INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, July 21, 2021

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

PRESENT:

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

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

COURTNEY FERRELL AKLIN, Ph.D., National Institutes of Health (NIH)(representing Francis Collins, M.D., Ph.D.)

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

SKYE BASS, L.C.S.W., Indian Health Service (IHS)

DIANA BIANCHI, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

SAMANTHA CRANE, J.D., Autistic Self Advocacy Network

PRESENT: (continued)

AISHA DICKERSON, Ph.D., Johns Hopkins University

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

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

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

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

MORÉNIKE GIWA ONAIWU, M.A., Rice University

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

CRAIG JOHNSON, B.A., Champions Foundation

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

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

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

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

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

VALERIE PARADIZ, Ph.D., Autism Speaks

PRESENT (continued)

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

GEORGINA PEACOCK, M.D., M.P.H., F.A.A.P., Centers for Disease Control and Prevention (CDC)

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

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

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

LAUREN RASKIN RAMOS, M.P.H., Health Resources and Services Administration (HRSA)

SCOTT MICHAEL ROBERTSON, Ph.D., U.S. Department of Labor (DOL) (representing Jennifer Sheehy M.B.A.)

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

NINA SCHOR, M.D., Ph.D., National Institute of Neurological Disorders and Stroke (NINDS)

JENNIFER SHEEHY, M.B.A., U.S. Department of Labor (DOL)

MATTHEW SIEGEL, M.D., Tufts University

IVANOVA SMITH, B.A. University of Washington

PRESENT (continued)

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

HARI SRINIVASAN, University of California, Berkley

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

DEBARA L. TUCCI, M.D., M.S., M.B.A., F.A.C.S., National Institute of Deafness and Other Communication Disorders (NIDCD)

PAUL WANG, M.D., Simons Foundation

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

NICOLE WILLIAMS, Ph.D., U.S. Department of Defense, (DoD)

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PROCEEDINGS

DR. SUSAN DANIELS: Hi, I am Susan Daniels, Director of the Office of Autism Research Coordination at the National Institute of Mental Health, and also the Executive Secretary of the Interagency Autism Coordinating Committee and Acting National Autism Coordinator.

I am happy to welcome you all to this first meeting of the new IACC, Interagency Autism Coordinating Committee. We are so excited to have the Committee here with us today on this virtual platform.

And welcome to our viewing audience who are watching on NIH VideoCast. A quick reminder that we have a live feedback link available on the VideoCast that anyone can access to provide feedback throughout the meeting. And any feedback that is collected through the first session tomorrow will be a part of our public comments tomorrow. Feel free to use that.

Welcome to everyone. Welcome to all our special guests, the special speakers we have today with us. We really appreciate you being here to help us to kick off the IACC.

So, without further ado, I am going to turn it over to Dr. Joshua Gordon, our IACC chair.

DR. JOSHUA GORDON: Thank you, Dr. Daniels. I am going to add my own words of welcome to this august group of committee members, to our special guests and to the public, all of you out there in Zoom land, watching the VideoCast and especially to those of you who have contributed public comments in advance of this meeting, which we will discuss at various times throughout the next two days.

It has been my pleasure to serve as the chair of the IACC for these past five years during its previous incarnation. I am really excited to welcome our newest group of IACC members and proud that we are able to host this first meeting even though we cannot do it in person.

The IACC is a crucial forum that discusses the needs of those in the autism community. It is comprised of members from the public and private sectors. It seeks to represent a diversity of perspectives that really cover the full nature of what it is to have autism in America and what the needs are for individuals and communities affected by autism.

The principal purpose of the IACC is to provide advice to the Secretary of HHS on issues related to autism. It is my pleasure to note that we are being joined today by the Deputy Secretary of the Department of Health and Human Services as well as the National Autism Coordinator, both of whom are charged with relaying this advice to the Secretary.

Of course, the purpose to the IACC and its influence goes far beyond this advice giving. It serves as a forum to give direct input to a number of federal departments and agencies across government via their representatives on the IACC. The IACC also serves as a two-way communication forum between the government and public. It creates and promulgates recommendations for priority setting for both research and care. And it gives voice to the full spectrum of people affected by autism.

The IACC then as a locus to discuss issues of import to those with autism and to those affected by it is really importantly charged with bringing forward issues, ideas, and controversies that are underappreciated and that need attention.

It is also a place where we can disseminate the latest and most impactful research findings so that the public and federal agencies alike are appraised of the next things to do to try to improve the lot of those affected by autism.

To that end, it is my intention as always to foster in this group a robust exchange of ideas both between IACC members as well as from panelists and other invited guests and of course the public. I expect that you will see that over the next two days as well as over the future meetings of this group.

Again, I thank you all for joining us today. I will turn it back over to Dr. Daniels.

DR. DANIELS: Thank you, Dr. Gordon. We have some special speakers today. We have Dr. Courtney Aklin, the Acting Associate Deputy Director of the NIH, the HHS Deputy Secretary Andrea Palm, Senator Bob Menendez, and Representative Chris Smith will talk to us. We will let them each go in turn. I will turn it over to Dr. Courtney Aklin. Welcome.

DR. COURTNEY AKLIN: Thank you, Susan, and good afternoon to all of you. On behalf of Dr. Francis Collins and the NIH, I would like to provide yet another warm welcome to all of the new and returning members of the Interagency Autism Coordinating Committee.

As you can see, we are truly excited and appreciative of the time, energy, and commitment. The work of this activity and the insights that you bring to the table on important issues such as research, housing, health care, services for individuals in the autism spectrum are invaluable and we thank you for that.

To Dr. Joshua Gordon, chair of the IACC, and Dr. Susan Daniels, Acting HHS National Autism Coordinator and Executive Secretary of this body, I thank you for your many years of leadership of this committee and NIH’s overall autism efforts. I understand that this year’s committee reflects the largest and most diverse membership from across the autism community. I am incredibly excited to see how the diversity of perspectives among this group leads to innovative and invigorating ideas to further support individuals on the autism spectrum and their families.

Please know that we are working alongside you to support the autism community through advancement of biomedical research to understand the underlying biology of autism, developing cutting edge approaches in schools to improve diagnoses, interventions, and services.

On today’s agenda, topics such as the impact of the pandemic on the autism community and addressing racial equity and disparity in autism are central to the conversation that we are now having across NIH – for instance, NIH recently launched an initiative called UNITE. It is designed to facilitate research to identify opportunities, make recommendations, and develop and implement strategies to increase inclusivity and diversity in science across the entire biomedical research enterprise.

We are looking not just as a broader research community, but within NIH as well to establish an equitable workplace and reduce barriers to equity among our workforce.

With respect to impact of the pandemic on the autism community, we are attentive to the fact that COVID has disrupted a way of life for many people on the autism spectrum and their families. At NIMH under Dr. Gordon’s leadership has provided specific focus in this area. Webinars and director’s messaging. They give voice to some of these – and encouragement and recommendation address these challenges by some of the leading experts in the field.

All of this wonderful work has been made possible by the activities of the congressional partners and leadership at HHS. Specifically, I would like to recognize Senator Bob Menendez and Representative Chris Smith and their colleagues for their instrumental role in sponsoring the Autism CARES Act of 2019. Their support of federal efforts on autism spectrum disorder and their dedication to helping individuals on the autism spectrum and their families has made it possible for us to gather today for the important discussion that will ensue.

The Department of Health and Human Services and our sister federal department and agencies also have been working together to address the needs of people with disabilities and their families. It has been especially true during this time when our country and the disability community has been impacted by the coronavirus pandemic.

I would like to especially thank Andrea Palm, Deputy Secretary of the Department of Health and Human Services for her leadership in enhancing the health and well-being of all Americans, including those on the autism spectrum and their families.

And now turning back to the committee, I would be remiss if I did not end with truly thanking each of you for your thoughtful stewardship and development of recommendations. You are engaged in the community and integrating their input to enhance our efforts to support the basic science on autism at NIH. We look forward to the continued work that the committee will do in addressing challenging issues and identifying opportunities for the NIH and our participating federal departments and agencies to enhance our program.

We all have the same goal in mind, to make a profoundly positive impact on the lives of people on the autism spectrum and their families. Thank you for your time and I look forward to learning more over the course of today.

DR. DANIELS: Thank you so much, Dr. Aklin.

And now, we welcome HHS Deputy Secretary Andrea Palm for your comments.

DEPUTY SECRETARY ANDREA PALM: Thank you, Dr. Daniels. Thanks all of you for joining us today. I want to echo some of what Dr. Aklin has conveyed already, but really are very grateful for the leadership and continued commitment of the IACC to the important work that we need to do to support folks in the autism community.

I also really want to echo her comments thanking Senator Menendez and Representative Smith for all of their work in leadership over the years. Thank you for joining us today. It really speaks to your commitment to this issue and we are very grateful for your partnership and your continued leadership in this space.

And then, again, I really want to thank the returning members of the committee and the new members who have accepted the task of really helping to build on the work that has been done thus far, to the IACC. There is a lot more to do certainly and we are anxious to get started as all of you are.

Throughout the past decade, throughout the work you all have done, we really want to recognize the important and groundbreaking contributions that you have made. When a mother testified to the IACC that autism was as common as Somali tea in the Somali community in Minneapolis, the IACC members reacted quickly and cooperatively to investigate. The resulting study funded by a number of our agencies and Autism Speaks, found that about 1 in 32 Somali children ages 7 to 9 was identified as having autism spectrum disorder in Minneapolis. This spawned treatment programs, support networks, and led to funding for autism awareness efforts and support groups in Minneapolis.

Another example of the impactful work of the IACC. After hearing public comments from a mother who had tragically lost her son after he wandered away from safety, this forum served to highlight the high risk of unintentional injury and death among individuals with autism, especially young children. This work has sparked national awareness of the issue that has resulted in improved training for first responders, police officers, and school personnel. It has encouraged innovative research on locating technologies that can help to minimize this risk.

In 2018, Kevin and Avonte's Law was passed, which protects children on the autism spectrum or with other developmental disabilities who may wander away from safety and promotes initiatives that reduce the risk of injury or death related to wandering.

These are but two examples of the extraordinary work of the IACC. You all have big shoes to fill and I know that you are up to the challenge.

The last time this committee met in July of 2019, we lived in a very different world. COVID-19 has changed all of our lives and placed new strains on individuals on the autism spectrum and their families.

Prior to COVID, individuals on the autism spectrum already faced systemic barriers in their everyday lives, access to health care, education, and other vital services and we all know that COVID has exacerbated those issues.

But as this committee returns to work, we certainly have reason for optimism. This IACC roster, as Dr. Aklin noted, is the largest and most diverse to date and it meets under a new administration that is committed to working with the autism community to address the challenging issues such as racial equity and disparities in autism and the need for increased opportunities for employment and housing.

The Biden Administration has already committed itself to funding cutting-edge research to help us understand autism and related health conditions in order to improve the quality of life for people on the autism spectrum and their families in every community across the country. Through his Build Back Better agenda, the President has committed to expanding access to Medicaid home and community-based services so that people on the autism spectrum can access needed services in their communities.

And the President is committed to investing in the care-giving workforce so that the people who dedicate their lives to caring for others earn a livable wage to help them care for their own families.

I want to close again sort of ending where we started, which was really to say thank you so much to all of you for your willingness to commit to this work to participate and partnership with us to move the ball forward. We look forward to learning here at HHS from the IACC to hear your recommendations so that we can make informed decisions on how best to support individuals on the autism spectrum and their families moving forward.

I know that you all are anxious to get to work. I do not want to take any more of your time. I hope that you find the meeting today and tomorrow both helpful and encouraging of the work that you have ahead you and we look forward to continuing our partnership. Thank you so much, Dr. Daniels.

DR. DANIELS: Thank you, Deputy Secretary Palm. Thanks so much for being here.

Now, I would like to give the floor to Senator Robert Menendez. Thank you so much for being here.

SENATOR ROBERT MENENDEZ: Thank you, Dr. Daniels. Good afternoon. It is my pleasure to join the inaugural meeting of the Interagency Autism Coordinating Committee. Since your last reauthorization of the Autism CARES Act of 2019, I was proud to champion this legislation in the United States Senate, which for the first time directed the Federal Government to consider the evolving needs of autistic individuals across their lifetimes. I remain committed as ever to meeting the needs of our autism community both in my home state of New Jersey and across the nation.

