INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

Wednesday, October 13, 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)

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

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

PRESENT (continued)

JUDITH COOPER, Ph.D., National Institute of Deafness and Other Communication Disorders (NIDCD) (representing Debara Tucci, M.D., M.S., M.B.A., F.A.C.S.)

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

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

AISHA DICKERSON, Ph.D., Johns Hopkins University

REBECCA DZUBOW, M.P.H., Environmental Protection Agency (EPA) (representing Elaine Cohen Hubal, Ph.D.)

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

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

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

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

ADAM HARTMAN, M.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Nina Schor, M.D., Ph.D.)

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

PRESENT (continued)

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

WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS (representing Nina Schor, M.D., Ph.D.)

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

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

MATTHEW MILLER, Ph.D., M.P.H., Veterans Health Administration (VHA)

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

YETTA MYRICK, B.A., DC Autism Parents

MORENIKE GIWA ONAIWU, M.A., Rice University

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

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

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

JALYNN PRINCE, Madison House Autism Foundation

PRESENT (continued)

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

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

MATTHEW SIEGEL, M.D., Tufts University

CORNELIA SIGWORTH, M.S., Department of Justice (DOJ) (representing Maria Fryer, M.S.)

MARTINE SOLAGES, M.D., U.S. Food and Drug Administration (FDA) (representing Tiffany Farchione, M.D.)

IVANOVA SMITH, B.A., University of Washington

HARI SRINIVASAN, University of California, Berkley

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

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

DEBRA TIDWELL-PETERS, M.A., Social Security Administration (SSA) (representing Alison Marvin, Ph.D.)

ANNA TSCHIFFELY, Ph.D., U.S., Department of Defense (DoD) (representing Nicole Williams, Ph.D.)

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)

STEPHEN WHITLOW, J.D., Merakey

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

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PROCEEDINGS

DR. JOSHUA GORDON: Hello everyone. This is Joshua Gordon, and I am the Director of the National Institute on Mental Health and Chair of the Interagency Autism Coordinating Committee. It is a real pleasure to welcome you all back to the second meeting of this incarnation of the committee.

I am joined by Dr. Susan Daniels, the Director of NIMH's Office of Autism Research Coordination and Executive Secretary of this committee. Susan is also the Acting National Autism Coordinator, as we noted at the last meeting. It is really my pleasure to welcome all of the members of the Coordinating Committee, both public members, as well as federal members. It is a real pleasure for us to have you all here with us today.

I want, in addition to welcoming everyone, to specifically welcome our two members who were not able to join us at the last meeting, or weren’t actually able to introduce themselves, and we will have them introduce themselves in just a moment later. I also note that we will not have a roll call since we know you are here. We have your names captured on the Zoom call that is underlying the videocast, so thank you for joining us.

You also will note that we have the draft Minutes from the July 21-22 meeting, and they are posted online, so I will ask committee members to note if they have any corrections of the Minutes. In a moment, Susan will ask you to state any of those corrections for the record and then vote to accept the Minutes.

Before we do that, though, I want to note the news that we all heard last week that Dr. Francis Collins, the Director of the

National Institutes of Health, my boss and mentor and friend, has decided that he will step down from his position as Director of NIH, and therefore as a member of this committee, as of the end of the calendar year. Although Dr. Collins has been deeply interested in autism throughout, and keen to be caught up on the activities of this committee, he is not here today and sent his representative, but his support for the IACC's mission and work will be missed. We look forward to the appointment of a new director by the President. We hope that director will be named soon after Dr. Collins departs, and we look forward to working with him or her in the future.

With that note, I am going to pass it on to Susan to take us through the business that we need to attend to and introduce the new members and the Minutes, et cetera.

DR. SUSAN DANIELS: Thank you, Josh. Welcome to everyone, so glad to see you here today and looking forward to addressing all the different items we have to talk about on our agenda. I would like to give the committee a moment just to turn on your cameras and say hello to our viewing audience if you would like, since we can’t do the same thing we would do if we were ordinarily in the room. If you would like to, feel free to turn on your camera and say hello, give a wave.

We have a large group of people here, 45 members, and not every single one is here but most of them are here. Really look forward to your participation. Thank you very much. You can go ahead and turn your cameras off.

Next, we would like to go ahead and talk about the draft minutes from the July 21st and 22nd meeting. I received some corrections online; people just sent me some small things to correct. Is there anything else that needs to be discussed about the minutes? Does anyone have any issues they wanted to raise?

I am not seeing any. With that, is there someone who would like to make a motion to accept the minutes? Second?

(Motion made and seconded)

All in favor, say aye. Any opposed to accepting the minutes? Are there any abstaining?

It looks like we have a unanimous vote to accept the minutes, so we will go ahead and make the few changes that were sent in to us and go ahead and post the minutes after this meeting. Thank you.

Now we have a moment to hear from two of our new public members who were not able to join us for the first meeting and I would like to give a moment to each of them to talk to you and introduce themselves to you. First, I would like to call on Yetta Myrick.

MS. YETTA MYRICK: Good afternoon, everyone. This is Yetta Myrick here. I am a parent of a youth who was diagnosed with autism, intellectual disability and ADHD. We live in Washington, DC. I am the President and founder of DC Autism Parents. I created DCAP to connect with other families that were experiencing challenges and navigating services.

I serve as the Centers of Disease Control and Prevention's "Learn the Signs, Act Early" ambassador for the District of Columbia, and I am currently leading the DC Act Early Covid-19 Response Team. Through this work, we aim to ensure that families have the resources they need to monitor their child's development, engage with their child's providers if they have concerns, and receive the services and supports they need as early as possible.

Additionally, I chair the Developments and Monitoring, Screening and Evaluation Subgroup, which is part of the DC Autism Collaborative, a multidisciplinary public-private coalition of stakeholders, all in DC, who aim to strategically address barriers to ASD care and advocate for solutions that will increase early and equitable access to high-quality ASD diagnosis, treatment and coordinated care.

I also am the parent, educator and advocate on the ECHO Autism hub team at the Center for Autism Spectrum Disorders at Children's National Hospital where we work with community providers to support families as they navigate autism services and supports.

As I shared in my invited public comment in July 2019, I found that there was a limit to research we could participate in, my son and I, due to his verbal abilities and his IQ. This to me is a health disparity that needs to be addressed. People across the spectrum need to be represented in research, especially people of color, lower socioeconomic status and non-native speaking populations, because these groups have been underserved and deserve the chance to be included. And I hope that through our work with the IACC we will work together to include these groups. Thank you.

DR. DANIELS: Thank you so much, Yetta. Great to have you with us. Next, I would like to call on Stephen Whitlow to introduce yourself.

MR. STEPHEN WHITLOW: Good afternoon. I am Steve Whitlow. I am from Baton Rouge, Louisiana. My wife and I have three kids, the oldest is 24, a daughter, and the youngest is 15, and my middle son is 21 and is on the autism spectrum. In about 2005, when Sam was in high school, we started a small nonprofit called Gateway Transition Center to provide transition services to young adults in the area, which was sorely needed at the time.

Since that time, we have grown into various services including pre-employment transition services, a residential facility, and we have been overtaken by a company called Merakey, a multi-state nonprofit, and so I am now their transition director.

I am so pleased to be a part of this group. I am honored to be among these giants in the autism world, and we hope that we can pull together to really make a difference in a lot of people’s lives, which we have been dedicated to do down here for a long time. Thank you for having me.

DR. DANIELS: Thank you, Steve, and welcome to the committee. Is there anyone else on the committee that didn’t get introduced last time that wants to take a moment now? I am not seeing anyone. I didn’t think there was, but I wanted to make sure.

Thank you so much, and we are ready for the next part of the meeting.

DR. GORDON: Thanks, Susan, and thank you everyone for introducing yourselves to the audience and for the members to tell us a little bit about themselves.

Before I introduce our first guest, Taryn Williams, she is the Assistant Secretary in the Office of Disability Employment Policy, I want to remind our committee members that we are going to have periods of discussion after each of the presentations we have as well as during the committee business section of our agenda. I recognize that some members of the committee have some challenges communicating verbally, and we have made our best efforts to ensure that you have the opportunity to participate actively in the meeting.

If, for any reason, you are having challenges either with the technological solutions or with catching my attention or Susan’s attention to bring your comments to view, please contact myself or Susan, I believe we provided you with our emails to do that, and/or in the chat box. The chat is open but only for you to communicate with the hosts, but if you put a little note in there the hosts will get that note and will bring the issue to our attention.

Again, we look forward to having everyone participate, everyone on the committee, and hope that we will achieve the necessary ability to do so to make sure everyone has their voice heard. We recognize that these virtual meetings are challenging so I consider this still a work in progress. We will be looking to improve our processes throughout the day and looking forward to tomorrow afternoon’s continuation of the meeting and subsequent meetings should they need to be virtual.

Again, thank you all for coming. We are really pleased to have you and we are looking forward to a vigorous and respectful discussion throughout the course of the next two days.

With that notice, if Taryn will join us on the video and unmute, thank you. Welcome. It is really my pleasure to welcome Taryn Williams. Again, she is the Assistant Secretary in the Office of Disability

Employment Policy at the US Department of Labor, and she has come to talk to us on an update from the US Department of Labor in recognition and celebration of the National Disability Employment Awareness Month.

Taryn, take it away.

MS. TARYN WILLIAMS: Thank you so much for that welcome, and hello everyone. I am pleased to join you today and to have the opportunity to tell you about the Office of Disability Employment Policy, or ODEP as we call it, and the work that it does and can do to support the community.

For those who are unfamiliar, Congress established ODEP in 2001 to ensure that there was a federal agency dedicated to working across agencies, programs, and sectors to increase employment opportunities for people with disabilities. We are a small agency, but we like to say that we are small but mighty, and through policy analysis and evaluation, technical assistance, and interagency collaboration, we work to achieve our goals. In that spirit, we are pleased to be a part of the committee.

This is an exciting time of year for ODEP because it is, as you heard, National Disability Employment Awareness Month. NDEAM is what we call it, and this year we are especially excited because it is also our 20th Anniversary of the office. I would like to briefly describe NDEAM, and also a new ODEP study on strategies to support the employment of young adults on the autism spectrum.

NDEAM is a nationwide campaign held each October that honors the many and varied contributions of people with disabilities to America's workplaces and economy, past and present, in all sorts of endeavors. People sometimes ask us about the history of NDEAM and how it got started, and of course, what we always want you to note is that people with disabilities have been contributing to our nation since its very beginning, but NDEAM traces its history back to 1945 when Congress declared the first week in October the National Employ the Physically Handicapped Week.

