reasons very young. That's going to be a big problem. But we know actually from DAVID MANDELL's paper a few years back when he looked at a psychiatric hospital, a state hospital in Pennsylvania where he screened the general population of the hospital for autism and found that 10 percent had autism and it hadn't been detected. We can just assume there's just a dramatic under recognition and misdiagnosis in this group. That's our current problem is that we don't even know where they are. But then our future problem is that they're coming towards us. It's the pig and the python, so to speak. I think we don't have a population to develop our knowledge base on, but we need to get started. I think the other question that this brings up is what is older age in autism?

DR. PIVEN: We define it by a lot of different things, but for this process and this kind of a study, we can't really just start with 60, 70, and 80-year-olds. We need to start with 40 and 50-year-olds and follow them forward to try and get a handle on that.

DR. GORDON: Speaking to that, JOE, of course, are the non-linear graphs that show decline in daily functioning that begins decades or earlier than 70. That also backs up that notion that we really need to approach from a research perspective. Anyway, as you mentioned, we need to approach this from a slightly earlier timeframe, but also longitudinal timeframe to be able to follow individuals over time. I also like that you pointed out that that doesn't mean we don't need research that can impact people now that won't take those decades. I think both those points are well taken. We have two more people with raised hands, and then I think we'll probably be wise to move on. What I would say, so anyone else has any other comments or questions, please raise your hands now so we can budget the time accordingly. But in the meantime, DINA, why don't you go ahead.

MS. GASSNER: I'm going to first defer to John because he has a comment. But I would say too, I think the scientific community is really weak about using gatekeepers. I had a women's support group last night, 22 attendees, eight of them are at least over

45. I think if you start looking at the autistic leadership, we'll be able to find you as big a sample as you want.

DR. GORDON: That's a good point, reaching out to our community-based organizations. I'm sorry, I don't have JOHN's hand up. But, JOHN, did you want to make a point?

DR. ROBISON: Yes, I did.

DR. GORDON: Okay. Go right ahead.

DR. ROBISON: Am I speaking through to people now?

DR. GORDON: I can hear you.

DR. ROBISON: Looking at the slides that the scientists put up, they talked about mortality not being different for people with or without intellectual disability. For example, JOE talking about how hard it was to find 60-year-old people and most of them were institutionalized. Now, I published a commentary in Autism a few years ago talking about exactly that topic, that the vast majority of autistic people who were alive 60 years ago have never been diagnosed and they are invisible. They're just part of the system now. They're not out there to be found.

If I look at my experience at the lab, and I can't give you a specific number, but if you just reason with me, and you imagine that lab is full of a lot of brilliant geeks who have a lot of traits of neurodiversity. If the life expectancy of smart scientists at the Livermore lab was 20 years less than the lifespan of the general population, believe me, you'd hear about it. I think that's true in other places where you have large neuro divergent populations. I don't think that it's likely that many of us folks die that early. But I think it's very significant, for example, that you found such a higher incidence of Parkinson's. I commented myself on tremors increasing with age. I think it's very significant that every single person who spoke with me on lived experience talked about anxiety. I think we definitely know some things are problems, some things are very likely problems.

I don't know how you're ever going to go out and assemble a cohort of 60 something individuals like me, with me being a person who was not diagnosed in early childhood and probably grew to adulthood without a diagnosis. I think that's a really hard problem. We spoke about that several years ago. I would just make people aware that this isn't a matter of just funding a study and going out looking for those 65-year-old autistics because most people who did not get diagnosed are not going to just come out and become diagnosed today because we want to do a study. That's a really major barrier to researching this.

DR. GORDON: Thanks, JOHN. Appreciate it. We'll go with Jalynn next and then Scott.

MS. PRINCE: Thank you. Here we go back to my video.

DR. GORDON: I can see you.

MS. PRINCE: All right. Thank you. I

appreciate so much the research that you have done. We started looking at lifespan issues as the first organization in the country just dedicated to that. When we first started trying to do a literature search for anything above 50 was almost impossible. To see that you are taking this very seriously and looking at it in depth and seeing what else needs to be done, is to be applauded.