This inaugural meeting takes place at a critical moment in our nation's history. As the United States emerges from the COVID-19 pandemic, we have to be mindful of the challenges faced by autistic individuals, their families, and their caregivers over the last year. New Jersey was one of the hardest hit states in the country at the onset of the pandemic. We also happen to have the highest rate of autism in the nation.

It is not surprise that throughout this crisis, my office heard from many health providers, advocacy organizations, parents, and caregivers of autistic children and adults about the unique challenges they face and those challenges were from the destabilizing impact of disruptions to education and school closings, to the difficulty accessing therapeutic services in a time of crisis, to the threat that COVID-19 posed to individuals living in group settings. Let us not forget the financial hardships endured by millions of families from all walks of life as a result of the pandemic’s economic fallout. These are just some of the many issues the IACC will have to contend with in the months to come.

However, I am optimistic that each of you will contribute to this important conversation. We remember that the C in autism care stands for collaboration, which is why I am especially pleased to see the four additional federal agencies will be represented on the IACC for the first time. The participation of the Department of Housing and Urban Development, the Justice Department, the Department of Labor, and the Department of Veteran Affairs will help this committee influence policy in a wider range of areas from disability housing to interaction with law enforcement to greater economic opportunity and beyond.

Finally, I want to congratulate the 20 new public members of the IACC on your appointments by Health and Human Services Secretary Xavier Becerra, whether you are a self-advocate, a parent, a clinical researcher, or community leader. Your expertise will be a tremendous asset to the committee and your insights will help guide Secretary Becerra and officials throughout the Biden Administration as they work to enhance services, create opportunity, and provide greater support to autistic Americans of all ages in every corner of this country. I appreciate your commitment to fulfil the mission of Autism Cares and we certainly thank you for your willingness to serve.

DR. DANIELS: Thank you so much, Senator Menendez. We really appreciate your comments.

And lastly, I will turn it over to Representative Chris Smith. Thank you for being here as well.

REPRESENTATIVE CHRIS SMITH: Thank you very much, Dr. Daniels and Dr. Gordon. Thank you for both of your extraordinary leadership. You really have made a profound difference in all of this. I want to thank you. HHS certainly. It is all one big team effort. It is bipartisan.

For me, it all started in 1997 although I got involved in autism in 1981 in my first term. I kind of went to sleep. I thought it was all being handled until we had a prevalence spike, we thought, in Brick Township. Two wonderful parents, Bobbie and Billy Gallagher came to my office and said, what is it? Is it the water? What is it? We have more children manifesting with autism than we can possibly have dreamed of. It really was a serious problem.

We invited CDC to come up. They took a look at it and said hmm. When we did the side-by-side comparisons, the data calls from other municipalities, they too had a prevalence spike. We introduced a bill. It became part of Title I of the Children’s Health Act and that launched

IACC. It was not called that at first. In 1995, it became known as IACC. What a wonderful job. All of the NIH programs ought to be done this way where you have stakeholders, the professionals, both in government, outside government, the very effective advocates, the self-advocates, who all sit at the table and have aspirational goals and make recommendations that are listened to on Capitol Hill. When you speak, we listen. We cannot always produce. We are trying again to – Mike Doyle and I formed the Autism Caucus, my good friend and colleague from Pennsylvania, back in the year 2000. We have 134 members in the House who are part of it. We work like brothers. We have a lot of women who work with us as well. It is a great bipartisan and bicameral effort to move this ball down the – in terms of research, services to HRSA and others and of course. CDC, just as a reminder and I think you all know this. You certainly know this, Dr. Daniels. When we introduced our bill in 1997, the office – the IACC Committee -- particularly the new ones probably do not know this. We were funding CDC at $287,000 per year straight line for five years. That does not even buy a desk. We are all sitting at desks. It does not even buy a desk. It just did not do anything.

We have changed all of that. Thankfully, it is at $23 million. It should be much more. Mike Doyle and I have asked the appropriators to increase all the different accounts in the aggregate of $150 million more. We are hoping we will prevail on that.

But, again, what you recommend we listen to. Your goals. I read your reports all the time. It inspires what we do. I want to everyone to know that you are not just impacting what the executive branch does, you are having a profound impact on what the legislative branch is doing as well.

Finally, I just want to say that COVID-19 obviously has been a challenge. New Jersey, as Bob, my good friend in New Jersey pointed out. We have been so hard hit. 26,000 people have lost their lives in New Jersey alone. Per capita it is the highest in the country. There are many – we are the highest prevalent rate according to CDC for people on the spectrum. The concern there is that not enough of those individuals have gotten the vaccinations for COVID-19.

I can say as a good news story, that needs to be replicated. The Visiting Nurse Association and Autism New Jersey staged a number of days where they brought in children with autism and young people, and they got the vaccination. The staff were very well trained on how to deal with the reactions that might occur. I was there for it and observed it. It went on without a flaw. We need to do more of that.

I would hope that CDC and the government would relook at how at-risk people with autism are to COVID. It is not gone. We all know that with the variant. I was very happy when Down Syndrome was added to that list of people who need to be taking further concerns about. But I do think given the number of concurrent anomalies that children and young people with autism experience, including gastro problems, that special relook at that would occur as to how do we prioritize those vaccinations.

So much more needs to be done and again we take so many good cues from you on housing, education. I have chaired hearings in the past with SAP, for example. They found when they hired young people on the spectrum, they turn out to be their best and most effective people working with code. They did that first in an altruistic mode and quickly matriculated into wow, these young people are good. I think there is an untapped resource there for helping those with autism obtain jobs.

Thank you so much for the great work that you do. It is extraordinary. Thank you, Dr. Daniels.

DR. DANIELS: Thank you, Representative Smith. Thank you to all of our special speakers, to Dr. Aklin, Deputy Secretary Palm, Senator Menendez, and Representative Smith for being here. We are deeply grateful for your comments of inspiration and motivation. We are so excited to be getting to work today.

At this point, Dr. Gordon, would you like to also make any comments?

DR. GORDON: Yes, thanks. I want to thank Representative Smith and Senator Menendez as well and the Deputy Secretary and Dr. Aklin. This is really wonderful to have you all here. And I think, as others have mentioned, it speaks to the importance that we all place on this particular endeavor.

I also want to echo what the Senator and Representative said about this group impacting directly efforts of Congress and as well as federal agencies. As Dr. Daniels can tell you and other members of my staff, we quite often see legislation that speaks directly to the impact of this group and particularly promoting autism research, which is of course of the most direct interest to the National Institute of Mental Health.

Also, as Dr. Daniels can tell you, the federal representatives meet on their own outside of this group to continually discuss how to improve their efforts in dealing with the issues that are raised here.

I will give you just one quick example that some of you are familiar with. In the previous incarnation of this committee, a lot of effort went into describing the needs of individuals with autism as they transition from childhood into adulthood. NIMH set about really a ten-year effort at the behest of this committee to enhance the research in this particular area. I am proud to say that it is really working. We are seeing an increase in the number of applications and in the investigators who are paying attention to issues of relevance for transition-aged youth and adults with autism. I expect within the coming five years to have the results of that research to talk to you about in this particular incarnation of this committee.

That is just one example of the many things that are raised here.

I will give you one more. I, myself, was personally affected tremendously by the presentations two or three years ago from parents dealing with the issue of self-injurious and aggressive behavior in profoundly disabled individuals with autism especially as they age into the teenage years. We have now started a program at NIMH and we are about to articulate our priorities in this area to try to address the underlying reasons for this dysregulation of aggressive behavior as well as to develop therapies and treatments that will hopefully one day help us get better control over that behavior than the current treatments that are available. Those are just two examples of issues that have been raised here that have deeply affected us as NIMH. I am sure each of the federal representatives could talk about things that their organizations are doing in direct response.

Thank you very much to all of our guest speakers. I guess we are running a little ahead of schedule, but I am still going to turn it back to you, Dr. Daniels. We will see what comes next. Perhaps we can start early with our introductions and hold off on taking our break.

DR. DANIELS: Thank you. So, yes. We can start early on our introductions. Would people like to take a five-minute break before we start the introductions and then just go through? We will take a five-minute break and then we will be back.

(Whereupon, the Committee took a brief break starting at 1:30 p.m. and reconvened at 1:35 p.m.)

DR. DANIELS: We are just returning from our break. We are going to be getting started with the introductions. As was said earlier, we have the largest and most diverse IACC that we have ever had and we really looking forward to getting to know all of you. We are going to go through introductions. We will start with Dr.

Gordon and myself and then proceed through the public members and then the federal members. I know that you all have an order that you are going in. But if you happen to forget, I will call on you.

I would like to start first with Dr. Gordon.

DR. GORDON: Hi everyone, I am Joshua Gordon. I am Director of the National Institute of Mental Health and in that capacity, I have been asked by the Secretary to chair this group. I am an MD-PhD, meaning I am trained in both medicine and research. I am a psychiatrist as well as a neuroscientist.

My own research is on the neural underpinnings of cognition, particularly as it pertains to disorders like schizophrenia. I study that in animal models. I have been here at NIMH for five years. Before that, I was on the faculty at Columbia University in their Department of Psychiatry.

With that, I will turn it over to Susan.

DR. DANIELS: Thank you. I am Susan Daniels, director of the Office of Autism Research Coordination at the National Institute of Mental Health where I have been for the past 13 years and working with the IACC. I am also the executive secretary of this group and the new Acting National Autism Coordinator. My background is I am a neuroscientist. I really love working with this group and with the autism community. Looking forward to getting to know all of you.

Next, we can start with our public members. The first is Maria Mercedes Avila.

DR. MERCEDES AVILA: Thank you for having me here. My name is Maria Mercedes Avila. I am a social professor of pediatrics at the University of Vermont. I am a parent, advocate, and researcher. And I strongly believe research should inform accommodations and services and equitable distribution of resources for all children in our society.

I live in the whitest state in the country. I live in Vermont. This is the first time Vermont is represented in this committee and we are very humbled and honored to be on the committee representing our small state. Even though I live in the whitest state in the country, I dedicated my career to educating providers around systemic racism, racial inequities, and how this intersects with health disparities and inequities. Thank you for this opportunity. I look forward to working with every one of you.

DR. ALICE CARTER: I think I am up next. My name is Alice Carter. I am a professor of psychology at the University of Massachusetts, Boston. I am really excited and deeply honored to have the opportunity to serve on this very diverse committee.

My clinical research is focused on early detection of social and emotional and behavior problems and autism, reducing health disparities and access to high-quality care, and promoting family well-being. I think all of my interests in serving this committee really focus on optimizing children, youth, and adult’s abilities to communicate their needs, interests, and desires. I really look forward to serving with everyone.

DR. DANIELS: Next is Sam Crane.

MS. SAMANTHA CRANE: Hi everyone. I am Sam Crane. I am the legal director at the Autistic Self Advocacy Network, and I am a returning member. We are pleased to be one of the many autistic advocates on this committee this term. At ASAN, I focus on access to the community, access to quality community-based supports and inclusion, access to self-determination and a variety of other issues.

While I was on the committee last term, I really enjoyed conversations about research on the needs of adults, research on co-occurring medical conditions and research on community inclusion and the best way to provide supports and services. I am excited to meet everyone today.

DR. AISHA DICKERSON: I am Aisha Dickerson. I am an assistant professor in the Department of Epidemiology at Johns Hopkins Bloomberg School of Public Health. I am an environmental epidemiologist and I study environmental risk factors for autism and other more developmental disorders as well as environmental justice issues and health disparities and historically marginalized populations.

MS. DENA GASSNER: Good afternoon, everyone. My name is Dena Gassner. I am a PhD Candidate at Adelphi University. I am completing a dissertation in this time, working on accessing social security systems. I am an adjunct professor at Towson University, going on five years. And my private practice focuses on social security access for autistic individuals. I am currently the co-chair of the Autistic Researchers Committee for INSAR, and I am on the board of directors for The Arc US in my seventh year, moving through the National Council of Self Advocates Policy Committee and now I am on the Access and Equity and Inclusion Committee. I am a reviewing member of the Autism Intervention Research Network, the AIR-P and a member of the AIR team for gender, sexuality, and reproductive health care on that node.

My most important thing that I am bringing to the table I think is being a mother to an autistic adult who was not supposed to live on his own. He still struggles with a lot of things, but he has his bachelor's degree after five years. I have a great a daughter who is an amazing sibling. And a 29-year marriage. But my favorite title is grandmother. I just became one about seven years ago. My son with diagnosed at three. It was through his advocacy that I discovered my own diagnosis at 40. I welcome everybody and I look forward to serving. Thank you.