In 1962, the word “physically” was dropped to acknowledge individuals with all types of disabilities, and in 1988 Congress expanded the week to a month and changed the name to National Disability Employment Awareness Month. And this history reflects progress in how we understand and speak about the contributions of Americans with disabilities to our workforce and economy.

At ODEP one of our top priorities is ensuring a disability-inclusive Covid-19 response and recovery, and this year’s NDEAM theme reflects that. The theme is “America’s Recovery Powered by Inclusion.” It is important to note that while ODEP spearheads NDEAM at the national level, the true spirit of the month lies in the many activities organized by groups and advocates across the country. We encourage employers of all sizes and industries to take part, including federal agencies. We also offer ideas and resources to help everyone do so.

However an organization chooses to participate, NDEAM is a time to celebrate but it is also a time to educate as well. It gives us an opportunity to emphasize the importance of ensuring all Americans, including Americans with disabilities, can put their skills and talents to work. Every year we have an official poster, and what is depicted on the slide is this year’s poster. I personally, love the vibrancy of the poster, which is an image of a yellow outline of the United States on a red backdrop with figures of all shapes and abilities depicted all across the US.

If you have not had an opportunity to order or download one of these posters, please be sure to do so by going to dol.gov/ndeam. While there, you can also browse ideas for how to participate and get ready to use materials such as sample press releases, newsletter articles and other tools.

On this slide is depicted a snapshot of the website that I just gave the web address to, and it says 31 Days of NDEAM, meant to reflect the 31 days of October, and it also has a small box with our web address in it, dol.gov/NDEAM. You will also find on this slide an outline of 31 different ideas for how you can celebrate National Disability

Employment Awareness Month. We offer, during this presentation, ordering a poster, but there truly are many more ways that you can recognize this month during October.

What is depicted on this slide are two screenshots of some of the ideas for what you can do during the month. One of the slides shows Day 9, Hold a Discussion, and it mentions that the employer and advocate can convene a discussion with colleagues or friends to talk about National Disability Employment Awareness Month and what it means to be a part of the workplace. There is also a slide that depicts an activity, Train Supervisors, and that is meant to share that, as part of October, you can also take advantage of the visibility of NDEAM to convene a training for supervisors on the steps they can take to make their workplace more disability friendly.

This year we have also offered a social media toolkit. This toolkit includes a range of ready-to-use materials including NDEAM advocate spotlights, and these spotlights highlight the contributions of many leaders who have made a difference in advancing employment opportunities for people with disabilities. Among these are several leaders in the neurodiversity community, and the slide depicts a snapshot from the website that I mentioned before and is entitled NDEAM Social Media Kit. Also depicted on this slide is an image of three folks who present as women, so we have Andrea LaVant, Kathy Martinez and Haley Moss, all important leaders in the disability community who have taken steps and advocated for the advancement of employment opportunities for people with disabilities.

Speaking of our work around neurodiversity, ODEP recently began a research project focused on supporting employment for young adults on the autism spectrum. This was in response to a request by Congress in fiscal year 2021 that ODEP conduct this study. We awarded a contract for this research project to Mathematica, and it launched officially in August 2021. It is a three-year project, and the goal is to examine strategies that promote work-based learning, gainful employment, and career pathways.

The project will employ listening sessions, surveys and other methods to learn about how to improve employment outcomes for young adults on the autism spectrum. Its findings also will likely broadly inform the work of the agency, ODEP, regarding people of all ages on the autism spectrum. The study has a special emphasis on people on the autism spectrum who have diverse communication styles, support needs and backgrounds such as in terms of race/ethnicity, gender, gender identity and sexual orientation.

Please do not hesitate to contact me regarding National Disability Employment Awareness Month, NDEAM, or the autism study that we just launched as an agency, and I am pleased to be able to join you today for the meeting. I am joined by my colleague, Dr. Scott Robertson, also from ODEP. He is a senior advisor, policy advisor, at ODEP. We look forward to being with all of you today. Thank you.

DR. GORDON: Thank you very much, Taryn, for an introduction to ODEP, and in particular, for noting the National Disability Employment Awareness Month, and for recognizing the importance of employment programs for adults with autism and other individuals with disabilities.

I wonder if there are any questions or comments from members of the Coordinating Committee. You can unmute yourself, turn on your video and speak, and/or, if someone else is speaking and you just want to let us know, if you use the “reactions” button on the bottom of your Zoom, click that, and you should see a “raise hand” function and click on that. Either one is fine. I see Kamila Mistry from AHRQ, and I just want to note that Dena is applauding.

DR. KAMILA MISTRY: Thank you so much for that great presentation. I wanted to learn a little bit more about both the quantitative and qualitative aspects of the study. For the qualitative, is it focus groups or is it interviews? Also, I’m wondering about -- I really appreciate you thinking about the sub-populations. Are you oversampling, or how are you dealing with that in terms of the quantity? With qualitative I think it’s a little different.

MS. WILLIAMS: I appreciate your question. We just launched a study, just had the initial meeting about three or four weeks ago so we are still working with the contractor, Mathematica, to finalize what will be the work plan for the three-year study. That will include the full design, particularly on the quantitative analyses that we will be doing.

I can speak to the discussion of the qualitative analysis that we will be doing, mostly focused on listening sessions, although there might also be the opportunity to do individual interviews with a sample of individuals who are young adults or adults on the autism spectrum.

DR. MISTRY: That’s wonderful. I think the qualitative will also be really important, and I was thinking about the things we don’t think about. In some ways, it kind of opens things up a little bit more, and I really encourage that and am excited about that.

MS. WILLIAMS: Absolutely, I agree. That part of the analysis is critical, and we will look forward to sharing with the committee over the next 36 months, so three years, not only what our final research design will be but also the emerging findings and what will be the final report. Look forward to updating you as we progress through the study.

DR. MISTRY: Exciting. Thank you.

DR. GORDON: Thank you, Kamila, for the question, and thanks, Taryn, for the response. Dena, did you want to make a question or comment?

MS. DENA GASSNER: Yes. I’m sorry that I caught part of it, but it escaped me. What is the age group that this study is primarily working on? And I have a follow-up.

MS. WILLIAMS: We defined it as young adults, and we are defining that roughly as ages 16 to 24.

MS. GASSNER: Given that we know that there is significant diagnostic delay, especially for marginalized populations, and diagnostic trauma and ensuing medical maltreatment of many autistic adults who have unfortunately experienced sort of a Swiss cheese approach to employment, is there any plan to look into the underemployment of more senior adults who are currently struggling dramatically to secure employment?

And my Part B is, are there autistic researchers collaborating on the study as researchers, not participants?

MS. WILLIAMS: Yes, absolutely. I will begin with addressing the second question and then come back to the first. With respect to the second question, we have already, as part of the launch of this study, convened a group of experts including autism advocates and autistic advocates and, in addition, researchers focused on autism to let them know of the plan to undertake this over the next 36 months, and that we would be, at various times throughout the study, engaging them in the qualitative study or the aspects of the qualitative study.

We will likely continue our focus on the age group of 16 to 24, so the young adults. That was part of the mandate that we received from Congress. But we do know that what we find as we work to finalize the study design may have implications for an age group that goes beyond what we have designated for this study.

DR. GORDON: Thank you. Sam Crane and then Ivanova.

MS. SAMANTHA CRANE: We have spoken about the study to Ms. Williams already, but I wanted to reiterate at this meeting that we are very excited about it. I think the people here are asking really good questions. It is something that we really have so little research on and I think it’s a great step. I think there are always going to be new things that we want to know. But we are really happy about this.

MS. IVANOVA SMITH: This is Ivanova Smith, and I have done a lot of work around employment of people with disabilities. One thing that a lot of autistics who want to get employed struggle with is not being able to have access to job coaches and job consultants because the assessments to get services like that require IQ scores, really low IQ scores. That makes it really hard for autistics whose IQs are in the borderline range or in the regular IQ range but still need support with employment and executive functioning skills that many with other IDDs struggle with.

It doesn’t matter what IQ score you have, autistics struggle with those things, and it is why we have such a high unemployment. And I am wondering is there any work to make job coaches and job consultants more accessible to autistics so that maybe the IQ is not effected but their functioning and executive functioning skills are very much effected. Thank you.

MS. WILLIAMS: Thank you for that question, Ivanova. I can say that this study is designed in part to do just that, to engage in listening sessions, surveys and other activities meant to better understand the employment strategies that will increase employment for young adults on the autism spectrum. That is the mandate that we received from Congress when they requested that ODEP undertake this study, so that is something we will consider.

And certainly, we welcome the recommendations of those strategies and we will be engaging with the community to ensure that both the qualitative and the quantitative aspects of the study really do capture the whole range of activities and tools necessary to advance employment.

DR. GORDON: Thanks. I am next going to read a message from Hari. I understand Hari’s text-to-speech app isn’t working right now, him being outdoors, but you can see his video there with his Cal mask.

Hari writes, Many autistics get into everything late, so they may enter education itself late and, therefore, employment also later, so this age group may be addressing only the ones who followed the neurotypical timelines and leave behind the majority. It should be on up to 35 years. That is Hari’s contribution. Do you have some thoughts about that?

MS. WILLIAMS: I will take that feedback to our contractor as we explore the design for the study. Thank you.

DR. GORDON: Yetta, do you have a comment?

MS. MYRICK: Yes, a quick question. Thank you for your presentation. I just wanted to know what your outreach plan is to the community, how you are planning to engage groups that are historically underrepresented in these types of studies.

MS. WILLIAMS: Thank you for that question. Part of that outreach, the strategy. As I cited earlier, we are still finalizing the design of not only the surveys and the protocols for the listening sessions but also the outreach.

I can say that it is a clear priority of this research project, the agency and fully the Department of Labor to ensure that equity is the cornerstone of all the activities that we undertake. I think not a day goes by that we don’t in some way talk about equity and talk about the extent to which the data collection that we’re doing, the research we are undertaking and the technical assistance that we’re delivering, that we understand what it means for the most marginalized communities, and specifically that includes individuals who have disabilities who are also racial and ethnic minorities and other intersectional identities that come into play. So that will be a critical factor for how we design and in consideration of the entire project.

DR. GORDON: Thank you, Yetta. Are there other questions or comments from members of the committee? I want to note that joining us on the call today is Scott Robertson who has represented the Department of Labor before the IACC before. Scott, I don’t know if you have any comments to add but you are welcome in any case.

DR. SCOTT ROBERTSON: Thanks, Dr. Gordon. I just wanted to add a thank you, Assistant Secretary Williams, for helping give the background on that, and I think the questions were very helpful. I just wanted to say that we will continue to have collaboration for the research study as it moves forward over the next three years. That is part of the collaborative spirit at ODEP. We appreciate all the input and feedback, and we will make sure that Mathematica receives that input.