I've seen some interesting things with the groups that I monitor. One week, this was a few months back, there were 28 individuals on the sites that I'm on that had brought their stories forward about being over the age of 35 and being diagnosed on the autism spectrum just within recent months. There's a large cohort that we are seeing with the sites that we are looking at. Again, it's not the people that were diagnosed as children, but they're coming up, and they're going to be having the problems. They're going to be having many of the same types of problems. It is something that has a much greater number than we're able to identify. It's interesting that you had mentioned the first autistic man, Donald Triplett.

I did want to mention this. I was going to bring it in later. But since some of our guests are here, the book In a Different Key was written initially about him and there is a movie about the first autistic man, and it's going to be on PBS. It was done by John Donvan and Caren Zucker. It is going to be airing on December 13th at 9:00 PM on PBS Eastern Standard Time. That may give a little bit more of a context to the challenge of what we've been facing since the first official diagnosis of autism and the individual that this story is centered on. I think you could find it very, very interesting. Again, thank you very much for doing this research, and I would love to work with you in whatever way I could perhaps be of help.

DR. GORDON: Thank you, Jalynn. Finally, Scott Robertson.

DR. ROBERTSON: Thanks, Dr. Gordon. I'll try to keep it brief because I know we're running short on time. What I wanted to emphasize was that maybe we could look to, for instance, the states at times for collaboration on this. I know that in Pennsylvania, for instance, some of my colleagues there had just accidentally encountered autistic adults who are older in different facilities, et cetera. It was like what was being brought up today that folks were never diagnosed and just by happenstance. Maybe we just have to consider all different types of connections on this as far as at the state and local level. Maybe this speaks to also inter-agency focus. I know this is primary the focus, for instance, for ACL, but the rest of the agencies could be collaborating on this as far as the economic facets, the housing facets, as far as transportation, how that changes as folks age. But this is very enlightening. Thank you for shedding a light on the research and the data in this space. It's really helpful.

DR. GORDON: Wonderful. Thank you, Scott. Seeing no other hands up, I think we can move on to the final item on our agenda today, which is round robin updates. Susan, I'll let you conduct this part of the meeting.

DR. DANIELS: Thank you. We are open for round robin updates. I believe Alice Kau had an announcement about the ACEs, if she is on the call.

DR. ALICE KAU: Yes, I'm on. Can you hear me?

DR. DANIELS: Yes.

DR. KAU: Good. I'm Alice Kau from NICHD. I would to share some exciting news about NIH Autism Centers of Excellence program. NIH has just awarded nine ACEs to support large scale research on a range of research topics. The ACE program was established in 2007 by NICHD, NIMH, NINDS, NIDCD, and NIEHS. This is the fourth iteration of the program. In this round of competition, each application must include a plan for enhancing diverse perspectives. Community engagement is also a core feature of the ACE program.

Each ACE will have an external advisory committee that includes individuals with autism and parents of individuals with autism as members. Half of the cohort of these grantees are new to the ACE program. The research aims of this newly founded ACE will address many gaps in autism research as identified in the IACC strategic plan. I will now mention three new ACEs here considering the discussion and presentation in this meeting. First, the new ACE at University of Wisconsin Madison will enroll a large sample of male and female adults with and without autism to examine how aging-related differences may contribute to different health outcomes. Second, the new ACE at University of Pittsburgh will examine emotional and mental health in autism adults. Their research team will examine predictors of suicidality and validate a suicide self-report measure.

The new ACE at Drexel University will use a public health framework to study health determinants, health inequity, and health services delivery, and their impact on health outcome across the lifespan in those with autism. We will post more information at the IACC website.

DR. DANIELS: Thank you so much, Alice, for that timely update, and we look forward to hearing more about the ACEs and probably we'll share here at IACC about them in the future. Larry Wexler, do you have an update for us?

DR. LARRY WEXLER: I do. Thank you, Susan. Good late afternoon everyone. I manage the Department of Education's Office of Special Education’s discretionary grants programs. I manage a fairly large portfolio of grants. We made a number of personal preparation grants that are focused on doctoral training and master's level training around autism. But what I wanted to share with you was a non-autistic-focused grant.