DR. DANIELS: Thank you and next is Morénike Giwa Onaiwu. Will you be speaking or do you want any assistance? I cannot hear. I do not know if anyone can hear.

MS. GASSNER: I believe she tried to post a slide instead of speaking.

DR. DANIELS: If the slide is posted and you need assistance reading it, I can read it if it is posted.

DR. GORDON: I do not see it.

DR. NINA SCHOR: In the chat, it says she was using text.

DR. DANIELS: The sound did not come through on the text to voice unfortunately.

MS. GASSNER: She just needs a second.

DR. DANIELS: Okay, we will pause.

(Pause)

MS. MORÉNIKE GIWA ONAIWU: Often drawing on my personal background as a person of color and neurodiverse --

DR. DANIELS: It was working. The sounded faded again so we cannot really hear it.

I am happy to read it if you post the slide for me. I am just going to read it from the chat.

Hello everyone. It is always hard to know what to say in introductions and on top of that speaking is challenging for me at times, so please bear with me. This bio might seem a bit impersonal as it’s in the third person. Morénike Giwa Onaiwu, PhD, MA is an educator, writer, public speaker, parent, and global advocate whose work focuses on meaningful community involvement in leadership, disability, racial and gender equity, dismantling stigma and inclusion and empowerment.

Often drawing from personal background as a person of color in a neurodiverse and sero-different family, a late diagnosed adult on the autism spectrum, and relevant educational and professional experience, Morénike is a highly sought-after presenter, consultant, and subject matter expert.

Morénike is the parent of six disabled children, including one with intellectual disability and two with autism. She has been an invited speaker in the White House, at the United Nations Headquarters, a keynote speaker and/or presenter at numerous conferences, and provides diversity, research, and disability consulting to several organizations.

Morénike, who is currently a Humanities Scholar at Rice University and a doctoral candidate in education, has been published by Beacon Press and Palgrave MacMillan and will release an edited collection on neurodiversity in the Black community in 2022 with Jessica Kingsley Publishing.

Thank you, Morénike.

Next on our list is Alycia Halladay.

DR. ALYCIA HALLADAY: Hi everyone. I am Alycia Halladay. I am so happy to be a part of such an esteemed group, and I am really very honored. I am currently the chief science officer of the Autism Science Foundation and I have been there since 2014. I also was recently appointed as the board president of the Phelan McDermid

Syndrome Foundation and Phelan McDermid Syndrome is specifically the result of a genetic change that results in not just autism spectrum disorder, but things like seizures and gastrointestinal problems as well. I am not officially representing either one of them, but I have both of those perspectives in mind when I am on the IACC.

The Autism Science Foundation really focuses on research across the entire lifespan even from birth before an autism diagnosis can be made. We support programs such as the Baby Siblings Research Consortium and a collaboration of patient advocacy groups called AGENDA, which is the Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism. And these are patient advocacy groups that need to work together to better understand how their experiences of families of people with rare genetic disorders are different and similar to those of other families across the spectrum.

We also support early career researchers. We have had a really strong focus on pre- and post-doctoral fellowships. We also funded COVID-19 research grants. ASF and I also produce a podcast, a weekly podcast, which tries to explain in simpler terms some of the major research findings, the recent ones, to the community. I also have a personal interest in safety issues in the autism community. I am the mother of twin girls, one of which is on the spectrum. Thank you for including me in these important decisions.

DR. DANIELS: Craig Johnson is next.

MR. CRAIG JOHNSON: Hi everyone. It is really great to be with you and be a part of this committee. My name is Craig Johnson. I have three children. I am the father of one of my sons, who is a teen son on the autism spectrum. I have been an author and advocate for people with disabilities for about 17 years now. I currently am president and founder of the Champions Foundation and Champions Club developmental centers for special needs children with over 95 centers around the world that serve several thousand families. I am also the associate pastor at Lakewood Church in Houston where we serve about 300 families weekly with special needs, most with autism.

Through Champions Foundation, we have developed a curriculum both for public schools and for churches as well as training platforms on video demand for training and special needs and for parent support platforms to encourage and give them hope weekly.

I have been married for over 31 years to my wife, Samantha. I have two other children, Cory and Courtney. I am tremendously honored to be a part of this committee. Thank you.

DR. DANIELS: And next we have on the list, Yetta Myrick. I want to give you a note about her. She was not able to be here because of an emergency on a medical issue. She is not able to be here and regrets that she cannot be with us in this meeting, but hopes to join us for the next meeting.

Next, we have Lindsey Nebeker.

MS. LINDSEY NEBEKER: Hi everyone. My name is Lindsey Nebeker. I have been involved in the national staff for the Autism Society of America for the past nine and a half years. In addition to that, I also do freelance presenting and training where I provide educational workshops to various professionals and families and individuals on the autism spectrum all across North America. I am based currently in Alexandria, Virginia, which is in the Washington, DC area.

In addition to that, I also am a self-advocate advisor for Felicity House. I was a founding board member for the Autistic Women and Nonbinary Network, and I also currently serve in a few different committees where we review very different grants that are addressing mental health needs and gender reproductive justice.

I am an autistic adult. In addition to that, I also have a sibling who is autistic who has high support needs. A lot of the work that I have done in my main inspiration for my advocacy work is that I want to ensure that all of us on the spectrum, including those with higher support needs, are validated, acknowledged, and included and part of the conversation. I feel very honored to be part of this committee. I am really looking forward to working with you all.

DR. VALERIE PARADIZ: Hello everyone. My name is Valeria Paradiz. I am vice president of Services and Supports at Autism Speaks. And prior to my role on staff at Autism Speaks, I served on the board of directors. As one of the first of two autistic individuals to serve on that board side by side with Stephen Shore at the time when we first joined then.

I love the work I do, being on staff. I will not get into too much what we do at Autism Speaks. But in the years ahead when we worked together, I look forward sharing more and learning more about everyone else, your organizations, and the work you are doing.

I want to share also that I am on the spectrum. I was diagnosed in my early 40s so rather late in life. Similar to my dear friend, Dena Gassner, on the call, my son whose birthday today – he is 31 years old – was my inspiration for much of my work, but also my own diagnosis and for learning about Asperger syndrome at the time when I was diagnosed.

I am just really looking forward to my service and serving with all of you and thankful for this opportunity.

DR. JENNY MAI PHAN: Hello everyone. My name is Jenny Mai Phan. I am a postdoctoral researcher at the University of Wisconsin-Madison Waisman Center. My research focuses on mental and physical health outcomes of adolescents on the autism spectrum, more specifically, how the process of pubertal developmental and inclusive sexual and reproductive health education relates to youth’s overall well-being.

I am a late diagnosed adult on the autism spectrum and a mother of four, ages 5 to 13, two of whom are on the autism spectrum with ADHD and one with an intellectual disability.

I am delighted to be a member of the IACC and really look forward to all of the conversations and the work we can all do together to support our autistic family, friends, neighbors, and their families.

DR. JOSEPH PIVEN: Hello everyone. My name is Joe Piven. I am a child and adolescent psychiatrist, working at the University of North Carolina where I direct the Carolina Institute for Developmental Disabilities. That is an organization that provides clinical services with people with neurodevelopmental disorders, trains clinicians and young researchers and conducts a full range of research from basic to applied research. And we are active in the development of community programs.

My own research has been very broad. I oversee a large research network on brain and behavior development in autism from infancy through school age. That is the current age of our cohort. But I have also done some of the first research at the other end of the lifespan on trying to understand the problems faced by autistic individuals as they enter older age.

I am thrilled to be able to bring these experiences to this committee, particularly at this very difficult time in the pandemic. I am looking forward to contributing in our work together to make a difference in the lives of autistic individuals and their families. Thank you.

DR. DANIELS: JaLynn Prince is next. Maybe JaLynn had to step away. We will come back to her.

Next is Susan Rivera.

DR. SUSAN RIVERA: Hello everybody. My name is Susan Rivera. I am professor and current chair of the Department of Psychology at University of California, Davis, and a faculty member of the UC Davis MIND Institute. I am a developmental neuroscientist by training, and I have been conducting scientific research on autism and other developmental situations for over 20 years now.

In my research, I use brain imaging and infrared eye tracking techniques to investigate questions about how the brain and its activity and behavior supports the development of skills that are necessary for adaptive, cognitive, and social-emotional well-being so things like visual attention, face processing, sensory processing and emotion regulation.

But in addition to the scientific work I do, I am also devoted to champion the tenets of neurodiversity and advocacy both to the public and to the academic communities. I have done this by participating in discussion groups, in consortia, and also by holding annual neurodiversity summits at UC Davis. I have done this along with my graduate student, Patrick Dwyer, who is autistic where we have assembled speakers from around the globe to talk about important but sometimes controversial topics surrounding neurodiversity.

Our third UC Davis neurodiversity summit is coming up on November 5 so a day-long event with in-person and virtual participation. I put that plug in to invite you to save the date for that.

I hope that the combination of my knowledge of and really deep involvement in scientific research on autism along with my advocacy activities will make me a productive and a valuable member of IACC. I am very honored to have been selected. I am really looking forward to the role. Thank you.

DR. MATTHEW SIEGEL: I am Matthew Siegel. I am associate professor of psychiatry and pediatrics at Tufts University School of Medicine. I am located in Portland, Maine where I am the vice president for medical affairs for the developmental disorders service line of our organization. I trained as a child psychiatrist and a pediatrician and then have been working with people with autism for at least the past 15 years. Perhaps similar to Dr. Piven, but a few years behind, developing a research program as well as a large system of clinical services and advocacy. We have now developed a system of care that stretches across from outpatient to specialized school settings to partial hospital and acute inpatient hospitalization for people with autism when they are struggling with emotional or behavioral challenges.

My research has focused on both psychiatric comorbidity for people with autism, and also focusing on the inpatient setting and how we approach and work with significant challenging behaviors or behaviors that challenge and how we approach those from a multidisciplinary perspective when the work of a single discipline perhaps is not enough.

I am very pleased to be here and share with all of you and learn from you and honored to be on this committee.

DR. DANIELS: We have Ivanova Smith next.

MS. IVANOVA SMITH: Hello. My name is Ivanova Smith. I am from Washington State. I am a self-advocate leader and a member of People First of Washington. I am a self-advocate faculty for the University of Washington LEND program. I am a borderline intellectual disabilities autism and chair of the self-advocate leadership at ASAN. I was institutionalized for the first five and a half years of my life. But now, I am able to overcome a lot of that oppression. I have a family. I am happily married with two daughters. Thank you for allowing me to be here today.

MR. HARI SRINIVASAN: I am Hari Srinivasan. I am a minimally speaking autistic, which means while I can repeat simple words and phrases, I cannot really carry out conversations in my own voice and have to rely on augmentative and alternative communication for all my communication needs and of course like any technology, my text to speech can crash and stop working at the most inopportune of times, so I ask for your patience should that happen.

In addition to an uncoordinated body, I have ADHD, medical co-morbidities and other challenges, all of which presents significant obstacles to everyday living as well as physical and mental health supports. I want to add that I have been in all manner of therapy treatments all my life from my diagnosis at the age 3 and in special education classrooms all the way to eighth grade with no access to mainstream education. I pretty much have a lived experience of the gamut of how education can be from low expectations in special education to my 180-degree difference to my current educational experience at UC Berkeley. The opportunity of education has been a hard one for me and I am thoroughly enjoying learning and contributing.

At UC Berkeley, I major in psychology and minor in disabilities studies. I am also a student journalist for the UC Berkeley newspaper where I have written a lot about disability and have had a column on autism. This will be my sixth semester teaching a faculty-sponsored semester long class on autism where I get to design the curriculum, covering many areas and across the lifespan, refining the curriculum each semester and hearing from speakers and other autistics, and their families have really given me a perspective of all the myriad issues and areas that are impacted and that needs to be worked on.

I was also the first non-speaking president of the autism student body at Berkeley. I worked on the various campus psychology labs in the areas of sleep, mental health, and ADHD. This year as a scholar, I will be doing my own mental health research project that involves emotions in autism, hoping to go to graduate school next and keep learning and contributing to the field.

I want to add to Dr. Gordon’s words about this group being an august group. I am both excited and a little nervous about working with heavy weights in their field. The pandemic during the last year has more than exposed the gaps and inequities and other issues faced by the autistic community and their families. Being on this committee is a privilege, which I hope will translate into my contributing towards collective and meaningful change. Thank you.

DR. HELEN TAGER-FLUSBERG: Hi. I am Helen Tager-Flusberg. I am a developmental scientist in the Department of Psychological and Brain Sciences at Boston University where I also am the director of the Center for Autism Research Excellence.