I think things will evolve over the next three years as the study progresses, and I am very excited at how the direction is going to go into improving access to gainful employment for people on the autism spectrum. And, as was noted in the presentation, while the focus is on young adults because of the direction from Congress, a lot of the lessons learned will apply not only across that age range but should also apply to other people with disabilities as well.

We are very excited about this research project and look forward to sharing more about the project over the next three years as it evolves. Thanks.

DR. GORDON: Thank you. Secretary Williams, I have a question for you myself. I am just curious if you can take us through -- obviously, three years is a good long time and it will give us plenty of time to prepare for what to do with the results, but I wonder if you could take us through what the thoughts are at the Department of Labor about implementation work that you might do after the findings. What are the goals or what are the tools that you have at your disposal to address the issues that you can anticipate will be raised by the study?

MS. WILLIAMS: I particularly appreciate that question. As I noted at the start of my presentation, ODEP is a small, non-regulatory agency that exists within the Department of Labor, and, somewhat similar or parallel to how the IACC serves to advise the Department of Health and Human Services and the Secretary on activities related to autism, we exist to advise the Secretary of Labor and other agencies throughout the Department of Labor and across the federal government about the policies and practices that can advance the employment of people with disabilities, including individuals on the autism spectrum.

Some of the tools that we might have available to us -- and I will just note that I am giving an example of the tools rather than suggesting that these will be next steps at the end of the study -- we have in the past used research such as what we are undertaking to fund pilot programs, so, small studies where we will test an intervention in order to determine the impact it will have on outcomes for youth or adults with disabilities.

And specifically at the Department of Labor, some of the outcomes that we are most interested in are employment, specifically competitive, integrated employment, and also wages and earnings over time. So that might be a type of outcome that we might seek following the completion of this study.

We do fund research similar to what we’re doing right now, so we might anticipate that the findings of this study will lead to an additional set of research questions that we ourselves might want to pursue or that we would, in collaboration with other agencies either within the Department of Labor, say the Chief Evaluation Office, or with our partners and other agencies like the Department of Education and Health and Human Services, that we might want to partner together to explore more in-depth.

I would also note that we provide technical assistance, and our technical assistance tends to be in one of two forms. The first is direct technical assistance to individuals. That direct technical assistance is often delivered through what we call the job accommodation network, and that is a technical assistance service that exists to provide employers and employees free guidance on the successful delivery of accommodations in the workplace. So one might imagine that we might have findings from this study that may have implications, very real world implications or practices, that can be implemented by an employer of any size or an employee.

Alternatively, we have technical assistance that is focused on policy development, because really at our core we are a policy development office and, as such, we are seeking to influence or rather advise other agencies, as I noted, on the ways in which their regulatory activities or the ways in which their investments in systems -- that can be the education, the K-12 education system, the workforce development system, the vocational rehabilitation system, VR -- the ways in which those systems can improve their coordination or even collaboration across systems in support of employment opportunities and increased employment for all people with disabilities but in particular individuals who have autism.

Those are some of the examples of pilot programs, additional research, technical assistance in the areas of policy development or directly to employers, employees or even job applicants. There are likely other tools or a menu of other options that we have available to us as a small office in order to ensure that we really truly put to work what we find in our research.

But a lot of that will depend on how it evolves over time and what we are finding. That is why it’s so important to us that we share with all of our colleagues both inside the federal government but really outside as well, because it is your input that will help us in shaping not only the findings but what we do with them to ensure that it truly meets what I think is Congress’ purpose, which is to increase our knowledge of what will work in the employment arena.

DR. GORDON: Thanks. And I will just add that this input will be helpful for us at NIMH as we think about the kind of research programs that we want to encourage particularly in the space of services for adults and transition age youth with autism. As many on the committee will know and many listening to the videocast will know, it has been an increasing emphasis. We are really trying to build our research portfolio in this area, so we look forward to any information that can help guide intervention research that is aimed at improving employment opportunities for individuals with autism, among other services that adults and transition age youth need.

Other questions or comments from members of the committee? JaLynn.

MS. JALYNN PRINCE: I have a question. You were talking about very positive things about aspects of the government participating, but I have some questions, too, that I wonder if they need to be anticipated prior to that. Sometimes there are disincentives for individuals to gain employment.

One situation that I am very well aware of, though it isn’t with autism, is someone who happened to be one of the major influencers in Washington with disabilities who uses a wheelchair. But along with all of his abilities as an attorney he has been highly respected, but he gave up his employment because he could not afford on his salary to have the supports that he needed to be able to exist. That is a huge disincentive. And I hear of other types of situations.

Would it behoove us to perhaps start some conversations now with Social Security and others about what the disincentives are and is that actually paying society or penalizing society as well as the individuals.

MS. WILLIAMS: JaLynn, I just want to acknowledge that I appreciate your comments and could likely spend a lot more time talking about what incentives and disincentives exist in our programs and in statute that impact long-term employment, including unemployment and underemployment, or even labor force participation of people with disabilities.

You can be assured that that is something we will consider as part of this work. Certainly, as a federal agency we wouldn’t necessarily be in the position of recommending statutory changes. We want to respect the areas in which Congress has jurisdiction. But we will note what we hear from the community. We will want to hear, as part of that outreach that we talked about before, what barriers individuals are facing when they seek employment, and I think you have highlighted an important one that has quite an impact on the community.

DR. GORDON: Alison, why don’t you go next and then I have Sam after you.

DR. ALISON MARVIN: This is Alison Marvin. I am from the Social Security Administration, and yes, this is very interesting to us and we would love to talk and discuss this more. I think it’s a great idea and obviously disincentive is part of the whole big picture, and I think getting the big picture is one of the things that the study is aiming for.

DR. GORDON: It has been proposed and seconded, so, Susan, I think we have an agenda item for a future IACC meeting. A discussion around disincentives and inviting Social Security and other members both from the public and private space here would be an excellent thing to do. Sam?

MS. CRANE: I wanted to add some information to this, which is that the problem of people not being able to keep their home and community-based services while working has been noted for a long time, and it’s something that affects the autistic community, particularly people who have a lot of support needs relating to activities of daily living, and that is a big part of our community.

There are Medicaid buy-in programs that were intended to address this problem, and those allow a person who needs home and community-based services to earn up to a certain amount while paying essentially a Medicaid premium in order to keep their Medicaid and then they can stay on the waiver program. However, those buy-in programs vary a lot from state to state and there can be really a lot of issues with them.

For example, DC, which JaLynn mentioned, has an income limit. You can’t buy into

Medicaid if you are earning more than $3,000 a month, which in DC is not a very -- In DC we have a very high cost of living. So, if you are, let’s say, an attorney, you are not necessarily going to be eligible for the Medicaid buy-in program while living in DC. It is certainly still very helpful for people who are maybe working full time but not earning more than that.

But I think we really need to have a conversation about getting rid of income limits. Many states don’t have income limits. Just, after a certain income you start paying a premium and are expected to pay a premium in order to stay in the program. But they won’t. You essentially are being forced to limit your income or stay in poverty or near poverty in order to maintain your home and community services, so that is something that we really need to be encouraging states to do more of.

DR. GORDON: Thanks for the comments, Sam. I think this is an important issue that we do need to come back to. But I also note your recognition that this is an issue that is well known.

MS. CRANE: And it is not something that necessarily requires federal statutory change, although we can. It would be great if the federal government could require states to operate these programs. But states are enabled to make their own decisions about what income and asset limits to impose on Medicaid buy-in programs, so people can engage in local advocacy on this as well.

DR. GORDON: Good point, thank you. Other comments or questions? Hearing none, as we approach the top of the hour, our next presentation is scheduled for 3:00 o’clock, and that is a presentation from Dr. Daniels in her capacity as National Autism Coordinator.

We are going to take about a nine-minute break and be here at 3:00 o'clock sharp to stay on schedule. During the break, please feel free to turn off your video and please do mute your microphones so that we don't have to hear you rushing off to take care of whatever needs you might have, and we will get started back at 3:00 o'clock.

DR. DANIELS: Just a quick correction about the agenda. We are going to be going to James Cusack next from the UK.

(Whereupon, the Committee members took a brief break starting at 1:51 p.m. and reconvened at 2:00 p.m.)

DR. DANIELS: It is my great pleasure to introduce Dr. James Cusack of the UK autism charity, Austistica. He is going to speak to us today about the new National Strategy for Autistic Children, Young People and Adults 2021 to 2026, and about Autistica's recent activities.

James and Autistica have been great partners to the OARC and IACC over the past many years and we have enjoyed working together on a number of efforts including our international portfolio analysis a few years back, and we look forward to hearing from you today about your latest activities.

With that, please take it away, James.

DR. JAMES CUSACK: Thanks, everyone. I have just been looking through the attendee list and it is great to see so many familiar names and people I haven't seen for quite a while as well. I am in the process of setting myself up to do my presentation and sharing my screen.

DR. DANIELS: By the way, the bios are all on the website for all of our speakers, so if you want to read more about James you can read it there.

DR. CUSACK: You should be able to see my screen now. Is that right? Great, I am going to assume that as a yes. Thank you all for inviting me along today. I really appreciate it. What I was thinking when I was putting my presentation together I thought I would tell you a little bit about our plans over the next decade and how that relates to what is going on in terms of public policy in the UK, and it’s a really exciting time for us in the UK but it is also quite an uncertain time, so we are still in the process of trying to work out what is going on next.

Before I do that, I thought I should probably introduce myself. I am James Cusack, and I am Chief Executive of Autistica. And just in terms of background about myself, (indiscernible) three years back was diagnosed as being autistic and then, as a consequence of that, at a young age I worked directly with autistic people, with family members, and became very interested in autism from a research perspective and how research could enable autistic people to live better lives, and while that was going on I also became quite involved with policy and the Scottish Autism Strategy.

I became Autistica’s Director of Research about six years ago and really joined because I saw a huge opportunity for research to make a real meaningful difference to people’s lives and to think about how we can relate research to the priorities of the people that we ultimately serve and to focus on really meaningfully improving outcomes for autistic people.

Last year, our chief executive moved on and I became Chief Executive following a recruitment process. So I am very excited to be here. I have really enjoyed collaborating with IACC and speaking with its members as well about what we are doing and how we can work with people in the US as well.