It's called the RHONDA WEISS Data Accessibility Center. It's one we're really excited about.

It's focused on blind and visually impaired. But we have found that many of our access projects relate to people with all sorts of perceptual disabilities. We're the people that brought you closed captioning, which is used a heck of a lot more by people watching Netflix now than by people who are deaf. This center, the issue we had is that our data are posted publicly. I oversee the data for 7 million children with disabilities in the United States. Anyone in the public can download those data into whatever format they want, and then they can manipulate the data. If you're blind or visually impaired, your screen reader will read the data, but it's incapable of manipulating the data. This is a $10 million, $15 million software development project over a five-year period to essentially answer that question, can we develop software that would allow someone who is blind or visually impaired, but for other reasons, isn't able to manipulate data in its normal format? Many of you who probably have doctoral students or graduate students, if they have a disability, know some of the challenges around accessing data when someone has a significant perceptual problem. Anyway, we funded that. The grantee is AEM, which is a DC-based large consultancy who frankly has done other software development for us and did a spectacular job. That project changed the way we collect data throughout the country. They're in partnership with Westat which actually has handled our data for decades. Anyway, stay tuned. I thought you might be interested. While it's not autism-focused, I believe it will have an impact on many, many people and give people access. Thanks.

DR. DANIELS: Thank you so much, Larry, for that update. We really appreciate it. Jennifer Johnson, do you have an update from ACL?

DR. JOHNSON: Yeah. I just wanted to mention a couple of other new projects that we're funding. I think you've identified several of the initiatives that we're supporting. I did mention the center that we've funded this September for individuals with co-occurring mental health disabilities and intellectual and developmental disabilities. That will continue our work in the area of health equity but also in an important area where people experience co-occurring mental health and intellectual and developmental disabilities. We also funded this September, the National Center for Diversity Equity and Inclusion. This is a center that will also contribute to the work that we're doing in health equity but also broaden it into other areas where people with disabilities experience discrimination. That is something that will continue.

We also just announced funding for National Center on the Direct Care Workforce that's focused on building capacity within states and communities to strengthen the Direct Care Workforce. I think everybody is probably familiar with the crisis that we have been in that was made that much worse through COVID. That people are really, really struggling these days to find direct care workers and retain the direct care workers that they have. This is a project that is jointly funded by the Administration on Disabilities and the Administration on Aging, because this is an issue that cuts across both disability and aging. That center is just getting launched. It has a number of aging and disability partners that, again, will be looking at the caregiver crisis and helping to address that.

DR. DANIELS: Thank you so much for those updates, Jennifer, on those different projects. Are there any other members that have updates to share? Oh, I see, Yetta, you have your hand up.

MS. MYRICK: Yes. Thanks, Susan. Just want to highlight a couple of things that are in the round robin document. The first of three that I submitted. One, is that I co-created a new book about developmental milestones. It's called Mr. Marshall's Block Party. It's a children's book, and really the focus is to support Black and African American families in monitoring their child's development. This was funded through the CDCs COVID response project. I am the CDCs Act Early ambassador to the District of Columbia.

One of the things that I was hearing from families is that they don't see themselves represented in the materials oftentimes. This was basically an answer to that for the families in DC. But the book is available as an e-book. The link is in the round robin document for free as well as can be purchased on Amazon, but literally for the cost of the printing of the book for sustainability purposes. Other than that, the book is free and you can access the e-book. Let families know that. Also, I work with Dr. ALLYSA WARE at Family Voices on a project that's PCORI funded.