I have been a researcher in this field of autism since the mid-1970s. For me, I have witnessed remarkable changes in this field. I could never have dreamed when I got started at what we are witnessing here today and really for me then it is such a privilege to be now a public member of the IACC.

My research focuses on language and communication in autism and related neurodevelopmental disorders across ages from birth through young adults. We have done work on early predictors to neural foundations, to interventions, to measurement development.

But for the last decade, I have begun to focus my research on all the children and adolescents who were essentially excluded from my own and most other research, the minimally and nonverbal, who along with their challenges in communication have many other complex problems, some of which derive from the fact that they have no means to communicate effectively. This has been a hugely significant development in my own research program.

I am also the past president of the International Society for Autism Research. I take great pride in the significant work that INSAR does and that I do as a professor to foster the research careers of the next generation of scientists, most of whom are also so interested in the public policy and broader societal issues that are critical to having a broad and deep understanding of autism. I am looking forward to working with everyone on this committee in the coming years. Thank you.

DR. JULIE TAYLOR: Hello everybody. My name is Julie Taylor. I am a returning member of the IACC, and it really is an honor and a pleasure to be able to continue this super important work.

My training is in developmental psychology, and I am currently an associate professor of pediatrics at Vanderbilt University Medical Center where I primarily am a clinical researcher at the medical center.

My work focuses on understanding how to improve the transition to adulthood and adult outcomes for autistic individuals. And we have a range of current studies on these topics, everything from longitudinal work, trying to understand the course of development over time for autistic adults, to studies that are really trying to understand the implications of the day-to-day experiences on mental health, and also intervention studies to improve service access for youth on the autism spectrum as they transition to adulthood.

Relevant for our meeting tomorrow actually, we have another study that is investigating the impact of COVID-19 on autistic adolescents and adults. I am really looking forward to our discussion on this topic.

It has been really wonderful to hear everybody’s introductions so far. This is such an impressive group and I am especially excited about the very wide range of expertise that people bring to the table. And I am really looking forward to working with each of you on the committee. Thank you.

DR. PAUL WANG: Hi everyone. My name is Paul Wang. I am deputy director for Clinical Research at the Simons Foundation. The Simons Foundation is a very large, nonprofit funder of research and the autism program at the Simons Foundation is known as SFARI.

I am trained as a developmental behavioral pediatrician and started in academic medicine, studying language and memory development and had the pleasure then of working with and learning from hundreds of children and adolescents and families from the autism community.

I also have experience working in industry in clinical trials for big pharma as well as for biotech, focused on neuropsychiatric conditions generally and Fragile X syndrome and autism specifically.

I have been at Simons Foundation now for about five years. It is really an honor to be serving with this expert and diverse group of committee members and I promise that I will do my best to try to promote the work of this committee and to promote the well-being of everyone in the autism community.

DR. DANIELS: Thank you. Right at this moment, I would like to go back to JaLynn Prince.

MS. JALYNN PRINCE: Can you hear me?

DR. DANIELS: We can hear you but we cannot see you.

MS. PRINCE: All right. I am trying to get the camera on and it is not working. I am sorry for the technical difficulties. But may I continue?

DR. DANIELS: Yes, go ahead, please.

MS. PRINCE: I am JaLynn Prince. I head Madison House Autism Foundation. We have a couple of purposes. We work nationally on policy and we have a 400-acre farm that fell into our laps a while ago. It gives us practical information because we work with adults with autism and others in the community.

I come to this as a parent of a 31-year-old son by the name of Madison. He informs us about a lot of the things that are happening. We had been challenged to go into the field of adult autism because we were told there were very few people working in lifespan issues at the time. This was 14 years ago and it is still a rather lonely space. I am glad to see that there are some people here that are working with lifespan issues. But we have taken that on.

I will tell you a little bit about my background. I will show you this book. Can you see this? You cannot see anything. I come to this having been a global photographer and humanitarian around the world. This informed me about a lot of very important things because I was able to go into NGOs around the world and see firsthand what was happening in the projects they were working on and photograph them and see the successes, the failures, and things that needed to be done.

As I was working on all of these things around the world, I realized that there was a humanitarian issue that was facing our country and that was working with the inclusion of adults with autism and being a somewhat unseen population. And we began working in that arena. It has been very rewarding. We have seen a lot of development, but a lot of things that still need to be accomplished and we hope to work with many of you and gain more insights and if we can share some of our knowledge.

I wanted to also mention that it was just a year ago this week that my husband who was a very well-known virologist who actually had the first monoclonal antibody ever approved, 23 years ago – he, my son, and myself all were exposed to COVID and spent 51 days battling it. There were great fears because we were very worried about our son who had a very heavy viral load, and we were able to test that through saliva tests through my husband’s laboratory. We were very worried about what would happen to him if he ended up in a hospital without us, without familiar faces, and without people that knew how to work with adults with autism or anybody with autism and in already stressful situation. I think there are a lot of things that we need to learn from this and a lot of questions that we need to ask. But there was the point about COVID and how it had impacted people.

We were able to do some things with our farm because we had therapeutic riding during COVID. Though our participants could not arrive there, we were doing Zoom calls between riders and their horses. We also had safaris on the farm.

You can tell that we have a component of working with people on a personal level on day-to-day development, but we are very interested and lead the country in aspects of developing housing for adults for autism, answering that age-old question of what will happen to my child when I no longer am around. But we also hear, what will happen to me when my parents are no longer around. We are trying to work with the sociological aspects of answering that question more. I am delighted to work with all of you and Dr. Daniels, who I have known for quite a period of time and respect her highly and admire the work that has been done with the IACC. Thank you for including me.

DR. DANIELS: Thank you. We have Stephen Whitlow, who was not able to be with us today because he had an unavoidable conflict for today but will be with us tomorrow. The two people who were not able to introduce themselves this time, we can introduce at the October meeting.

Next, let us move to the federal members. We will start with Dr. Courtney Aklin.

DR. AKLIN: Good afternoon. I am Dr. Courtney Aklin. I had an opportunity to speak with all of you earlier. I just would like to say that this is a really special time for me. I started my federal career as a fellow actually working to help stand up the IACC meetings. This is an exciting time for me. I am a clinical psychologist by training with specialties in pediatrics and anxiety disorders. Thank you for allowing me to be here today.

DR. DANIELS: Thank you. Next, we have Skye Bass.

MS. SKYE BASS: Hi everyone. My name is Skye Bass and I am a licensed clinical social worker within the Indian Health Service Division of Behavioral Health. The Indian Health Service is the federal agency that is responsible for providing health care to American Indians and

Alaskan Natives. In this role, I work to equip health care providers working within IHS, our tribal, and our urban Indian health clinics with the training and education they need to provide excellent care for individuals with autism. I also connect to autism as a behavioral health provider and as a friend. I am so grateful to be here today and to work with all of you. Thank you.

DR. DANIELS: Next, we have Diana Bianchi.

DR. DIANA BIANCHI: Thank you, Dr. Daniels and Dr. Gordon. I am Diana Bianchi. I am the director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development. I am always jealous of Josh because when he introduced himself, it is a lot shorter.

It is our privilege to co-fund the Autism Centers of Excellence Program. We also fund the intellectual and developmental disabilities research network. We are also leaders at NIH in the Return to School Initiative and we will be talking about that tomorrow in great detail, recognizing the particular challenges that the past year has had on children who could not be in school in person.

I also co-chair the INCLUDE initiative, which is investigating co-occurring conditions across the lifespan to understand Down Syndrome. And, of course, people with Down Syndrome have an increased incidence of autism.

I am a clinician scientist. My medical training is in medical genetics and in newborn intensive care. I do have a research lab at NIH as well. My research is in prenatal, genomics, and fetal therapy. I am a returning member, and I learned a tremendous amount from being on the committee in this past iteration. I hope that I and our institute can contribute significantly to the work going forward. Thank you.

DR. DANIELS: Do we have Anita Everett here from SAMHSA?

We may move on and then if Dr. Everett is here later, we can come back. Let us move on to Dr. Tiffany Farchione.

DR. TIFFANY FARCHIONE: Hi. My name is Tiffany Farchione. I am the director of the Division of Psychiatry at the Food and Drug Administration. I am a child and adolescent psychiatrist by training. In our division at FDA, basically if there is a drug that is under investigation from a pharmaceutical company that would target either an associated feature like behavioral symptoms, aggression, things like that associated with autism or even the core features of autism itself, we would evaluate that program. We would help to make sure that the study designs are appropriate. We would review the evidence as that comes in and if a drug were ever approved, we would be the ones to approve that.

DR. DANIELS: Next is Maria Fryer from the Department of Justice.

MS. MARIA FRYER: Hello. Good afternoon. I am happy to be here today with all of you. My name is Maria Fryer. I am a policy advisor at the Department of Justice Bureau of Justice Assistance. I oversee the justice and mental health work in that portfolio at the Bureau of Justice Assistance. I do work at the Office of Justice Programs in Downtown DC on 7th Street. But right now, I am working from my home in Fredericksburg, Virginia.

I have connections to autism in this work with working with criminal justice professionals and law enforcement to respond, improve response and to people with autism on the autism spectrum disorder through programs and tools and technical assistance and in my own personal life as well in my own family in working with my daughter to be successful in school and in work and in her own relationships. Thank you so much for having me.

DR. DAYANA GARCIA: Hi. Good afternoon. I am Dayana Garcia, the disabilities and inclusion specialist with the Office of Head Start, Administration for Children and Families.

My connection with autism comes from being an early childhood special education teacher, a disabilities coordinator, and a family advocate. We are doing a lot of work for the past 20 years. I work with Early Head Start and Head Start programs, promoting collaboration between Head Start grantees and also Part C and Part B agencies to promote services for children with disabilities and working closely with other ACF offices and the Department of Education.

I am happy to be here. It is an honor. I look forward to helping you all in advancing the work for this committee. Thank you.

DR. DANIELS: Next, we have Elaine Hubal from the Environmental Protection Agency. We will come back.

Next is Jennifer Johnson. I believe she had to step away so we will also come back to her.

Next is Cindy Lawler.

MS. CINDY LAWLER: Hello. Good afternoon. I am Cindy Lawler. I am the IACC alternate representative from the National Institute of Environmental Health Sciences or NIEHS for short. Our institute director, Dr. Rick Woychik, was really disappointed that he was not able to attend this meeting today, but he will definitely be planning to join all of you for future meetings.

I was trained as a behavioral neuroscientist. In my work at NIEHS, I am the chief of the Genes, Environment, and Health Branch in the Division of Extramural Research and Training. I have been a program director at NIEHS for more than 20 years and I manage a portfolio of grants to investigators at every career level at institutions across the country who are conducting research to understand how environmental exposures and their interaction with genetics affects autism.

I can say that my work at NIEHS and NIH has provided lots of opportunities to hear from many autistic individuals and their families, oftentimes through this committee, but other venues as well. Those discussions really stay with me and remind me of the importance and the potential impact of the work that we all do. These IACC meetings are ones I have always looked forward to. I am happy that the committee is back up and running and it is definitely bigger. I think we will be better than ever. Thank you.

DR. ALISON MARVIN: Good afternoon. I am Alison Marvin. I am a statistician and health sciences researcher with the Division of Analytics Center of Excellence at the Social Security Administration. At Social Security, I lead projects involving supplemental security income determinations and case selection and provides statistical support for agencies supplemental security income outreach efforts.

Prior to joining the Social Security Administration, I was research manager of the Interactive Autism Network, IAN, an internet-mediated autism research project and registry at Kennedy Krieger Institute in Baltimore, Maryland.

I continue my association with Kennedy Krieger on a limited basis as research manager of the Autism Research and Engagement Core at the Maryland Center for Developmental Disabilities, one of a national network of university centers for excellence and developmental disabilities. I am still publishing and keeping count in the field of autism research. I have a PhD in health sciences, an MPHil in public administration and an MS in statistics and operations research.

I have followed the IACC since it launched, and I am honored to become a federal member. Thank you.

DR. DANIELS: Thank you. And next, we have Matthew Miller or Scott Patterson from Veterans Affairs.

DR. SCOTT PATTERSON: Hi. I am Scott Patterson. Just a forewarning. I am dealing with a little laryngitis right now, so I am going to do my best to get through this. I am a licensed clinical psychologist with the Department of Veterans Affairs, Veterans Health Administration.

I am a local recovery coordinator for the VA. That is a staff educator position and internal consultant to our mental health services across our system.