I am aware that many of you are also new to this committee, I think almost all of you are new to this committee, so I thought I would start by sharing a little bit about Autistica. Autistica is the UK’s leading autism research charity. What we do is we create breakthroughs that enable autistic people to live happier, healthier and longer lives. And that is ultimately the goal of the organization, is to try to improve outcomes in these areas, and we focused on these areas because, sadly, we know that autistic people can face quite substantial inequalities in these areas.

We focus on creating breakthroughs by shaping and growing research across the UK, by funding new and innovative research solutions, campaigning for better services and shaping national policy, and sharing the latest evidence-based tools, resources and information.

We try to make a difference by working closely with the autistic community and families and other interested stakeholders to try and set an agenda for change based on lived experience, and then in partnership with those communities we try and create groundbreaking research which will build evidence, which will pilot projects and really lead to evidence change. We take the evidence as well as evidence we produced elsewhere across the world and try and influence government and partners to try and implement change by shaping new agendas and influencing new policies and hopefully changing attitudes in the broader community. We hope that by doing that we ultimately will have a real impact and also create a bigger societal shift that changes lives of autistic adults and children.

So, in a broader sense, what that means is that we as a strategic organization are trying to understand the different issues and try to define where opportunities lie and look at setting clear goals in terms of what we do. We have to think about how we raise the funds to meet our ambitious goals and then we undertake a certain policy and implementation work, sometimes sequentially and sometimes in parallel, to try and ultimately achieve our goal. And the whole time we have very clear measurable outcomes which we are looking to achieve.

In terms of the principles and in terms of how we like to do our work, we are a big believer in involving autistic people and their families at every stage of the work we do. Roughly about one-quarter to one-third of the people who work at Autistica are autistic themselves, and we also have a number of family members engaged across the organization, but we also have an inside group of autistic-informed families that we work with to help shape our work and to help shape the research that we ultimately support as well.

We want to, as much as possible, reflect the diversity of autism, meaning that being autistic means that people have a diverse range of experiences oftentimes because of their autism or being autistic, but also in terms of other factors such as socioeconomic factors and race and culture and so on. So we know that we have to be acutely aware of that, and one of the things that we are always looking to improve on is how we can more actively reflect that.

Ultimately, we are a research charity so we believe in the best science and evidence, but one of the things we really try to think about in that context and the context of lived experience of autistic people and families, and the best science is how do we deliver change and how to think about how we can ultimately make that happen and to influence other people to deliver that change as well.

I am aware that much of what I’m going to talk about next applies to many people and will be quite similar in the US but there might be differences as well, and I will be interested to learn about those because I’m sure there are differences in terms of how services are provided and so on.

I thought I would give you a snapshot in terms of where we are now. Ultimately, a number of things I am focusing on here are slightly negative, but hopefully it is ultimately about ensuring that we understand these facts and ensuring that we can actually deliver change which meets people’s needs.

Although I want to focus on some of the negative statistics that we are aware of in the UK, I think it is really important first of all to clarify that many autistic people do live fulfilling lives and are in a fantastic position and have had some very good support from families and so on and have found ways to ultimately survive in society, and many of those people I am sure are not identified.

But we do know from research from a range of different sources that it is clear that autistic people continue to die earlier than the general population, in some cases decades before the general population. We have a clear figure from our Office of National Statistics that shows that autistic people face the lowest employment of any disabled group, and this is true for autistic graduates as well.

Autistic people dominate admissions to inpatient mental healthcare, which is frequently inappropriate for autistic people. And sadly, there are continual stories of neglect and abuse in state-funded care, and it has become so harrowingly common that these stories hit the headlines on a monthly basis and sometimes more frequently as well.

So the picture in the UK is, although there are certainly good things to learn, unfortunately, the outcomes are quite negative in many respects and we have a lot of work to do to try and build services for autistic people that ultimately meet their needs as well as society does that as well.

So, what is the situation in terms of services in the UK? Well, the situation is that autistic people have access to very few services or adapted supports. Autism diagnosis is in some regards well developed but ultimately over-stretched. There is a pathway that can allow autistic people to receive a diagnosis.

We have a national health service in the UK which means that everyone is entitled to free healthcare, but that health service is over stretched, and it is struggling to adapt to things that are new to it such as autism, and so, what happens is that people face quite a long waiting time in terms of getting diagnosed. But what we do see clearly from the data is that there has been about a seven and one-half fold increase in the number of people who are being identified as being autistic in the UK over the last two decades. And so I think that is certainly positive, but what we clearly see evidence of is that people have to wait quite a while to receive that news in many cases.

What is, however, nonexistent is post-diagnostic support for autistic people, and it is either very limited -- here is a leaflet and here is some information -- or it is non-existent, and this is particularly the case for adults, many of whom just feel like they are waiting for this information for a very long time; they receive it and then they are very much left to their own devices. And I think many families feel that way as well.

We find that healthcare is not particularly well designed for autistic people. There are very few places of healthcare that are particularly well adapted for autistic people. In the UK, the main way that you gain access to the healthcare system is you see a GP, general practitioner. My wife is a GP so I am a very big defender of GPs, but I think we have to recognize that the system doesn’t particularly effectively address the needs of autistic people.

At the moment, we know that the model for social care in the UK -- When we say social care we mean support the lives of autistic people to live as independently as possible, to make sure they get the right support outside of a healthcare setting. We know that social care is effectively broken in the UK; there is not a system or model for paying for it, and it is something the government is trying to address. At the moment they have just made tax increases specifically to address the fact that we don’t have a model for paying for social care in the UK, which means that people with a learning disability are very poorly served, and their families are often left stranded. And the underfunding of services also inevitably leads to some of the scandals that we talked about, although there are other issues related to that as well.

There is very limited support for autistic people who want to get into work, and education services can be very poor. In the UK about one-half of autistic people have been informally excluded from school, so basically told not to come in. So we know that even from the beginning of education autistic people are experiencing some significant disadvantages, and that can happen in quite a kind way. For example, it happened to me when I was 12. People said, sorry, we can’t really accommodate him. He is not behaving badly, but we just can’t accommodate him, so you are going to have to take him out of education until we can find a better plan. So this is happening to quite a lot of people and it happens to people in quite subtle ways.

Data on autistic people’s use of services is good in some areas and we are getting better at identifying people who have been diagnosed, and systems are being built at the moment to try and make that better. I think we know that across the world there are people that are better at this than others, and people are top of the class, people in countries like Scandinavia, and the UK is somewhere in the middle.

We know that attitudes towards autistic people are poor, as they are in many cases globally, and understanding of autism is low, but it is developing, and we do know that awareness of autism is actually quite high. So 99 percent of people in the UK have heard of autism and they know what it is. Well, they know that it exists. But in terms of their understanding of autism, we know there is some work to do. We really need to think about how do we address that across a range of different audiences.

This inevitably leads to quite a lot of avoidable crisis situations for autistic people. There are a number of people who are being diagnosed; there is a huge backlog which has unfortunately been exacerbated by the pandemic, and that leads to avoidable deaths, inpatient admissions to mental healthcare, crisis and A&E visits, and people who want to and are very capable of working being missed opportunities or being discriminated against or not getting the support or a world built for them that ultimately enables them to thrive.

In terms of where UK public policy is for autism, there have been some positive developments, partially driven by the fact that there are quite a lot of public stories around autism and the scandals that are emerging, but also because Autistica and the National Autism Society and many other organizations have worked quite hard to enable the government and their services to understand how they can begin to create a plan for autistic people. And that has been driven by the fact that our view, and I'm sure the view of the National Autistic Society, is that if this was any other group, we wouldn’t be accepting these outcomes, so why are we accepting them here.

I am involved with two different groups. The first group involves the national strategy for autistic children, young people and adults, a group made up in much the same way that the IACC group is, who has been advising us and has made many commitments including an Autism Research Action Plan. This is a huge step forward in the UK because, historically, research and the need to have an evidence base behind everything we do has been neglected, and that has really been to the detriment of autistic people because they have been exposed to things which are not evidence based.

But we are also missing a huge opportunity to build evidence-based services for autistic people, and there is a huge opportunity to do that in the UK. The UK, throughout the pandemic, has done many of the world’s leading clinical trials on the effectiveness of different medications. And for Covid, although we wouldn’t necessarily be thinking about medications in the context of autistic people, we could be looking at how different supports work for autistic people and using that same infrastructure, which has been so effective in the context of the pandemic, to serve a group of people who we know have faced stark inequalities for years, and we are very much making our argument to the government.

I will go on to talk about the commitments they are making. They have made a number of commitments to improving diagnostic and post-diagnostic pathways, education, employment, access to welfare support, funding for people who need extra support, public understanding of autism and to make healthcare better and to ensure that community care and support in the criminal justice system is better because we also see huge issues in terms of the criminal justice system for autistic people at the moment.

A related thing, an early focus and piece of good news has been the NHS long-term plan. Back in 2019, the National Health Service - just to remind you all again, National Health Service is a state-sponsored health service. It is the main health service that most people use and is provided free to all UK residents.

It had received a lot of funding from the government, an increase, a relative increase in funding from the government, and because of that they had to produce a 10-year plan. This is only in England, so of course the United Kingdom. I am from Scotland. The United Kingdom is made up of England, Scotland, Wales and northern Ireland, and England is the main part of the United Kingdom, about 80 percent.

NHS England, when it was given its funding, was asked to come up with a long-term plan for NHS for the next decade. That long-term plan had four priorities, and those priorities were cancer and heart disease, which are really key issues of course; mental health which is an emerging issue; but also autism and language disability, and that is a hugely important recognition for autism. They set up their first autism team looking to coordinate services for autistic people.

And they made a number of commitments including to ensure that autistic people can live happier, healthier and longer lives, which we were very pleased about because that is the mission that we have set out as a charity, but also within the plan they have committed to delivering health checks, and the health checks for autistic people, and the clinical trial that we are supporting is successful so that was very good.

In addition to that, our head of research and head of policy of Austistica were seconded to help develop a research strategy and to support the work streams on diagnosis, health checks and access to mental health services.

To go back to the autism strategy, the commitments from the autism strategy are to create a research action plan to identify research projects for the next five years and to work together with the research sector to try and ensure that we have a better set of services for autistic people. This is a very promising step. We have seen a recognition of the need for research in other areas of healthcare like dementia and, for example, in cancer, which are obviously very different from autism, but it doesn’t change the fact that research is very important for autistic people, and it is really exciting to see this going on.

They have an ambition to ensure that autistic people get high-quality and timely diagnosis and then the support they need following diagnosis in the autism strategy.

They want to make headway on reducing healthcare inequalities for autistic people and ensure that autistic people are living healthier lives. Underpinning that commitment is, like I said earlier, delivering health checks for autistic people. And they have actually matched the funding that we have done for the health checks clinical trial that we are funding at the moment, so they are very much invested in that.