We trained 36 African American parents and stakeholders over the summer. Some of the things that came up in that conversation and we're still in process that I think relates to the strategic plan specifically for the African American community, is really focusing on life after the diagnosis and integration into the community across the lifespan. We've already been talking about that today. Another thing that we found through this process is that quite a few of the self-advocates that participated were self-diagnosed. Just want to flag that for the committee as well. Then the third thing, which I think is of interest to everyone is the Supporting Access for Everyone Initiative, and I believe Morenike is also on this consensus panel. They have extended out the call for public testimony on their website. The due date is October 31st. There was a public forum held last month, two days where people provided testimony. Initially they closed it, but they opened it back up because we recognized we want to make sure that we're getting diverse points of view. But really think about this as the autism-friendly hospital initiative and really wanting to make sure that providers have a clear understanding of how to support individuals and their families across the lifespan. Definitely check out more detail in the round robin document, and I hope that you all will submit testimonies. Thank you.

DR. DANIELS: Thank you so much for sharing that, Yetta. I didn't mention this, but there is a round robin document for anyone who's watching this meeting today. You can go online and our members have submitted in writing a lot of different updates. Please check out that document. But next we'll go to Alycia Halladay.

DR. HALLADAY: Hi, everyone. Thank you, Susan. I'll be quick. We have some announcements first. Our pre and post-doctoral fellowship mechanism, along with our new post-undergraduate fellowship mechanism is live. The deadline is early December, so before our next IACC meeting. I thought I would put a plug in to make sure that everybody was aware of that. Also thank you, Susan, for mentioning the Participate in Research portal. This is something we had wanted to do for a while. Years ago, the Interactive Autism Network, which I know has now moved over to Spark, had a dashboard where you could enter in the characteristics of your family or yourself, and then a number of options would pop up for you to participate in research.

Frankly, I don't know of a study that doesn't have problems recruiting individuals and families, so we thought this was a great opportunity. It's free for families. It's free for researchers. You can search by age. You can search by your preference and type of study. You can search by what is available in your community and online. We're hoping to, as we go forward, help the researchers who post make them more friendly and accessible to the community. I know that's not always equal. Then finally, since our last meeting, we have hosted and shared the meeting we did. We collaborated with the Phelan-McDermid Syndrome Foundation, the International CDKL5 Foundation. I'm obviously forgetting the University of Indiana on initiatives to better understand gastrointestinal symptoms in individuals with neurodevelopmental disorders. These can be fatal.

A lot of times individuals don't sometimes understand or are able to tolerate the diagnostic procedures involved in gastrointestinal assessments. We has a two-day meeting around it specifically focused on those with neurodevelopmental disorders and identified areas of need going forward. We had also conducted both the quantitative and qualitative study about people's experiences with GI issues and autism and neurodevelopmental disorders. You can go to our website, candidgi.com and watch all the videos and see all the presentations. Then also there's some other features on that website that you can see. That's it.

DR. DANIELS: Thank you, Alycia. I'm going to go to Steven. Did you have something that came in in writing?

MR. ISAACSON: Yes. Hi. Jenny Mai Phan is promoting a research study from California State at Fresno. They're recruiting Asian families of children between the ages of three and 21. She says, "Asian families of children with intellectual developmental disabilities are asked to share their experiences participating in a child's IEP, individualized education program meetings. Families are asked to complete questionnaires in a 30-minute interview. For more information, please contact KRISTINA RIOS at krios@mail.fresnostate.edu."

DR. DANIELS: Thank you, Jenny. Next, Dena Gassner.

MS. GASSNER: I just wanted to share that Drexel is sponsoring a power policy luncheon

November 2nd virtually from 12:00 until 1:00 Eastern Time. Myself and three other colleagues who are part of the AIR-P network on reproductive healthcare are going to be unpacking reproductive rights and disability rights. If anybody is interested, it's been on Facebook. You can look at a variety of different people's pages and pick up on it. I also dropped a link here in the chat. Thank you.

DR. DANIELS: Thank you, Dena. If you need to send that, if it's not in the round robin document, you can send it to us and we'll update the document. Scott Robertson.

DR. ROBERTSON: Thanks, Susan. If I could send a few things for URLs to update the document, that'd be great. I apologize for not having sent it earlier in the written form is both for the neurodiversity in the workplace guide/toolkit that was updated, askearn.org that was mentioned in the remarks at the beginning of the day on National Disability Employment Awareness Month. We had an event recently of corporate employers and disability advocacy leaders who came together to discuss innovative approaches to fostering mental health friendly workplaces.