I specialize in assessment of adults with autism and specifically, high-functioning adults, peer support models as well as general recovery efforts in the community.

The VA is very excited to be included on the IACC. We are brand new members and we would like to say thank you for bringing us into the fold and we look forward to what work we can do – thank you.

DR. DANIELS: Next, we have Kamila Mistry from AHRQ.

DR. KAMILA MISTRY: Hi. I am Kamila Mistry from AHRQ. I am the associate director for Extramural Research, Education, and Priority Populations for the agency. I am a health services researcher by training, and I focus on both health equity and intersection of maternal health and child health. I also serve as the senior advisor for Child Health and Quality Improvement at AHRQ.

I am excited to join. This is my first meeting. Thanks very much.

DR. GEORGINA PEACOCK: Hi. I am Georgina Peacock. I am the new representative for CDC to the IACC. I wanted to thank Stuart Shapira, who is the former representative, and he is now serving as our alternate.

I am the division director for Human Development and Disability at CDC's National Center on Birth Defects and Developmental Disabilities. I am a developmental behavioral pediatrician. I oversee CDC's autism and disability portfolio, including the "Learn the Signs. Act Early" Program, the SEED epidemiology study to explore early development and the ADDM surveillance network.

I am also the CDC representative to the American Academy of Pediatrics Autism Subcommittee and finally I also continue to see young children in a few different developmental clinics here in Atlanta. Glad to join. Thanks.

MS. LAUREN RAMOS: Good afternoon. I am Lauren Ramos. I am representing the Health Resources and Services Administration, which is also part of the Department of Health and Human Services. I oversee our autism investments, which include training, research, and state systems developmental programs, including the LEND program, which you heard about earlier today.

My background is public health and maternal and child health. I am a new representative to the committee and looking forward to working with all of you. Thank you.

DR. NINA SCHOR: Good afternoon, everyone. I am Nina Schor. I am delighted to be returning to the IACC. I am the deputy director and currently the acting scientific director of the National Institute of Neurological Disorders and Stroke. I am a child neurologist by training. I have a PhD in medical biochemistry. For many years, my laboratory worked on preclinical pharmacology, particularly for tumors of the nervous system in children.

For 12 years before I came to the NIH three years ago, I was the chair of pediatrics and pediatrician in chief at the University of Rochester where we were privileged to launch the first Project SEARCH chapter in the region. My department hosted that chapter for many years. I must say I learned more from the individuals that came through that program than I am sure they learned from me.

We also had a very large, very active division of developmental and behavioral pediatrics and a very active group in national consortia and in Autism Speaks. I am particularly excited about being a part of this group. Thank you.

DR. DANIELS: And next, we have Jennifer Sheehy or Scott Robertson from the Department of Labor.

MS. JENNIFER SHEEHY: Hi Dr. Daniels. I am Jennifer Sheehy, the deputy assistant secretary for the Office of Disability Employment Policy at the US Department of Labor. Our mission is to develop policies and practices that increase the number of quality employment opportunities for all people with disabilities. Thank you very much for inviting DOL as an official member. I do want to especially thank Dr. Scott Robertson, who supports our autism portfolio.

In September, ODEP is going to launch our newest research project on supporting employment for young adults on the autism spectrum. We look forward to telling you more about that.

This year, ODEP is also commemorating our 20-year anniversary as an agency and our commemoration theme is America's Recovery Powered by Inclusion. We are truly committed to ensuring that autistic individuals can participate equitably in that recovery. Thank you.

DR. TERESA SOUZA: Hi. My name is Teresa Souza. I am a social science analyst in the

Office of Policy Development and Research at the US Department of Housing and Urban Development. I have a doctoral degree in urban studies and planning from the University of Maryland. I have been at HUD for the past 12 years. At HUD, I oversee the evaluation of evaluation contracts and grants that are focused on supportive housing programs for persons with disabilities.

HUD is a new member of the committee and I am honored to represent HUD in this committee. I look forward to working with everyone and learning from you. Thank you.

MS. JODIE SUMERACKI: Hi. I am Jodie Sumeracki. I serve as a senior advisor in the Disabled and Elderly Health Programs Group or DEHPG, as we call it, at the Centers for Medicare and Medicaid Services and have been in this position for about nine years now.

Prior to this position, I was a health insurance specialist for two years in DEHPG's Division of Benefits and Coverage, which is the division with a lead for autism spectrum service related benefit policy.

Prior to joining CMS, I worked at the National Association of State Medicaid Directors and held various service coordinator and case management positions in Maryland, Pennsylvania, and Virginia, working with individuals with multiple disabilities, depending on the job. One of these roles was as a service coordinator for individuals enrolled in the autism waiver in Maryland.

I am very well connected to many of the autism subject matter experts at CMS. I hope to be able to serve as a bridge to those folks as well. I look forward to participating on this committee. I am grateful to have the opportunity to serve.

I will also note that I work very closely with Melissa Harris, who is the deputy director of DEHPG and previously served as our IACC member for the last several years and will now be our alternate member. Thank you. I look forward to working with you all.

DR. DEBARA TUCCI: Good afternoon, everyone. I am Debara Tucci. I am director of the National Institute on Deafness and Other Communication Disorders at the NIH. I have been in this position for a little less than two years, so I am a new member. I am very much looking forward to learning from all of you and participating in this committee.

Before I came to the NIH, I was at Duke University. I am an otolaryngologist, head/neck surgeon or an ENT surgeon. I practiced there for my whole career so almost 30 years.

My work has been related to hearing mostly. The work of our institute, our mission areas are in disordered voice-speech language, hearing balance, taste and smell. And most of the work related to autism is related to the communication abilities and challenges experienced by individuals with autism. Thanks very much for the opportunity to participate.

DR. LARRY WEXLER: Good afternoon. This is Larry Wexler. I am with the US Department of Education, the Office of Special Education Programs. I administer the discretionary program under the Individuals with Disabilities Act. We have a portfolio of state professional development grants, 35 technical assistance and dissemination centers, over 100 parent centers, a technology portfolio. We also have a personal preparation portfolio where we support about 5000 graduate students each day. I also oversee all of the data for the 7 million children with disabilities. I am in my 47th year in government. I have a doctorate from Johns Hopkins with an emphasis on severe disabilities and have some particular expertise in restraint and seclusion. Good afternoon to you all. I look forward to working with you.

DR. NICOLE WILLIAMS: Hi everyone. My name is Nicole Williams. I am the program manager with the Autism Research Program and I have been in this role since 2016. My PhD was actually in biophysical chemistry where I study the role of gene proteins and bipolar disorder.

The Autism Research Program or ARP, as we are abbreviated to, is one of 36 programs within the congressionally directed research programs under the Department of Defense. Our organization manages funding for biomedical research programs and are directed to us by Congress.

The ARP has actually been in existence since 2007 and our total appropriations are around $119 million. We have been able to actually fund 181 awards centered on both preclinical and clinically-focused autism research. I am just very excited to continue serving the IACC and really look forward to meeting everybody in person hopefully sooner rather than later. Thank you.

DR. DANIELS: Thank you. We have two people I just wanted to return to in case they happen to be here. Do we have anyone from SAMHSA? Is there anyone from the Environmental Protection

Agency? I think they were not able to be here this time, but maybe they are here at the October meeting. They can introduce themselves then.

DR. JENNIFER JOHNSON: Sorry to interrupt. This is Jennifer Johnson. I am sorry I had to hop off for a phone call. I just wanted to take an opportunity to introduce myself. I am going to do something a little different. I am going to provide a visual overview for those who cannot see. I am a middle-aged white woman with shoulder length hair that is going gray. I have on glasses and a black top and my background is showing the logo for my agency, which is the Administration for Community Living or ACL as we call it.

ACL is an operating division in HHS with a mission to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

I am the deputy commissioner of the Administration of Disabilities, which is one of the centers with ACL. In AOD, we seek to equip individuals with disabilities of all ages with the opportunities, tools, and supports to lead the lives of their choice in their community and moving people – we focus on moving people with disabilities from experiencing institutionalization and isolation, discrimination, poverty, joblessness and dependency to one where people experience community living, inclusion, and participation, financial well-being, and independence and self-determination.

AOD funds several programs in the states and territories, including programs in developmental disabilities, traumatic brain injury, and programs supporting independent living services.

We also fund two national resource centers, one on paralysis and another on limb loss. And we also provide support for the President's Committee for People with Intellectual Disabilities.

We have four major priority areas. In addition to the programs that we fund, our priority areas are promoting health equity, achieving economic security and mobility, empowering individuals, families, and communities and protecting rights and preventing abuse.

I have been with the Federal Government going on 18 years and have always been involved with the disability programs. I have actually been involved with the IACC at the time when it was being formed. I have quite a lot of experience with the IACC. I have been a member of it over the years. I look forward to continued participation in the IACC. Thanks.

DR. DANIELS: Thank you. Jennifer, I have a question. With the President's Committee for People with Intellectual Disabilities, is that committee active now?

DR. JOHNSON: It is not active right now, but we hope to be having that committee active in the coming months. More to come on that hopefully.

DR. DANIELS: Thank you. We look forward to updates. Thank you so much for all these wonderful introductions. We have a terrific group and look forward to working with all of you.

I will turn it back to Dr. Gordon.

DR. GORDON: Thanks. I wanted, again, to extend my welcome to each of you. Thank you for telling each other as well as the viewing public about your expertise.

I just want to make a few observations. I am really incredibly proud of this group, not just as others have mentioned for their tremendous experience, but also the diversity of viewpoints, diversity of perspectives, and the diversity of abilities that each of you have displayed. I am excited that we have a broader representation from across areas of government because that means that we can have a broader impact. I am also excited that we have a broader representation of the full spectrum of abilities that individuals with autism and their families face. I am really pleased with this group, and I am very much looking forward learning more. I have already learned a lot from these introductions. I look forward to learning more over the coming years in working together with you.

I think then we have time now for a break. We're just about five minutes ahead of time. But I would propose that we take the full break until 3 o'clock and resume with the National Autism Coordinator update and committee business at that time.

(Whereupon, the Committee took a brief break starting at 2:48 p.m., and reconvened at 3:00 p.m.)

DR. DANIELS: Welcome back everyone. I am going to start with the next portion of our meeting, which is the National Autism Coordinator update. Let me tell you a little bit about the National Autism Coordinator. I know that you were familiar with Dr. Ann Wagner, who had served as the National Autism Coordinator these past few years. And on July 1, I was designated as the Acting National Autism Coordinator.

The role of the National Autism Coordinator was established as a part of the Autism CARES Act of 2014 and the job of the National Autism Coordinator is to oversee ASD research, services and support activities across the Federal Government and for them to implement ASD activities taking into account the IACC strategic plan. The coordinator is also supposed to ensure that ASD activities across federal departments and agencies are not unnecessarily duplicative.

How will I, in this role, as the Acting National Autism Coordinator, carry out these requirements and interface with the IACC? I am going to be working on strengthening the interdepartmental and interagency communication and collaboration on issues related to autism, including convening and managing the Federal Interagency Workgroup on Autism, which I will tell you about in a moment. This is an all-federal interagency workgroup that is facilitating implementation of autism-related activities and fostering interagency collaboration. We also will be gathering agency input on tasks that are mandated under the Autism CARES Act and other interdepartmental and interagency reports.

The National Autism Coordinator will also share regular updates with the IACC as in the past, on relevant interagency autism activities, including recent reports and other activities of federal committees working on issues that are related to disabilities.

I wanted to share with you some updates from relevant federal committees. As these committees are working on autism issues, too, it is really important for the IACC to be aware of these other activities so we are not duplicative and we can build on other groups' success and their interest areas.

With the Federal Interagency Workgroup on Autism, I am the chair of this group. And this is an all-federal working group that includes multiple federal departments and agencies with programs related to autism and disabilities. And many of the members of the IACC from the federal side are also on the FIWA, or the Federal Interagency Workgroup on Autism.

This group allows for cross-agency exchange of information on projects and programs related to ASD and consideration of IACC Strategic Plan recommendations. In the past, this group has assisted with Reports to Congress required under the Cares Act such as the Transition Age Youth and Young Adults report released in 2017, the earlier version of the FIWA worked on that. And the current FIWA is working on the 2021 Report to Congress on the Health and Well-being of Individuals on the Autism Spectrum. We are working on that to meet the requirement of that report for the Autism CARES Act.

We also are working on tracking federal activities related to transition age youth and young adults following that 2017 report.

Those are some of our activities and I will be reporting back to you about other things that the FIWA is doing.