They will try to ensure that community care is better for autistic people and to ensure that less people end up becoming mental health inpatients by 2024, and in particular, inappropriately become mental health inpatients.

They want to, by 2026, have data that shows that there is a meaningful reduction in the employment gap for autistic people and that by 2026 public understanding and acceptance of autism has also improved.

So this is extremely positive, a positive set of visions which we entirely support. It is great to see the government seek to set out such a positive vision for autistic people and their families. We are really pleased about that.

This is a good start. The way the government has worked is that the government funded and deployed what we call a

Comprehensive Spending Review. So that means over a defined period of time the government makes spending commitments following this comprehensive spending review. Because of the pandemic, the government only had a 12-month comprehensive spending review, which means that in the autism strategy civil servants and ministers have been in a place where they have not been able to make comprehensive commitments, and so the amount that has been actually committed to autism as an area and autistic people and their families is actually quite small, so we only have an implementation plan for the first year.

At the moment, to achieve NHS's goals and to achieve the visions set out in the autism strategy, we have not got enough clarity yet on the level of funding being delivered. But like I said, we have a new Comprehensive Spending Review coming out.

We are very clear in terms of how we brief the government and how we brief civil servants, how we brief ministers and how we brief the Treasury who are ultimately responsible for how funds are deployed, that it is both irresponsible and unacceptable to not fund this strategy properly. You will ultimately let down autistic people and their families, and if you are not interested in that, this is also fiscally and economically irresponsible to not fund the strategy appropriately.

So we are hopeful and also realistic about how the government will respond to this, but we are very clear in our briefing that an investment needs to be delivered if they are going to realistically the visions that they are setting out.

We hope though that the research strategy and the research action plan developed by the NHS could really help begin to start partnership and discussion and also learn how we can fund meaningful research but also what can be done internationally as well.

That is where we are in terms of public policy. What you might notice if you visit Autistica, and since we came to speak to you in 2016, and I remember it very well because I had a very bad back. I have only ever hurt my back once and I remember having to stand at the podium and had difficulty. But we have changed quite a lot as an organization since then, so we have a policy function, and we are also sharing more information.

When I became Chief Executive, I appointed through quite a competitive process, and in that process, I was forced to think about how the charity should and could change to become more impactful and become better at serving the needs of autistic people and their families. And so, what I want to outline here is how we have been planning to change as we exit the pandemic, how we are hoping that we can make more of a difference ultimately for autistic people and their families.

We feel that we are beginning to succeed in terms of influencing public policy and practice in the UK. For example, our focus on early death means that this issue has been recognized as an issue. We want to continue to ensure that more of our work continues to improve lives. To make more of a difference, we need to focus on lives, and we want to be much more focused in terms of what we do.

We have now focused on six topics which we are going to use to drive Autistica’s research funding of partnerships and policy development functions over the next 10 years.

What we are doing is we're setting ambitious goals. We are looking to develop tailored and very detailed, long-term plans for each goal and with clear projects and deliverables sitting underneath them which we think are most likely to deliver meaningful breakthroughs for autistic people.

In terms of the guiding principles for the goals, the first one is, is it a priority for our communities. We have made that judgment on the basis of evidence we have gathered from both formal and informal consultations. We have done JLA, apologies for the acronym, that stands for James Lind Alliance, as a James Lind Alliance priority-setting partnership, and we developed something in 2016 which was focused on the top 10 questions for autism research. If you look at Autistica priorities, you will see some of those top 10 questions there.

And on discussions with community engagement work that we have done over the last five years, as we have got insight from around 250 autistic people and the founding members that we work with closely, the detailed project work and the network of 16,000 people on the Autistica network, whom we also engage with. Also, based on ideas that we have brought to the community, which have been positively received. So that’s the first question.

The second question we ask ourselves is, is there an opportunity to make a difference. Is this something that Autistica can solve? We are not a huge organization. We do some things well, and we do other things less well, so we need to know is there a unique role we can play. Is this something that if we don’t do someone else will? That is what we tried to think about here.

The next question is, is there an opportunity to do good research? Do we have the project ideas, do we have the scientific expertise in the UK? Are policymakers ready for whatever it is we are looking to deliver?

And then, can we raise the funds? There is no point in us setting, as a charity, ambitions that we can’t deliver on.

So that has led us to these goals. Effectively, each goal has a real clear rationale. As I said, in Goal 1, we know that too many autistic people get almost zero effective support in the UK, but we know that if we can offer maximized support for autistic people, we can ensure that autistic people receive the help they need and when they want it, which is why by 2030 we want autistic people to have proven support from day one.

We know that too many autistic people are deprived of meaningful and sustained employment, but yet, many autistic want to work, so we need to radically upscale the support that autistic people get and the support that employers get to help them to ensure that they get proper standard recruitment and working practices accessible with respect to employment support, and be sure that workplaces are ultimately embracing what autistic people can bring to the workplace, and when we engage people and organizations we are very clear that this is an opportunity for them as well.

We know that too many autistic people experience anxiety that really places limits on their lives, and anxiety should not be inevitable for autistic people. We should not be in the position in the UK where almost one-half of autistic children meet the criteria for an anxiety condition by mid-childhood. And we know that if we can upscale effective support and we can understand the issues and the anxiety, we can both get better at supporting and treating anxiety but also ultimately preventing it before it happens.

As I said earlier, we have an ongoing program of work around health care and that is because we know that too many autistic people die earlier than they should, and these deaths are often avoidable, and they are often socially constructed as a consequence of a lack of access to healthcare. And if we can start a holistic health check, which means that healthcare is more accessible for autistic people, we hope that we can address that. So we are hoping that by 2030 every autistic adult will be offered a yearly tailored health check.

We also know that public spaces can be overwhelming for too many autistic people, and that we can adapt public spaces to be more inclusive for autistic and neuro-divergent people and design new developments with neurodiversity in mind, and so we want public spaces to be more accessible for neuro-divergent people by 2030.

And something which is a relatively new focus for us is we know that, as I said earlier, many people are aware of autism but don’t understand autism. There is a huge focus on improving attitudes toward autism in the UK but there is a lack of empirical evidence regarding what works and what works for different audiences. The general public are a very different audience from healthcare professionals, for example, and we want to work with other organizations to provide empirical evidence of what approaches do work and what approaches ultimately change attitudes to autistic people and ensure they are understanding of autism overall.

In terms of how we have done this work, people on our team have done some initial scoping. We have had a set of priority-setting exercises and we have built internal knowledge of community priorities over the last five years. We then worked and tested those different goals with different audiences and then we have taken these goals to a workshop and shortlisted and worked on ideas with autistic people and professionals and scientific experts on a topic.

Then we work internally with our team which is very neurodiverse, which is to say we have got both autistic, neuro-divergent and neurotypical people on our team, and we work to create the plan. And based on the feedback we received, we then send it out again for expert feedback, and by this time a larger group of people, dozens of people who are autistic, professionals and who have scientific expertise, and then we begin to have partner meetings to share the draft plans before finalizing them.

I wanted to give you an example of what that ultimately looks like, and I have used the first goal, the support from day one goal. What we basically do for each goal is we break it down into three pillars. We have a vision that by 2030 autistic people will have support around diagnosis so will be empowered to understand their diagnosis and come to terms with being autistic, or, if this is in early childhood, to help the family unit come to terms with the fact that the child is autistic; to prepare evidence-based supports tailored to each autistic person’s profile of need, and to ensure that

that is as person-centered as possible; and then to ensure that we have a system in place that ensures there are lifelong supports in place.

For employment, what we are looking to do is to ensure that we can create a world where autistic people are ready for the world of work, so we have, for example, programs around readiness for employment to ensure autistic people feel empowered.

One of the ways in which I feel very privileged is when I was in the late '90s, I went to the first ever autism-based in the UK and I got really specialist support around preparing for the world of work, and this should be evident from the engagement that we have done that that is actually not something that every autistic person has the privilege of accessing.

And so, to try to empower autistic people and give them the freedom to think about how they want to build a career, if that is what they want to do.

To ensure that autistic people can find the right job, to ensure that recruitment practices give autistic people a fair chance. We have got quite clear empirical evidence that shows that the recruitment processes actively disadvantage autistic people and don’t give them the chance they deserve to show their talents.

And then, as autistic people get into a job -- and this is actually very, very key as well, because we know that many autistic come into work -- to ensure that there is a proper evidence-based library of workplace adjustments and employment support for those autistic people that need them.

In terms of anxiety, one of the things we are really interested in is whether or not we can begin to understand how to prevent and mitigate anxiety in autistic people from an early age. One of the things we have talked a lot about internally and with autistic people and families is that, in any other area of healthcare, if you know there is an increased likelihood that someone is going to develop a mental health condition as a consequence of being diagnosed with one of those conditions, we are proactive about ensuring that that does not happen.

It feels a little bit like in the UK that anxiety is just seen as inevitable for autistic people, and we would like to think about how we, from the moment someone gets the diagnosis, try and ensure that that does not happen, and we shouldn’t be waiting until it is a crisis to support autistic people who are experiencing anxiety.

But if autistic people do experience anxiety, as many people in the general population do, it is important we have access to therapies that we know work. We know that there is emerging evidence of things like, for example, CBT for children, but we know that really doesn’t work for everyone, and actually some people feel very strongly about CBT not working. That is not surprising because we know that that is treating, again, the general population, so we need a suite of approaches that can work for a range of autistic people and really high-quality evidence as well.

Then we need proper services so that when autistic people do find their mental health is at risk there are serious interventions in place before it is serious.

We want public spaces to be more accessible for neuro-divergent people, and to do that we know we have to at least have up-to-date information on sensory environments for any public space. There is an awful lot of talk around making spaces autism-friendly but not an awful lot of empirical evidence at the moment, and so are working with the Alan Turing Institute, which is an institute specializing in data science, to create a citizen science platform that will allow autistic people to tell us about their experiences of the built environment.

And then to try to understand how we can influence design to ensure that it is more evidence-led and meets the needs of neuro-divergent people.

I touched on the health checks plan in some detail earlier, but just to say that we co-designed and are rigorously testing the health check with autistic people, families and GPs as we always do, and have a multidisciplinary research team working on that. We are also working to prepare GPs to deliver annual health checks to autistic people and to try and make it easy to understand how we can make sure that GPs can adjust appointments to suit each autistic person’s needs. We have developed a new digital tool at the moment which will allow the GPs to understand the adjustments that they need to make, and to prepare the GP as well.