I can send you the link for that, for the video for that in honor of National Disability Employment Awareness Month. This was an employer chat on workplace mental health and wellbeing. Then I can also include the link for our general and National Disability Employment Awareness Month slide. I know the month is ending, but if anybody still wanted to organize any events or wanted to organize events for 2013. Then the other brief thing to mention too is that our partnership on inclusive apprenticeship now has an equal employment opportunity toolkit and some other updated resources on inclusiveapprenticeship.org. I can send you those links. Thanks, Susan. Again, sorry that I hadn't sent these in a written form before.

DR. DANIELS: That's fine. You can go ahead and send them to us. We appreciate it.

DR. ROBERTSON: Thank you. I appreciate.

DR. DANIELS: Aisha Dickerson.

DR. AISHA DICKERSON: They won't let me turn my camera on, which is fine, but it just occurred to me right now that I did not send in this information for a symposium that's being hosted at Tufts University on November 10th on the role of food and nutrition in autism. I'll add that to the round robin document so you all can share it.

DR. DANIELS: Feel free to send that in. If anyone has anything else to send in, you can send it to us and we will update it, and you'll have all of that information. We really appreciate everybody sharing events and activities from around the community. In closing and Dr. Gordon can join me on this, I want to say thank you to all of the panels and presentations we've had today. We've had really great discussions on employment and aging. Both of these topics every year, we do try to, at NDEAM, talk about what's going on in employment, and it's been a goal for a while to really have a good discussion on aging and autism. I feel like we did a great job hearing from a lot of different perspectives and discussing what's known in the research field right now. Thank you so much for all your engagement on that and also for your engagement on the strategic plan process. We have some action items, which I outlined earlier, and I'll follow up with email to let people know what we need for the next steps before our January meeting. Josh, do you have some remarks?

DR. GORDON: I want to thank everyone for their respectful discussions. I know that some of the comments are controversial, but I think they also give us things to think about, and as was brought up by several individuals, for example, thinking about making sure that we are considerate about the language we use and also making sure that we are representing the full spectrum of autism. I thought there was some very thoughtful discussion about our efforts in that regard.

Thank you very much to that. There was a comment made by someone, and I think echoed by someone else that there have been concerns about some people monopolizing the conversation.

I felt like today that was not the case. In fact, someone else said, "Oh, I'm worried I might be monopolizing the conversation, but I want to say this anyway." I have to say that it's my job to make sure that doesn't happen. If there are other folks who haven't spoken yet waiting in the queue, I can elevate them, et cetera. But so far, we've been able to fit in the full breadth of the conversation around most of the issues that we've talked about today with some limited exception. I feel like today was very good in terms of different people chiming in, and I think we definitely saw that perspective. But I will continue as chair of the IACC to watch out for that. If anyone does have any concerns about not being able to get in their comments, please let me know offline, and

I'll be happy to make sure that everybody gets their opportunities. Thank you very, very much.

Last, as Susan will talk about upcoming actions, I do want everyone, as they look over the strategic plan, think about what they heard today and whether we might need to make changes to the document as we go towards finalizing it early next year.

DR. DANIELS: Thank you. I've listed here the upcoming action items, but don't feel like you have to memorize them off the slide. I'll send you an email or several emails to get all of these from you. Don't want to close without saying thank you to the wonderful staff in the Office of Autism Research Coordination who brought you this meeting today, have been working very hard behind the scenes on all aspects of the meeting. The over 100-page strategic plan draft that we have in front of us is the product of a lot of hard work to try to incorporate all of your valuable feedback and comments. Thank you to the team and thank you to all of you for your really engaged participation. We've very much appreciated hearing from every single person, including all the different public commenters, panelists, presenters, and the members of the committee. Thank you so much. We look forward to seeing you next time.

DR. GORDON: Let me add one final thank you, which others have already done, which is to thank you, Susan, for your fearless leadership of this endeavor. We'll see you all hopefully in person early next year.

(Whereupon, at 5:00 p.m., the Subcommittee adjourned.)