Next, I wanted to share some other federal advisory committees that are working across the government. There is new one forming that I wanted to inform you about. This is called the National Advisory Committee on Individuals with Disabilities and Disasters. This is a new federal advisory committee being established that was created under the Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 to focus on disaster planning for people with disabilities. It is going to be looking broadly across issues and programs and making recommendations for enhancing all-hazards public health and medical preparedness related to people with disabilities.

It includes a number of different agencies and departments, including the Assistant Secretary for Preparedness and Response from HHS, the Administration for Community Living, the

Biomedical Advanced Research and Development Authority or BARDA, CDC, the FDA, the NIH, FEMA, the National Council on Disability, the US Accessibility Board or the US Access Board, and the Department of Veterans Affairs. It also has seven public members, and they just closed their nomination period a few days ago for the seven members that they are looking for to serve on this committee. We will be bringing you updates as we hear more about what they are doing.

There is the Federal Partners in Transition, and this is a group that is managed by the US Department of Labor. I am a part of this group. It is an all-federal workgroup formed in 2005 with representatives from several federal departments, including the Department of Education, HHS, the Department of Labor, and the Social Security Administration. And its goal is to support all youth, including youth with disabilities, in successful transitions from high school to adulthood.

This also facilitates exchange of information across agencies on the issue of transition. They have a strategic plan called the 2020 Federal Youth Transition Plan. This is going to be updated in the near future and that is going to be the task of the FPT in the coming months. We will keep you updated on their work in that area and bring you the report when it is completed.

There is another committee that is a managed by the Administration for Community Living called the Interagency Committee on Disability Research. I also sit on this committee. It is an all federal committee established under the 1973 Rehabilitation Act to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehab research programs. They have released a number of reports recently. I have listed them with hyperlinks so that you can look at those. We will put them up on the IACC website as well and keep you updated on the activities of this committee.

There is the National Council on Disability and this is an independent federal agency charged with advising the President, Congress, and other federal agencies on policies, programs, practices, and procedures related to people with disabilities. It issues a number of important reports and letters that it writes to various different departments and agencies all on its website. I have provided a listing of a few of the recent ones. They have an upcoming meeting actually tomorrow and they have a meeting in October. Their meetings are open to the public so you are welcome to attend those. We sometimes have brought the National Council on Disability here to the IACC and we will in the future if there is something important they need to share as we would with any of these committees.

And next, I wanted to share with you another newer committee. This one formed in 2019. The RAISE Family Caregiving Advisory Council, which is also managed by the Administration for Community Living. The RAISE Family Caregivers Act directs the HHS Secretary to develop a national family caregiving strategy. This committee is currently working on the strategy.

The Act also directed the establishment of this committee and it is providing recommendations to the HHS Secretary on models for both family caregiving and support to family caregivers as well as improving coordination across all federal government programs, similar to the IACC. And caregiving is an issue that many people on this committee have already raised to me as something that you are interested in. We want to carefully follow the work of this committee that is directly focused on caregiving.

Their issues relate to family caregiving for both older adults and individuals with disabilities. Their first meeting was held in August 2019, and they meet three to four times per year and their meetings are open to the public. We may be hearing more about them as well.

I gave you some of their most recent updates. They have 26 recommendations that they have provided and they are working on a Report to Congress that will be issued pretty soon. There are some different updates here that you may be interested in.

Those are the updates that I have to share with you as far as my role as Acting National Autism Coordinator. I am happy to bring you more updates in the future about collaborative activities across the Federal Government. I am really pleased to have this opportunity to serve my federal colleagues as well as the community in this capacity.

I am sorry. I forgot one last thing that I had in my presentation is I wanted to share with you something that is not a federal activity, but it is another activity that I want all of the committee to be aware of in case some of you are not in the research arena. The

International Society for Autism Research is a professional organization, a scientific organization devoted to advancing knowledge about autism and promoting the highest quality of research. There is information on their website about their virtual annual meeting.

They currently are running a summer institute, a webinar series. And this is year’s topic is autism and intersectionality. You may be interested in those. Those are free webinars.

I wanted to highlight for you something that INSAR released recently. INSAR produces a number of policy briefs on issues related to autism. They recently issued a policy brief on Autism Community Priorities for Suicide Prevention that was published in April 2021. I know this committee has done some work on suicide. That is another topic that has been mentioned to me as a topic of interest.

There are two versions of this report. There is a short version, which is the first hyperlink I provided there, and a long version.

And I also served on this international delegation that was made up researchers, research funders, community stakeholders, and policy professionals. I encourage you to have a look at those documents if you are interested in the issues surrounding suicide and autism.

With that, I will conclude the National Autism Coordinator update. Dr. Gordon, do you have any questions or comments?

DR. GORDON: I am just noting that we have about at least one question from the committee. I think we have time if people have questions for Susan in her role as National Autism Coordinator. Now would be a great time to ask them. I am going to use first names. I think it helps us establish more collegial relationship amongst each other. But if you prefer otherwise, just let me know. Paul.

DR. WANG: I am happy to be called Paul. Thank you very much. Susan, I think everybody who knows you and the work you have done for this committee and more broadly is very happy to know that you are available to serve as the interim National Autism Coordinator. You have incredible experience, expertise, and commitment. That is fantastic.

At the same time, I think we all have the hope that a permanent NAC will be appointed because it is such an important position and having someone with a permanent appointment will be very important whoever that person may be. What is the timeline for that?

DR. GORDON: I think I ought to answer that. The Secretary has asked me to search for and find a new National Autism Coordinator. We are currently going through the bureaucratic process of declaring an opening for that position. We hope to begin the search within the next six weeks or so and hopefully have one named by the end of the calendar year, which would be pretty quick for a federal government process. We are going to have a national search. But the details of that will be forthcoming.

DR. WANG: Thank you.

DR. DANIELS: Dena, did you have a question?

MS. GASSNER: I just wanted to share that the INSAR Autistic Researchers Committee currently has an open call for additional members. If you go to the INSAR website or you reach out to me, I can link you up with someone if you are an autistic researcher.

The other thing I wanted to ask is do any of these committees address the needs of autistic adults who are not transition age, but are desperately seeking employment.

Many of those individuals have not had access to accommodations or supports and yet they are still very interested in employment. I am just wondering if there is any activity on that front.

DR. DANIELS: I see that Scott Robertson has his hand up and he may be able to talk about more specific employment-type initiatives. In these committees, employment is not a type of priority of any of the committees, but it is a point of discussion in some of the committees. Employment is discussed in the Federal Partners in Transition committee. Scott?

DR. SCOTT ROBERTSON: I was just putting my camera on. I am filling in for Jennifer for this afternoon portion. Jennifer had to leave to go to another meeting. I am the alternate rep for IACC and a senior policy advisor at ODEP and an autistic adult myself.

Yes, employment is in Federal Partners in Transition. Obviously, we have our own research project that Jennifer mentioned on employment opportunities for young adults on the autism spectrum that was requested by Congress. That is one of the reasons that we are doing that research study.

If I think of something else, I can mention it later on as far as relevant things as far as on the employment focus. We look forward to contributing also to other employment-related facets, especially since social determinants of health, employment, and health and well-being are well linked.

I also just had a question, Susan, related to the other committee. Is there any update related to the Interdepartmental Serious Mental Illness Coordinating Committee? I believe it is HHS that coordinates that committee too under the 21st Century Cures Act. I do not know if you have anything that you have heard from that committee.

DR. DANIELS: I do not have an update from them, but I will defer to Dr. Gordon, who may have more information on the SMI committee.

DR. GORDON: Unfortunately, I do not have any news with regarding that committee. They were on hold, waiting for the new Assistant Secretary for Mental Health, who has been named now and I believe confirmed. I would imagine we would be hearing something about that soon.

DR. ROBERTSON: Thanks, Dr. Gordon.

DR. DANIELS: I am happy to bring you an update on the SMI committee if you all are interested in that committee as well, at the next IACC meeting.

Jennifer, do you have a question?

DR. JOHNSON: I just wanted to respond to the earlier question about activities related to employment. As I mentioned, the Administration for Community Living and the Administration on Disabilities within it, does have a priority area on achieving economic security and mobility. Employment is obviously an important feature of achieving that. We do have a number of activities that we support related to employment focused on youth, but then some of those focus on adults.

One of the things that I wanted to point out in the work that we do in the area of employment is we last year announced price competition, unemployment, specifically focusing on talent pipeline programs within businesses and creating more inclusive talent pipeline programs. Through that price competition, we identified five entities that we thought had really promising ideas for creating more inclusive talent of pipelines within businesses. We whittled that group of five down to three. Later this year, I think in the fall, we will be announcing a grand prize winner for that competition. It is really just a way to lift up and raise awareness about some promising work that is going on that hopefully can be replicated to support employment of people with disabilities. There is information on our website on that prize competition if you wanted to learn more about it.

DR. DANIELS: Thank you, Jennifer.

Alison Marvin, do you have a question?

DR. MARVIN: Hi. I am from the Social Security Administration. I just wanted to mention the Social Security Administration’s Ticket to Work Program, which it supports career development for Social Security disability beneficiaries aged 18 through 64 who want to work. It is free and voluntary. That is something for people to look up as well. That may be of interest.

DR. DANIELS: Thank you so much.

Craig Johnson, do you have a question?

MR. JOHNSON: It is still centered around what we were talking about. One of the really cool things that is taking place within states is around employment. We have been working with Texas Workforce Solutions and they connect with businesses all throughout the state. And then we are able to set up a job fair. We had about 60 businesses that came in that were willing to hire special needs adults. We are starting to see some connections where they are doing overall employment, but now they are focusing on special needs. I think about 150 were able to put in applications. That is some exciting things. I think different job solutions within state organizations are able to work with whatever organization that would be interested.

DR. DANIELS: Thank you. It is great to hear all these updates regarding employment. Employment is definitely a priority for a future IACC meeting and we can have more in-depth discussions on employment. I know this is an area of interest for our committee.

Does anyone else have any other questions on anything I shared just now?

If not then I will move on to the next part of our afternoon, which is to talk about IACC committee business. As you know, the IACC is a federal advisory committee, established first under the Children's Health Act of 2000. It has been reauthorized by a number of different laws and most currently the Autism CARES Act of 2019.

The charge of the committee just to get us all on the same page so that we all can hear about this, including our viewing members and the audience. The IACC's charge is to provide advice to the Secretary of Health and Human Services on issues related to autism spectrum disorder, to coordinate federal activities related to autism, provide a forum for public input on issues related to autism, develop and annually update a strategic plan for ASD, develop an annual summary of advances in ASD research, monitor federal activities related to autism, and the committee is required to meet at least twice annually.

In the Autism CARES Act just to give you a few highlights of what was different in the CARES Act. When the committee was reauthorized, it is going to run through September 30, 2024. There were some increased membership requirements. There are three categories that are named specifically in the law that need to be on the committee, including individuals on the autism spectrum, parents and legal guardians of individuals on the spectrum, and representatives of leading research, advocacy, and service organizations. As you can tell from the introductions, we have all of those and we are required to have a minimum of three and we have more than three in all of those categories and a lot of people wearing multiple hats.

We also under the CARES Act of 2019, added the Departments of Labor, Justice, Housing and Urban Development, and Veterans Affairs, as you know, from the earlier introductions. The committee will be continuing to prepare those annual updates of the Strategic Plan in the Summary of Advances.

The new law also continues with 2014 to ask the IACC to continue in its Strategic Plan to address services and supports for individuals with ASD and their families as well as research and recommendations to ensure that federal ASD research and services are not unnecessarily duplicative.

The new law added an emphasis on IACC activities being inclusive of issues across the lifespan of individuals, which was mentioned this morning in our opening talks. It also limits public members to 2 four-year terms.

Our new committee is composed of 23 voting ex-officio federal members representing federal departments and agencies involved in autism and disability research services and policy, 22 public members that represent the whole span of different areas, as we just mentioned. And the composition allows the collaboration of federal agencies and community stakeholders to work together.

The core values of the committee from the initial inception of the committee were expressed in the Strategic Plan from 2009. That was the first Strategic Plan of the IACC. They have the values of a sense of urgency, excellence, a spirit of collaboration, community focus, partnerships in action, and equity, which do not sound outdated. They sound like they are still timely today.

Ways that the IACC can uphold the core values are respectful dialogue and thoughtfully listening to each other's perspectives, seeking and listening to input from community stakeholders, bringing forward evidence and best practices to inform decisions, being inclusive, and bringing together diverse points of view and multiple disciplines to address issues, which have always been strengths of the IACC.