The only one we haven’t shared yet is the attitudes one, and that is because that spans, that spans, -- and we are just finding a new way to communicate that one, and that one is quite early on so we are just putting that together at the moment. Just to give you a bit more of a tangible sense of what that means in more detail, we have a set of projects which sits underneath each pillar. So, for example, here we have for each project psychoeducation. We don’t like the word “psycho-education” so we talk about empowerment programs, and we have been talking internally about how we use the right terminology. We are very much aligned and I’m sure we will develop this as we receive feedback from people as we go on.

Ensuring that there are funds in place to undertake trials in terms of preparing supports for the future but also ensuring that there is lifelong support as well. So, how do we step up and step-down services for autistic people, how can we get the situation where autistic people can own their health records. How can we point people to low intensity supports when autistic people don’t need access to more complex services, but actually through early intervention we can really support autistic people more effectively?

Just to give you an example of what that would mean as a project, this personal support profile is something we are sure we can fund quite shortly. What we are looking at doing is, once an autistic person gets a diagnosis, to help them understand the needs and the goals and strengths that autistic people have but also any difficulties they have, and that should hopefully mean that autistic people understand exactly what they should be offered, what support they need, and to help to empower the parents of an autistic person who receives a diagnosis or the family to understand what this diagnosis means in greater detail, but also to ensure that the system is set-up to address those needs. That would hopefully ensure that interventions are more effectively designed for people as well.

And by having that consistent format, hopefully that means the services can be better designed. This is really based on the work through the ICF and the Karolinska Institute, and we are going to fund adaptation and piloting of this instrument for use by the NHS for provision of services for autistic people.

Ultimately, why is Autistica doing this as an organization? Why are we being a little more concrete in terms of what it is that we are attempting to do as an organization? Well, we need to be clear with the people we serve about how we make a difference and what it is that we are focusing on, and so that clarity I think should really helped. The process of being transparent around what is it we are looking to fund and why we are looking to do it, I think is really key. If you are a research organization it can be confusing, whatever you are attempting to do, and I think we need to do a better job of being clear about what it is that we do.

We also feel like, and I feel like, there is at times lack of vision around how we are trying to improve people's lives and I think that is because autism is slightly more complex than other areas and we don't have a simplistic narrative like we do in other areas of healthcare, and so having clarity in terms of what we are trying to do can be inspiring for everyone at Autistica but also everyone that we work with but also everyone we are trying to influence, to show a clear plan, a clear theory of change as well.

Also we want to know what success looks like and whether or not we are doing what we are aiming to do. Also, we think ultimately and fundamentally and the most important reason we’re doing that is we think this is the best way in which we can make an impact for autistic people.

As we try and influence and build strategy and public policy in the UK, we are trying to ensure that we are building a world which is better for autistic people and their families ultimately, and we believe that clarity and vision and focus actually are ultimately going to help us do what it is that we are seeking to achieve.

Thank you all for your time. I always find it odd speaking on Zoom. Thank you for being patient with me. This is my email address if you have any questions.

DR. DANIELS: Thank you so much, James, for sharing all of that. It was very thought-provoking and gives the committee some things to think about as we are considering our update to the Strategic Plan for the IACC. We appreciate your comments, and we would love to take some questions from committee members.

First, I will go to Hari, or is there someone else who is going to present?

DR. GORDON: I don't see anything from Hari.

DR. DANIELS: We will go to Alycia.

DR. ALYCIA HALLADAY: Thank you, and thank you, Dr. Cusack, for that summary of all that Austistica is doing. You mentioned the other organizations in the UK, and since this is a coordination committee, I am interested to know how Autistica works and coordinates their priorities with other organizations that want to do things that are beyond -- basically, how did you coordinate your priorities which are clearly employment, health, mental health and understanding and awareness? How did you develop those with all the different needs of the autism community and all the other organizations in the UK that are working towards similar goals?

DR. CUSACK: We have regular meetings. We are the only sort of national research charity in the UK, so an organization specifically focused on autism research. In that regard, there isn't another organization like us.

But in terms of how we engage with the National Autistic Society, which is probably the major autism charity in the UK, the largest autism charity, and they have a significant level of reach across the UK, I meet regularly with their chief executive, and we have policy meetings regularly, so we always coordinate in terms of policy whenever we meet government ministers. But often it is both myself, and the National Statistical

Society, and we make sure that we are aligned in terms of what we’re asking for. We know we have different priorities occasionally and so we compromise on that basis.

The same is true of other charities that we have across the UK. I meet with them regularly. There is a charity, for example, focused on employment and we look at how we can work together. Fortunately for us, because we have focused an awful lot on research, partnerships can work and work quite effectively. And we are definitely trying to get better at it as well so that we can also be trying to think about, within the context of these goals, where are the things we can work with the National Autistic Society on.

We are just mapping this out. I should tell you we finalized the wording for these goals on Friday, so it is quite new stuff and we are still developing a lot at the moment.

DR. DANIELS: Wonderful. Next I will go to Scott because I still don't have Hari's comment yet.

DR. ROBERTSON: Thanks, Susan. James, wonderful presentation, learned a lot. I think it was very enlightening, especially the ambitious goals that you all have in the UK to increase access to employment, healthcare, accessible spaces, et cetera.

Would it be possible to connect later on offline about any resources you all may have and information that maybe we can share back and forth, especially on employment? For us it would be especially helpful in terms of the latest developments of what you have as far as articles, and some of the plans in that space I think would be very beneficial for our research project and our other pursuits in supporting better access to gainful employment, so, competitive, integrated employment, for youth and adults on the autism spectrum with different support needs, communication needs as far as AAC access, et cetera.

I just appreciate the facet also that what you shared can help inform, as Dr. Daniels mentioned, for the Strategic Plan, so I think it is very helpful to us. I think you all are trailblazing a lot in terms of needs assessments, et cetera, and the focuses across all the different areas of quality-of-life and the life course. I appreciate all the work you all are doing in the UK and look forward to hearing more over time. And thank you for the detailed perspective in terms of the work that you are doing to increase quality-of-life and health and wellbeing.

DR. CUSACK: Thank you very much. I am very happy to connect. We are aware there is a lot of great work going on in the US which would directly feed into this. What we will produce is a report which is not a final report. Although we want to have clear goals, our plans are not in concrete; they are designed to be agile and designed to learn from everything that is going on. So we are very keen to share what we have with you but also to learn as much as possible about what is going on in the US because there is an awful lot for us to learn and I'm sure there are a lot of things that we -- assumptions and things that we have made which are incorrect and we would benefit from feedback from people in the US and beyond.

DR. DANIELS: Thank you, Scott and James. So I have Hari's comment. It says, I especially love the spaces plan which will help with inclusion and that health checks will be tailored. Will the latter include looking at medical comorbidities? Currently, most medical professions dismiss everyone as off as a part of autism.

DR. CUSACK: I want to make sure I follow that. Are we looking at co-occurring conditions alongside autism? One of the things we are looking to do, and Susan tell me if I answer the question properly because sometimes I miss things, is one of the things the health check report will be doing is trying to correctly identify those health problems that autistic people are experiencing the most. We certainly recognize that clinicians don’t always believe autistic people when they come asking for support, and the autistic people struggle to identify health conditions themselves.

So I think I told you all the story that when we released the early draft report, I was going around telling people to not allow diagnostic overshadowing so that the fact that you’re autistic clouds judgment around identification of health problems but failed to identify the fact that the reason I had been coughing for 10 years is because I was asthmatic, and that was just by having a wife who is a GP as well.

So I think there is an awful lot of work to ensure that clinicians get better at identifying and believing that health problems exist and people like me identifying that they have a health problem as well, because I haven’t really coughed since I’ve been using an inhaler. I think there is an awful lot of work to be done there. I think it is really a good point. I totally agree. Did I answer the question, Susan?

DR. DANIELS: Yes, I believe so. Hari will let us know if there is anything else. Thank you so much. Next we will go to Helen Tager-Flusberg.

DR. HELEN TAGER-FLUSBERG: Thank you so much. It is really interesting for me to hear your presentation, Dr. Cusack. The UK has certainly come a long way since I left many years ago, and maybe I shouldn’t have left after all.

I especially appreciated the detail and the process and the thoughtfulness that has gone into your plan and I wanted to talk about this issue of anxiety that seems to be a very strong emphasis in your program and there are a number of research projects.

As we know, the construct of anxiety is probably as ephemeral and ill-defined as the construct of autism, and it certain spreads. And I am wondering whether in your plans and the projects that you support on anxiety, how widely do you extend the definition?

So for example, in working with severely impaired individuals, minimally verbal people with autism, the behavioral challenges, the self-injurious behavior, aggression, probably wandering even, and other behavioral patterns that we see in this population, are potentially an expression of anxiety as well.

And so I am wondering whether, as you work towards achieving a goal of personalized treatments, you are thinking about extending treatments that would not be suitable from the other end of the spectrum, but for this end of the spectrum. Thank you.

DR. CUSACK: It is a really good question. At the moment, we prioritize research into groups which are commonly under-researched. We did a scoping review in 2017, which showed that in the UK we don't fund an awful lot of research, and this includes autistic people who also have a learning disability. So we recognized that is something which we have a responsibility to address.

So the first thing we are doing is funding a study, a bigger consortium of people, to try and understand how we can make this actually more inclusive for that group of people. But also in terms of anxiety specifically, we are currently funding a couple of projects looking at how we can get better at assessing anxiety in autistic people who are minimally verbal and also have a learning disability, because we recognize that clinicians are finding it challenging to identify when this group of people are experiencing anxiety.

Also, we are piloting an intervention which supports parents to adapt their environment to help that autistic child to manage their anxiety.

And so, yes, we are very conscious we need to serve the whole spectrum in terms of how we find ways to support all people who are autistic and experiencing anxiety.

And certainly, one of the things that we recognize as well is that, as you said, autism is heterogeneous, and so are people's experiences of anxiety and we have to be very careful about saying ah-ha, we found this CBT that can work for some people and, therefore, it works for everyone, because actually people have very poor experiences even if they have autism-adapted CBT as well.

We are currently funding another pilot trial which is looking at how we can personalize treatments for anxiety in autistic adults to try and understand whether or not we can match treatments more specifically to the types of anxiety that people are experiencing. I think that is going to be really key in the future.

DR. DANIELS: Thank you. We have a question from Dena.

MS. GASSNER: Hi, James. Thanks so much for joining us today. Your contribution has been really helpful I think for us, and I just wanted to ask you about COVID. You mentioned it briefly. We are starting to get in some data that looks really complicated whereby over 54 percent of autistic adults are experiencing global losses in terms of job coaching, support services, the businesses that they are volunteering in or training in are being closed.