Things that the IACC does are providing advice to the Secretary on issues related to autism and it is done in the forms of IACC Strategic Plan recommendations, letters, and sometimes statements.

It also provides a forum for public input and discussion of issues related to autism, including public comment periods. It provides coordination of federal and member organization activities through the Strategic Plan, also the monitoring of activities, including collecting data from agencies and organizations, and fostering collaborations as were mentioned in the Deputy Secretary’s speech this morning. The IACC also identifies issues and priorities for autism research, services, and policy that can be communicated in the form of recommendations and reports.

One of the most important things that I shared with our public members in their public member orientation was that the IACC plays a key role in illuminating issues in its meetings, workshops, reports, and other activities and that sometimes an emerging issue that is first raised in the IACC gains the spotlight that it needs to be recognized and then to lead to action.

What the IACC does not do is that because it is an advisory body, it does not fund research. The IACC has no research budget and it is not able to allocate any research dollars. It also does not control the funding or content of federal programs. And it does not itself implement federal programs or policies. But it can make recommendations about these things.

IACC activities, as I just mentioned, can be full committee, subcommittee, and working group meetings and discussions, reports and documents, recommendations, letters to the Secretary, holding workshops, townhalls, or other events, listening to and considering public comments, publishing requests for information, and coordinating activities with other federal advisory committees.

We encourage our members to attend meetings, to plan to share updates when you are at our meetings and just like today, be able to jump in and offer additional information that may follow on from presentations you hear, and to actively contribute to our discussions. You can always suggest topics and speakers for future meetings and workshops. You are welcome to, you know me, if you have any suggestions. We can identify opportunities for coordination and collaboration and we would love to have you volunteer to participate in or lead working group activities.

For IACC meetings, some of the things that you will see regularly on our agendas are committee business. This will be a discussion of how we fulfil the responsibilities required in the Autism CARES Act. We will have panels, presentations, and discussions of timely topics in autism research, services, and policy. We will hear public comments, including oral comments, written comments, and live feedback that is collected during our meetings. We will be sharing agency and organization and committee member updates.

With this, for such a large group, I have asked the committee to prepare some comments about their latest updates. We put them into a written document that is available on our website that has been distributed to all the members because we might not have time to go around one by one to share all of our updates, given that we are such a big group. But we wanted you to have it in writing so that you can – when you go back to your home organization or agency or to your home - that you can read these updates and you will have hyperlinks to some of the reports and activities that are going on across our country.

We have a schedule that is upcoming just to share with you. We have three full committee meetings per year. We are planning this one as the last one of this fiscal year for government calendar. We plan to have another virtual meeting in October. In January, perhaps we will have a hybrid meeting, depending on how things go with the pandemic. In April 2022, we will have a meeting. We have a slot in July 2022 for an activity such as a workshop or some other activity if the committee wants to do something else.

I want to tell you a little bit about the specific responsibilities of developing and annually updating a Strategic Plan for ASD, developing and annually updating a Summary of Advances in ASD research, monitoring federal activities with respect to ASD, and making recommendations to the Secretary.

The IACC Strategic Plan, which was first developed in 2009 or it was released in 2009 after a one-and-a-half-year developmental period, offers a blueprint to guide autism-related efforts across federal agencies and partner or private organizations.

The current plan is organized into seven community-based questions that follow different topic areas that are related to autism. And the current plan has 23 objectives, or these really are the recommendations of the plan, but address both research and service activities as well as policy. There is a budget recommendation and a recommendation regarding not having unnecessarily duplicative activities. Those are all required in the law.

With the IACC Summary of Advances, this is an annual report that is required by the Autism CARES Act. And to do this report, we prepare lay-friendly summaries of the 20 most significant advances in ASD biomedical services research as selected by the committee. You all will be participating in making those selections. It includes peer-reviewed articles or summaries of these peer-reviewed articles addressing all seven topic areas of the Strategic Plan.

To help us with our activities to monitor federal activities, the Office of Autism Research Coordination, which is the office that I direct, prepares an annual portfolio analysis report in which we collect information from across federal agencies and private funding organizations across the US and collate these into a report where we compare it against the

IACC’s Strategic Plan objectives to identify where there are gaps, where some of the objectives are being met, and provide analysis of funding trends and provide other funder information.

We usually do it – we usually combine two years of data in one report just for convenience because it is a large undertaking to collect all of this. To accompany the report, we have a detailed federal and private organization project database available that is called the Autism Research Database. That report also informs the IACC.

Our immediate tasks that are upcoming are that we need to develop an update of the IACC Strategic Plan. We need to come up with an update for that. We also need to develop two volumes of the IACC Summary of Advances in ASD Research. We missed 2020 so we have to catch up with that one and then get caught up on 2021.

I am going to talk a bit about the processes for those. I will not read this. But I have provided the IACC Strategic Plan vision statement. And the mission statement is the purpose of the purpose of the Strategic Plan is to focus, coordinate, and accelerate innovative research and foster development of high-quality services in partnership with stakeholders to address the urgent questions and needs of people on the autism spectrum and their families.

Our office came up with a proposed plan for the update of the IACC Strategic Plan for 2020 and 2021. I wanted to discuss this with you to see if you have any other suggestions. We would like to help you achieve this within the coming year. In the past at times, we have had a more complicated procedure for doing the Strategic Plan Update and sometimes it takes us more than a year to get it completed. We would like to help you all catch up since the committee has just gotten started.

The proposal would be for the streamlined process to establish a working group for the IACC Strategic Plan Update. This working group would be volunteers from the committee and it can be large or small. It can be everybody on the committee or it could just be a portion of people on the committee. This working group would be a group that could work closely with the OARC in developing some initial plans for the Strategic Plan Update and any activities we need to do to gather the right information for the update.

One suggestion that we have would be if you authorize us to do this, we could do a request for information. We could issue a request for information to gather public and expert input on areas of the Strategic Plan that need updating. In the past, we have done this where we put out basically a questionnaire that is available on the website and people can go in and give us their feedback on each of the areas of the Strategic Plan and what they think are the gaps in the current plan, what they would like to see and what are the issues they are concerned about in each of these areas. If you are agreeable to that, we could work on issuing an RFI to start gathering that input for your review.

We also would like to have potentially a discussion session with the committee during the October 2021 IACC meeting to identify areas of the Strategic Plan that need updating and let you, as the committee, review the current plan and come to the committee meeting with your thoughts and suggestions that we could air during that meeting and evaluate the current list of objectives and consider public input.

The last piece of the process would be that our Office could assist you with gathering some of the latest literature, federal reports, and reports such as the Portfolio Analysis, HHS Reports to Congress, and other sources of data for doing this update.

To continue, we would be able to also hold a longer public comment session at the October meeting if that was desirable. We could also invite experts to share at the next couple of IACC meetings if you wanted to hear specific presentations from people or get verbal input from certain experts or community members.

I would propose that we use OARC to capture the comments and develop the draft for review. In the past, we have done some writing by committee. It is perfectly great to do that, but it is a long process when we have multiple people writing and then consolidated into a draft. We would like to offer the opportunity for you to take advantage of our team to collect this information and put it into the draft for your review. We would bring the draft to the committee to review, comment on, discuss anything controversial and make decisions about what needs to stay in or be removed. With the Strategic Plan, we usually try to come to a consensus on a lot of issues and with issues that are controversial, sometimes we issue parts of the report that express one point of view and another point of view. But where we can, we try to come to a place of unity on many of the things the whole committee feels are important to put forward to the community.

As just a procedural thing, the final report has to be approved and reviewed by the Full Committee even if there is a working group preparing some of the parts of it. It has to be approved by the Full Committee and it becomes a Full Committee report. Our goal would be to publish this by either spring or probably summer of 2022.

That is my proposal for you. I wanted to talk with you about it, see if you have any thoughts about things that might be missing from those suggestions or other thoughts you may have. I am opening it for discussion.

DR. GORDON: You have a proposal from Susan. It is severalfold. Number one, have her Office issue an RFI. Number two, provide time for you all to look over the current Strategic Plan and make comments. And number three, have the discussion in October that would include your remarks and the RFI results. And then finally, number four, permit the office to incorporate those comments into a revision that would be brought back to this committee – that would be worked on by the workgroup first and then brought back to this committee once a complete draft that the workgroup had approved was ready. Does that encompass all the recommendations, Susan?

DR. DANIELS: I believe so. We do not necessarily need the workgroup. We can decide with the workgroup how we want to work that. It may be that once we get all the components into the draft, really the Full Committee can look at it and help finalize it. We would probably try to streamline the process as much as possible so that there are not too many extra meetings that are not needed.

DR. GORDON: Comments, questions, or concerns? It looks like there is already two people. Susan, I will let you call on them.

DR. DANIELS: JaLynn, you have a comment.

MS. PRINCE: Can you hear me?

DR. DANIELS: We can hear you.

MS. PRINCE: For some reason, my camera thing is not working. But I do have a question about the town hall meetings. I do not know exactly – I think there was something on housing. I do not know if that was considered a town hall meeting or if there is something that can be done even inviting people around the country to talk about different subjects and so forth so we get individuals giving us feedback in a town hall meeting that might inform some of our opinions and some of our actions. How would that work if it does work that way.

DR. DANIELS: Sure. In the past, we have done town hall meetings before. Usually, we schedule maybe two hours. And given in this new day and age where we have Zoom, we could have people registered in advance for that town hall meeting. We would have to keep people to a schedule to make sure that we could get through all the people that may comment and would ask them to share experiences that they think will or comments about the Strategic Plan that will inform the Strategic Plan. We could do a town hall meeting if we wanted to. We could either structure it as a part of an IACC meeting like to take a couple of hours for public comment and to have that be largely oral comments for a couple of hours and followed by whatever we brought back in writing. We could do that if the committee would like to do that.

I think that doing it as a part of an IACC meeting would be the easiest way to make sure that the whole committee is there. We could schedule it as a separate meeting and then those who are able to attend could attend. But we would want to make sure that a lot of the committee was there to listen to people if they are taking the time to provide us with public comments.

MS. PRINCE: Excellent. Thank you.

DR. DANIELS: Valerie, do you have a question?

DR. PARADIZ: I have a comment. I just wanted to say that I am supportive of these recommendations for the proposed process for this. I am also very interested in serving on that work group. If I am jumping the gun and expressing that too soon, sorry about that. I just want to share that.

I would also be very eager for the resulting Strategic Plan to move through a process to ensure that it is as accessible as possible to a wide range of users, I guess, is how I want to put it. Thanks.

DR. DANIELS: Thank you. The accessibility question, I think that would be a great use for the working group to look at the draft to see if it looks accessible. Our office does try to put things in plain language. It is a balance between having richness and nuance in the document and trying to make it easily understandable. We certainly could use the workgroup that way.

Next, Jennifer Johnson, do you have a question or comment?

DR. JOHNSON: I just want to add to the last comment about the accessibility of the document. We have done quite a bit of work to ensure that some of our key documents that include things like road maps or strategic plans are truly accessible across the range of abilities and can provide some expertise in that area to ensure that there are, as we call them, clear language versions of documents that that people with different levels of literacy can access it. I think it is not only what we sort of expect in terms of accessibility, but really ensuring that the content is such that people with different levels of ability can access the information.

DR. DANIELS: I have a question for you, Jennifer. Do you usually issue more than one version of the same report or do you try to make the main report in that language?

DR. JOHNSON: We will do two different versions. For example, for the President’s Committee for People with Intellectual

Disabilities, their last report, we included a fair language version of that report. For other types of documents again, we will do one version of the document and then again, another one that is fair language.

DR. DANIELS: Great. We appreciate knowing that you have some experience in this area and would be happy to tap into your expertise there. Thank you.

Scott Robertson, do you have a question or comment?

DR. ROBERTSON: Susan, thanks for this discussion about the Strategic Plan development and I think we are very excited to collaborate on that for the employment and other aspects, and especially for us particularly traditional questions five and six, around needs of adults and services and supports obviously interweave a lot for us on the employment and related aspects of employment.

I just want to concur with what folks have said about what – to enhance accessibility when possible and also to support use of inclusive language and that could be discussed I guess at future meetings in terms of what language can make sure this is fully supportive of folks and sort of strengths based on the language in the document.

I also want to suggest that regardless of whether you do one version or two versions, maybe considering including a lay summary even if one version is not the more accessible then maybe have a lay summary at the beginning that has the plain language on it anyway regardless, which can help so folks know the gist at least even for the more complex document.