A lot of the forward-facing agencies that would be responsible for this have been backlogged and I think a bit overwhelmed by Covid long haulers who may also require a tremendous amount of support, and many of them intersect with our population, of course, because we were identified as more vulnerable to co-occurring conditions.

So I’m just wondering where are things in the UK? Is it comparable? Are you seeing a surge of either early retirees or newly disabled retirees that could be challenging systems?

DR. CUSACK: I think, to be honest, the answer to that question is I don’t think we know. Actually, the level of data that we have on that is probably quite poor. We have, with the National Autistic Society -- we supported them with what they were doing around people’s experiences during the pandemic, and the overall theme was one of feeling left stranded, isolated from the services, isolated from the education services that they rely on.

Anecdotally we have also found, when we talked with the staff at Autistica, that many of the staff and autistic people that we speak to have found the move to remote working in many ways easier than some people in the general population, although that is not true for all autistic people. It very much depends on people's circumstances and needs and personal profile.

While we are particularly concerned, the UK has a fairly aggressive approach to this pandemic, probably one of the more aggressive approaches in the world, and so our government is fairly -- people in the UK and England don't really wear masks anymore anywhere, so I find that concerning, and as we exit, and there is a lot of COVID-related anxiety but also anxiety around returning to normal and the fact that many autistic people have made substantial efforts to try and adapt to the world and then to feel -- many people have to do it all over again, and that is a real worry for me.

MS. GASSNER: Thank you very much.

DR. DANIELS: We will take one last question from Ivanova and then move into our break.

MS. SMITH: I just want to say thank you for your presentation. I really enjoyed it. Also, I felt like I have lost a lot of ability because of COVID, and I have lost a lot of access to my community because of Covid protocols. My question is, I want to know what efforts you are doing to make sure that autistic people in the UK are not being institutionalized. I have heard in the UK that a lot are ending up institutionalized based on people with disabilities, and I would like to know what your efforts are in stopping that and making it so that people get to stay in their communities and not be institutionalized. Thank you.

DR. CUSACK: I would be interested in your definition of the word institutionalized but I assume you mean in a situation where they are excluded from mainstream society. So first of all, we want to stop autistic people from ending up in quite severe inpatient mental health settings. We would really like to avoid that, so we want to make sure that the proper support is in place, that proper social care systems exist, and we are working with the School for Social Care and trying to make sure there are evidence-based forms of social care.

And really it is about providing a system of stepped support that avoids the situation where autistic people feel -- where people are not put in that position and there are better community-level services because that is the model. And that aligns with what I think the UK is attempting to do, but unfortunately it just doesn’t always bear in reality.

Those are some of the things that we are looking to try to achieve. I hope that answers the question.

I know this was the last question so I would just like to also say thanks so much to you for the really interesting and stimulating questions. And thank you to you all for listening. I hope you understood me because I know people sometimes say my Scottish accent can be a little difficult to follow. Thank you.

DR. DANIELS: We enjoyed your presentation, James. Thanks so much for being here and sharing all of this exciting news about what you all are doing in the UK. We will take it into consideration as we work on our tasks ahead. Thank you.

We will take a five-minute break and return at 3:11, and at that point it will be the National Autism Coordinator update.

(Whereupon, the Committee members took a brief break starting at 3:05 p.m. and reconvened at 3:11 p.m.)

DR. DANIELS: Welcome back everyone. I am here this afternoon to give you an update from the National Autism Coordinator perspective, and I would like to share with you some of the different coordination activities going on across the federal government and with partners, and some of the people that are directly involved in these activities are here on the Zoom with us. At the end, if there are specific questions about some of these activities there may be opportunities for those agency representatives to share a few words as well, but I am going to give a brief overview of some of these activities.

My first update is that the HHS Report to Congress under the Autism CARES Act of 2019, whose focus is the health and wellbeing of people on the autism spectrum, has been completed and is submitted to Congress. This report features information from over 20 federal departments and agencies, divisions and offices, and includes a set of recommendations for federal agencies to address health and wellbeing-related issues.

Our Office is going to be making this report available on the IACC website later this fall, so stay tuned for that information. I am happy to share more information about the inside of the report once it is released and available for everyone to view. Our Office helped coordinate this report and we worked with the Federal Interagency Workgroup on Autism, which is an all federal working group, to help develop the recommendations, and we really appreciate all the contributions from the various federal agencies, departments and offices, to help put this report together, so we hope that you find it very valuable.

Next, I would like to update you on the Federal Partners in Transition, which is an all-federal workgroup that works on issues related to transition-aged youth with disabilities. This workgroup right now is working on the new Federal Youth Transition Plan that will replace the previous plan that went up to 2020, and the goal of this plan is to enhance coordination of activities, goals and policy priorities across federal agencies to improve outcomes for youth with disabilities. Stay tuned for more information on that, too, but that is in process.

The Interagency Committee on Disability Research that is managed by the Administration for Community Living, has been doing some interesting activities recently. They have published two toolkits, one on disability and emergency preparedness and another on employment, and the employment one is a part of a new page that I am going to be telling you about later, on employment that is on the IACC website.

So these toolkits have a lot of useful information about federal activities related to these topics. They also held a virtual symposium in July 2021 on employment for youth and young adults with disabilities, especially during the COVID-19 pandemic, and this virtual symposium’s slides I believe, are available on the web and so we provided the link for that, too.

The National Council on Disability, which is an independent federal agency that is charged with advising the President, Congress and other federal agencies on policies, programs, practices and procedures affecting people with disabilities, held its recent Council Meeting on October 7th, last week. On their agenda were the topics of home and community-based services, health equity, voting rights and employment. The minutes are not up yet but they will probably post those minutes pretty soon.

The Council, interestingly, has two progress reports that are upcoming. Their 2021 progress report is going to focus on the impact of COVID-19 on people with disabilities, and their 2022 progress report, they just announced the topic for that. It’s going to be related to climate change or focusing on environmental justice and the impact of extreme weather events on people with disabilities. So when the 2021 progress report is completed we will make sure the committee has a copy of that in case it is helpful while you work on the Strategic Plan.

Next, I would like to share an update about the RAISE Family Caregiving Advisory Council. This one is also managed by the Administration for Community Living. This federal advisory committee, similar to the IACC, is charged with providing recommendations to the HHS Secretary on effective models of family caregiving and support for family caregivers, which I know is an important topic for this committee.

In September, the RAISE Act Family Caregiving Advisory Council delivered its initial report to Congress, and that is available on the web, and I provided the link in this slide. This report focuses on infrastructure and systems to appropriately recognize, assist, include, support, and engage family caregivers, which is the acronym RAISE. There are 26 recommendations in this report.

There’s also another report that is an inventory of federal programming related to caregiving and I provided the link to that report, too, which may be useful to committee members as we are thinking about the update to the Strategic Plan.

The full Council Meeting that was held in September included a discussion on looking ahead on the development of a national family caregiving strategy which will serve as a guide for future efforts, so they are going to be working on another document in the future.

Last time someone asked about ISMICC, the Interdepartmental Serious Mental Illness Coordinating Committee, and wanted an update on that so I am providing here a little bit of background about what they are doing. So this is managed by the Substance Abuse and Mental Health Services Administration. This federal advisory committee is charged with addressing issues that are related to serious mental illness and serious emotional disturbance.

They had their last report to Congress in 2017, and autism was mentioned in the report in the context of co-occurring serious emotional disturbance in children, so that was the only specific mention of autism. And they last met on August 27th, 2021, and discussed advances in services for SMI and SED, and they have an upcoming virtual meeting that some of you may be interested in attending online on October 27th, 2021, from 1:00 to 5:00 p.m., and the link is provided there.

Next, I would like to share an update from the Disability Advisory Committee of the Federal Communications Commission. This is an advisory committee that makes recommendations to the FCC on a wide array of disability issues including communications and video programming access. The DAC held a meeting on September 9th, 2021, and we provide the link to information about that meeting.

They hosted the White House Office of Public Engagement Associate Director and talked about the Biden Administration's commitment to partnering to advance the priorities of the disability community in terms of communications access. The committee also discussed recommendations to improve communication access for individuals with disabilities. If you want more information, you can look at that website.

Finally, the last update I have for you is on a new initiative that is across many departments in the federal government. The MITRE Neurodiverse Federal Workforce Initiative is a collaboration of federal, academic, and private industry partners with the MITRE Corporation, which is a nonprofit. They have a partnership that is increasing high-tech career opportunities within the federal government for individuals on the autism spectrum. This project was started as a part of a prize program that was supported by the Office of Management and Budget in the General Services Administration.

With lessons that they are learning from this pilot project, MITRE is hoping that it and its federal partners and private partners will help to change the conversation around workers with disabilities and open the door for more neurodiversity inclusion in the federal government. They are going to be holding a meeting next week called the Federal Autism at Work Summit on October 19th and 20th to discuss issues related to this effort. The first day is open to the public and I provided the link for that.

Those are our updates and I hope that they are helpful to you as you are thinking about the update to the Strategic Plan. I will pause for a moment in case anyone has questions.

I am not seeing any questions. We are ready to move on to the next session which is going to be our committee business. We are going to be talking about a few topics today for committee business for the IACC, and this is the part of the meeting where we will be taking on discussions related to the responsibilities of the committee under the law. First, I will give you a couple of brief updates from our Office that are related to the IACC, and then we are going to talk a little bit about the Summary of Advances and we are going to talk about the IACC Strategic Plan update.

I wanted to bring to your attention from our Office that we have a new IACC website resources section that has been in the making for quite a while. We over time have heard from many IACC members and members of the public that they would love to see our website have more information about timely topics that the community is interested in and so we developed this new expanded resources section to cover some topics of interest.

It has room for expansion in the future, but we started with these few. We have a page called About Autism that gives some general background information on autism, and pages on transition, housing, and employment, as some initial topics. And we revamped our coronavirus web page that relates to coronavirus and autism, and we have a new page on agencies and organizations that work on autism.

This whole section of our website includes both federal and non-federal resources and has websites, toolkits, videos, reports, journal publications, a whole variety of different resources on these topics. We will be adding more topics in the future. If anyone on the IACC has suggestions of topics, feel free to let me know.

Next, I just very briefly, wanted to point out that we had a Fall 2021 OARC Newsletter that just went out. You can look at this newsletter to get the latest updates from the IACC as well as from the community and you can find it on the website, and if you would like to subscribe there is a link there that you can use to subscribe.

Now we are going to talk about the IACC Summary of Advances. First, I would like to start with the process. We have gone through the process of soliciting nominations from the IACC, and so many of you have sent in nominations, and thank you for that. We really appreciate that. We have a robust list of nominations.