And then I just wanted to mention very briefly that I forgot to mention the employment discussion and we look forward if there are any opportunities later on this year or next year to share more on the employment related activities. I am the federal project manager for our partnership on exclusive apprenticeship. We mentioned that in our agency update. It is inclusiveappreniceship.org. It may be of interest and folks can learn about that more down the line that a lot of folks who are on the autism spectrum have been engaging in apprenticeship as a pathway to careers for gainful employment. It has a lot of relevance for this community. It is something that is relevant for folks of different support needs. I think that is one of the myths out there is that apprenticeship and other pathways to careers – they are only for some portion of autistic people.

I just want to emphasize that folks of different supports or combination needs – what we are exploring in that area with the partnership on inclusive apprenticeship at inclusiveapprenticeship.org and all their initiatives are – we are looking at for all folks with disabilities and in this case for autistic people, autistic people with broad range of experiences and support needs and combination needs.

DR. DANIELS: Thank you.

Julie Taylor, do you have a question or comment?

DR. TAYLOR: Yes. I just wanted to express my strong support for this plan of developing the Strategic Plan for this year. I led one of the work groups last time, for developing a section of the plan and it was a very positive experience and I enjoyed it very much. But I also know there was a tremendous amount of work to take all of the different pieces and put them together into one cohesive document. I think this plan gets us to the exact same place at the end with fewer kind of in between steps. I think we will still get all of the input that we need and I think the plan that we end up with at the end of the day is going to be a really strong one, just as it was when we did the process the other way around. But I think it will just be a more streamlined way to get there. I think it is a great idea.

DR. DANIELS: Thank you so much, Julie. I appreciate that.

Dena, do you have a question or comment?

MS. GASSNER: I do have a question. Is there a way that we can suggest other information we would like to get through collaborative agencies? Can we just email you, Susan, if we have some ideas?

DR. DANIELS: You can email us. We will have to think about that.

In terms of data calls, we already do quite a few data calls to the agency. We would have to consider it if it would be a data call. We may be able to mine data out of what we already have because we collect quite a bit of information for Reports to Congress and the portfolio analysis, but happy to consider. If you want to email the suggestion. But that is the kind of thing we could talk about in working group.

MS. GASSNER: I think in terms of accessibility too, I think it would be lovely if we could earmark a time to talk about language use.

DR. DANIELS: That is something I think that the working group also could discuss. I have heard those kinds of suggestions and I think the working group would be a perfect place to discussing using inclusive language and what kinds of language we might want to consider.

I am moving a little fast because I see that we are getting close to time, and I still had a couple of things I wanted to talk about with you.

MS. SMITH: This is Ivanova Smith. My question is would there be any discussion in giving visual support or audio support for people who cannot read. There are people, autistic people and people with intellectual disabilities that cannot read. Visual supports and audio like having - making sure the website is screen readable friendly and that kind of thing I think would be important as well for people who cannot read or write.

DR. DANIELS: For the federal government when we post things on the website, we are required to be 508 compliant. That usually does include screen reader accessibility and even things like what colors we use in graphics and so forth. They are 508 compliant. They have a set of standards and they keep updating them. Those basic things are done. But if there is anything special, we are not already doing, we can discuss it.

It sounds like overall we have support for this general process. I will send out an email to see who wants to be a working group for this and develop more detail about this for the October meeting and share back with you.

Unless anyone has any other comments, I want to move the next item. Thank you so much.

For the IACC Summary of Advances, which I shared with you what that is, I also have a proposal for you for a process for doing this for 2020. We need to catch up on the year that we did not issue a Summary of Advances for 2020. To help jumpstart this process, since you all were not on board at that point to be able to contribute nominations, our office went ahead and solicited federal agencies to contribute nominations on your behalf. We have created an initial list. Also, the OARC searched for nominations for you and put together a list of peer-reviewed articles that were from federal agencies and ourselves to get you started and we want to send this out to the committee as a starting point and you can feel free to tell us if there is anything that should be deleted off that list and then also to start nominating articles that you would like added to it before we take the opportunity to vote.

We usually do the voting by electronic ballot once we have a list of nominations. Up to 20 publications under each of the – total under each of the seven questions of the Strategic Plan are ultimately selected by the committee vote.

After we vote on the articles, OARC issues a draft of short, lay-friendly summaries of the selected articles. We take the papers that are usually somewhat lengthy, and we boil them down to a page or less in lay-friendly language and summarize those, put them together in a volume and that becomes our Summary of Advances.

We would like to propose – we have already provided you with a list. It is in your materials and people who are looking online, you can see it. It is there. We would like to start that process by email to get you to all nominate additional articles or give us any feedback on what is there.

When you do the nominations in the past, we have had the committee provide a justification just briefly for why that paper is worthy of consideration for being a part of the Summary of Advances. Then we have an opportunity to vote. We do provide with the PDFs of the articles so you can read the whole article if you are interested.

That is my brief summary of what we are planning to do for the 2020 Summary of Advances.

Does that sound acceptable to you all? Do you have any questions about it?

DR. GORDON: I guess, Susan, it is just worth clarifying for a moment that for the 2020 summary, what we are talking about is papers that were published in which year.

DR. DANIELS: In 2020.

DR. GORDON: In 2020. Ordinarily, we would be doing this in January. We are six months later or something like that. That is just to clarify the timing.

DR. DANIELS: Perfect. I am not hearing anything. We will just send you all the instructions by email. And, of course, everything gets – if there are discussions about it, they will happen in the committee meeting so the public can hear any discussion. But other than that, we would just be voting and then trying to complete that document in a timely fashion. This is a timeline that we set for how this will work and when we will be sending out the various emails. The ballot would go out in September barring any other concerns and that we would prepare this for publication early in the next calendar year.

Scott, do you have a question?

DR. ROBERTSON: Just a quick question just to clarify. You said that we can potentially suggest additions to the list. Did I understand that correctly?

DR. DANIELS: Yes.

DR. ROBERTSON: I think it might be helpful particularly since 2020 including obviously COVID-19 that maybe making sure the list includes – if it does not already include papers relevant to COVID-19 and autism because I think there will be a lot of expectation, I think, from the community at large that we make sure that is covered in the scope of major research progress.

DR. DANIELS: You will have the opportunity to nominate additional things.

I am going to move quickly to 2021 so the next Summary of Advances. In the past, we have had the committee provide nominations year-round. We did this via soliciting you for nominations on a monthly basis via monthly email. I did want to find out from the committee if you want to receive a monthly email or would you rather be solicited four times a year on a quarterly basis for articles for nomination. Of course, you can just send them any time you want. The last committee said that they liked having monthly reminders. But in practice, we found that I think maybe it got a little bit repetitive and were sometimes ignored. We do not want to send you extra email if you do not want it. Would you like to nominate things on a quarterly basis or would you like it monthly, or would you like to do it at the end of the year, which is what previously committees have done in many years past? Any suggestions?

DR. RIVERA: I think monthly is a good strategy. That way we stay really current.

DR. DANIELS: Who is speaking?

DR. RIVERA: I’m sorry, it is Susan Rivera speaking.

MS. GASSNER: This is Dena. When I was asked what kind of accommodations I needed, my list was really short. But as you progress through the meeting, you are like this would have been nice. I think that Susan is right. I think anything we can do to continue to stay current would be great.

The other thing I wanted to ask is if we could all get copies of the last Strategic Plan because it has been two years. I do not even know where mine is at this point. So that we could be more familiar and more prepared for the conversation next time.

DR. DANIELS: We will give it to you for meeting materials. It is on the website. Are you talking about a paper copy?

MS. GASSNER: Yes. I do not read anything on a screen. If you do not mail me one, I have to print it. That would be great.

DR. DANIELS: We might have to just print it out on a printer and send it to you because we are not working in the actual office right now. We do not have access. I think everything is packed up and stored.

DR. WEXLER: Susan, this is Larry Wexler. My vote is not monthly based on the fact that we did it monthly for years and it really was not an approach that worked well. I would say every six months and then you are likely to get good participation. If people want to send it in more often then that would be fine too. That is just my vote.

DR. DANIELS: The happy median between the two of them would be to do it quarterly like before the IACC meeting just to send a reminder to look back at the last three months or if you have not done anything for the last six months, to look back and see if there is anything you want to nominate before the meeting.

DR. GORDON: Susan, there are a couple more people who would like to speak.

MR. SRINIVASAN: This is Hari. My vote is on quarterly updates and reports.

MS. SMITH: This is Ivanova. Having the document printed out would really help me because I cannot look at the documents and pay attention to the meeting at the same time because I am using my computer. It would be hard to try to look at them on my phone. Having it printed out would make it easier for me as well. Thank you.

DR. DANIELS: We can have some staff contact folks that need a printed copy. We would just be printing it out on our printer and putting it in an envelope for you because we do not have a professionally printed copy available right now.

DR. ROBERTSON: I was good with – I think we are good with monthly, but I think if quarterly seems like more of the compromise or whatever, quarterly would be preferred over six months, I think, if that is where the spirit is in terms of compromising.

DR. DANIELS: I think for compromise, quarterly sounds good. I will not go through any more of that. I know that we are close to time here. If you will allow me to, I want to ask you one other question, which is whether you would give me permission to reconvene the co-occurring conditions working group, the working group on improving health outcomes for individuals on the autism spectrum because this group had prepared a draft report the last IACC round and the report just needs to be taken to completion. If you give me permission to reconvene this group, we will get the group together to finalize the draft for the committee’s review and publication in 2022. Does anyone have any concerns about doing that?

MS. FRYER: This is Maria. No concerns at all. I am in full support. I just want to say thank you for your effort on this.

MS. GASSNER: This is Dena. I have greater concerns if we do not.

DR. ROBERTSON: This is Scott. I am glad that you are moving that forward. Does that include – is there something that could be finalized for what happened with the housing group too, or is that not in a state of readiness where it could be released in the way that the health care workshop focus was or the health care workshops?

DR. DANIELS: With the Housing Working Group, because it happened so late in the term of the IACC, we had a workshop, but we did not actually have a chance to do any kind of a written project around it so there is no draft to consider. If this committee wants to reconsider housing on a deeper level, we can certainly do that in the future, starting with maybe consideration at an IACC meeting and if we want to do more work, we can. But there is no existing project that we need to complete. But with this topic of co-occurring conditions, we do have a project that is well along and we want to complete it so that we can release it to the community.

DR. ROBERTSON: That sounds good, Susan. And just related to the housing, I think housing I imagine may come up with discussion with future meetings now that HUD is one of our sisters – a new member like us.

DR. DANIELS: We are excited about their participation.

Hari, do you have a question?

MR. SRINIVISAN: Does this mean we are done with this topic after this report or can we keep looking at comorbidities and health outcomes even in the future as that is an important issue?

DR. DANIELS: We can always keep talking about it. I would recommend if we wanted to say other important things that we get it into this report, which is why it will be coming to this committee. If you think that there are gaps in the current report, we can certainly address them now. It is a lot of work to put together a report. We might as well get this one the way the committee wants it. We welcome your input on this current report to get it complete.

Teresa.

DR. SOUZA: Hi, thank you. I will be totally in favor of having a report on housing and will be glad to participate in that and provide any help on that topic.

DR. DANIELS: Thank you.

I am not going to go into this right now, but just - I have received a number of topics from members of the committee. You can continue to send those to me. I am putting them together. We can bring this back in October to talk about it more. But I am using these topics as suggestions for future IACC meetings. And down the line if we want to do an activity next summer, we might plan around one of the topics you suggest. On this slide, I have shared some of the topics I have heard from you.

Lastly, I am not going to talk a lot about our Office, although there are some bullets there to explain what we did. But I want to recognize the incredible staff we have at the Office of Autism Research Coordination and help make this possible. They will be working with you very closely. They are super excited to work with this new group of the IACC. Here are their pictures. You will be meeting them and interacting with them.

I just shared a few slides that if you want to go back to about the website, our newsletters, and the autism research database. You are always welcome from all the agencies and organizations and individuals to share updates with us. If there is anything that is appropriate to put on our website to share with the public or to put in our newsletter, we are happy to do that and help advertise upcoming workshops and events or new reports that you have put out. We want to help disseminate information to the community and that is what we are here for.

Thank you so much for you time. We are excited to welcome you and look forward to working with you.

DR. GORDON: We will see you tomorrow at 1 o’clock. Is that right?

DR. DANIELS: Two o’clock.

DR. GORDON: Two o’clock tomorrow. See you all then.

(Whereupon the meeting adjourned at 4:05 p.m.)