Today we would like to have a few moments just to discuss the nominations that were provided in case anyone wants to speak up in support of particular nominations or if you have any questions or concerns about anything that was on that list of nominations. And after the meeting ends, we are going to create a ballot for the IACC to vote via email on the top 20. The entire list that is decided after today’s discussion, will be in the back of the volume that we put out, but the top 20 will be summarized individually in the document. Our Office, the OARC, will work on developing those summaries and producing the report once we have made some decisions here in the committee.

I would like to give Dr. Gordon the first opportunity to say something about the Summary of Advances process.

DR. GORDON: Thanks for that, Susan. I am really looking forward to input from the committee on the submissions, all the submissions that were listed, in particular, those of you who have particular studies that you would like to highlight, it would be great if you could do so in the discussion right now.

I want to thank everyone for the submissions that you have put in so far. It is really wonderful to have a robust response from the committee in terms of nominating these manuscripts.

I also want to remind the returned members of the committee, and suggest to the new members of the committee, in the past we have had – in an effort to really make sure that the items that we are considering when we vote, that they represent true advances in the research space. That has meant that we have in the past agreed, although it is certainly open for discussion now, that reviews, that is papers that don't actually have new data or new findings in them but rather review the state-of-the-art of the field or the state of past findings, that those are not generally included unless for some reason they bring to light something in the collection of reviews that is not apparent from an individual paper. That is point number one.

The other thing we spent a lot of time talking about in the previous incarnation of this committee is the notion that it’s important not to put too much emphasis on manuscripts, on papers, that present data from small groups of individuals with autism given the heterogeneity of the disorder and the challenges we have had in the past of replicating findings based on those small groups.

So, while pilot experiments showing exciting results in a handful of individuals with autism may be very exciting for scientists and very promising for those of us who care deeply about discoveries that will help individuals with autism, we have to recognize that having the imprimatur of this committee assigned to those might give false hope and/or a false sense of officialness to results that are not quite ready for prime time.

Then finally, we want to make sure that the manuscripts that we refer for potential recognition in this document represent advances for individuals with autism as opposed to general manuscripts that may provide insight into a broader array of mental illnesses or cognitive disabilities.

And so I think it is important to ensure, as we consider inclusion in the list on which we will vote, manuscripts that really focus on autism as opposed to manuscripts that are more general.

There are other things that I may be leaving out that we talked about or agreed upon in the past, but I wanted to raise these three issues to get some concurrence from you all about it. Perhaps you disagree. This is the past pattern that we had.

Again, the three things that we generally try to avoid are peer reviews that don’t bring new information to light, new findings to light, number one. Number two, studies that are really underpowered; even though they might be exciting, they are not powered well enough to be definitive. And three, studies which are more general, and which really don’t have that specific impact in autism.

I am going to open it for discussion then first about these general principles or other general principles people might want to remark on, and then I think we should solicit comments on the list of manuscripts that we received.

Dena, is this comment in regard to the general inclusion of papers in the discussion?

MS. GASSNER: Yes. My question is, given that qualitative research often has a significantly smaller sample by the very nature of the methodology, where will that particular type of methodology be incorporated into this?

DR. GORDON: I think one has to weigh the significance of the qualitative findings for advancing the field, alongside the, as you suggest, the generally small sample size of such studies. I think there is room for it. I think more promising are mixed-method studies which typically involve some form of qualitative as well as quantitative research, or large surveys of data that really reveal something new that we did not know in the past.

By all means, I don’t mean to suggest that qualitative research or small pilot studies aren’t important for the field; they are tremendously important for the field. But the notion that if the IACC gives its stamp, what we are saying to Congress is these are the major developments that you need to look forward to in terms of changing care patterns or bringing up new avenues of science to bear on autism. In considering those studies that involve small samples, I think bringing that forward to Congress and saying, hey, this is something to look at, it requires a little bit closer examination and we have generally been hesitant to do that, even if they might be important for future researchers to consider.

MS. GASSNER: I am just concerned that that is going to close a lot of autistic voices out of the discussion. Numbers are very important, I agree, but qualitative is uniquely able to get to people’s lived experiences. But I will keep that in mind.

DR. GORDON: Let’s keep that in mind. In general, we don’t remove papers automatically. We bring them up for discussion here, and so there is certainly the opportunity to say I know it’s only 30 individuals with autism, but this is the point that it makes. This is why it’s a particular important advance.

But I do appreciate that input. If there is strong opinion, we have generally held this standard for things like clinical trials, for example, where underpowered clinical trials are particularly problematic, although we can see when a paper is brought up for a small number, whether it might be having that effect.

MS. GASSNER: Thank you so much.

DR. GORDON: Sure. Alycia and then Ivanova.

DR. HALLADAY: I would like to put a plug in for us to reconsider the inclusion of systematic reviews. These come with a specific hypothesis in mind and use the existing literature to not just aggregate but to also identify gaps and also answer research questions that no single research study has done itself.

I am not saying that every single systematic review is worthy of a listing on the Summary of Advances, but I would kind of like to re-think that as being like a standard exclusion criterion.

DR. GORDON: Alycia has a good point. Let’s be clear that when we are talking about reviews or meta-analyses, systematic are better than non-systematic reviews; meta-analyses are generally better than systematic reviews in terms of the rigor of the methods applied. But you are bringing up a good point that when a review is done rigorously and reveals something that any individual collection could not reveal, or definitively answers something in a way that individual papers were not able to do, I would agree with you, inclusion is important.

We can also consider that as we think about bringing up reviews for exclusion from the voting. Is that satisfactory, Alycia, or would you more strongly argue for not excluding papers just because they are reviews, at all?

DR. HALLADAY: No. I think that’s fine, as long as we can make an argument that they should be included and not as a group excluded, that is fine.

DR. GORDON: So two important points so far, one that we want to keep a watch out to make sure that the small study size exclusion doesn’t eliminate papers that use qualitative approaches that may discover important areas that we want to bring to the attention of Congress and of the American people. The second is that reviews that do shed novel light or definitive light onto a question shouldn’t just be excluded only because they didn’t have new data that they brought to the field but because in aggregating data they can bring new ideas to the fore.

Ivanova, you are next and then Paul and Joseph.

MS. SMITH: My question is a lot of the research articles are really hard for me to understand. I couldn’t understand any of them. Is it possible that there could be like a plain language format for me to review? I couldn’t understand those. Are there maybe like audio versions I can listen to instead of trying to read them to review them?

DR. GORDON: I appreciate the comment, Ivanova, and I think many members of the committee, even us scientists, have trouble understanding the papers that are in our own fields, and so we look to multiple levels of expertise across the committee to judge the papers. We may be able to help with accessibility in terms of -- I don’t know if there are audio readers that will read pdf manuscripts or something like that. We can look into doing that.

And it is important to note that for those that are selected for inclusion lay summaries are created that will be more accessible. I don’t know if we can spare the manpower to create lay summaries of all 60 or so nominations that we tend to get per year, although some journals now have lay-friendly abstracts that they require, so maybe a handful of the recommendations are there.

Let’s note, Susan, to think about the accessibility issue in particular with regard to whether there might be places we could refer committee members for at least audio reads of the pdf versions of the manuscripts and think further on how to make those more accessible for those members who might need it.

DR. DANIELS: We might be able to have individual meetings with people to talk through their questions about the papers, so our team might be able to do it that way.

DR. GORDON: Thanks, Susan. Paul.

DR. PAUL WANG: Thanks for the opportunity. Just a comment, and I want to say I am generally very supportive of the guidelines, the principles for thinking about this that you put forth for us, Dr. Gordon, and that Alycia has helped extend our thinking about. I just want to offer my own opinion as a member of the committee who will be working on this to sort of flesh this out a little bit more.

In an ideal world, absolutely, we want publications that truly show how the field is moving forward in a positive way to new developments, new understandings, proving that new supports and services are valuable, cost-effective, that they work, et cetera. In my opinion as one of the more biologically oriented members of this committee, there are a number of articles in the section on Question 2, biology, which represent very nice science, beautiful science, challenging science that was successfully carried out, but which don’t meet that criterion for significance to the community.

We simply don’t know. I will pick on the very first one because it’s the first one in the list. We just don’t know how important Mint signaling in TBE R.1 mutants is ultimately going to be for the autism community, regardless of how beautiful that paper was. So I think there are a number of things in the biology section and some of the other sections that are sort of like that and that will not be getting my vote.

My question is, if you can extend, Dr. Gordon, a couple more tangential comments that you made about papers that perhaps show we do not have an answer, have not figured something out, can we recognize these -- you might call them -- negative results as important publications? And similarly, can we recognize very high-quality research that was carried out on relatively small populations, but which showcase the kind of good research that could be done and that we want to see more of?

DR. GORDON: Thanks for that, and thanks for expressing your thoughts in particular about the basic science. I think we do often get many more submissions -- I don’t know if we did this year -- but we often get many more submissions on the basic science side, and we do try to make sure that the results we forward on to Congress are more broadly representative.

And so I think it is incumbent upon us, as we discuss the nominations here and as we vote, that we make sure, those of us with the basic science expertise, to separate out those things that are major advances versus simply beautiful science that we might admire but are of potentially questionable impact.

Regarding the second question about negative results, my own -- and remember, we didn’t exclude negative results from the list; just small studies, reviews and -- I’m forgetting the third one. Susan, help me out.

DR. DANIELS: I have five things on the slide. You can see them.

DR. GORDON: Editorials and opinion pieces, preliminary studies, literature reviews and systematic reviews, expert recommendations, fields related to ASD. Right. So not amongst there is negative results. I think my own personal view on this -- and I don’t think I would ask for a paper to be excluded simply because it was a negative result. But my own personal view on it is we want to present negative results that close off an avenue that we thought was going to be there, but we want to make sure is not something that folks are pursuing, so, definitive negative results that really might change the course of a researcher’s path or definitive negative results that communicate to the community this is something that you shouldn’t pursue. Say a treatment that is out there that people are trying to get or are interested in getting or are using but where there is clear lack of efficacy and/or harm. Those kinds of results I think we would prioritize.

But I think any negative result is something for us collectively to consider whether it is an important negative result that we want to make sure we note as an advance in the field for any number of different reasons. So I agree with you on the second point for sure.

Joe, you are next.

DR. JOSEPH PIVEN: I wanted to just echo Alycia’s comment about reviews, but maybe my contribution here is a little nuanced but aiming somewhere between opinion pieces and reviews. What I think of as very important for this field are papers that are more conceptual frameworks, that really pull together the field around a particular point or perspective and try and move it forward. I think those can have a huge impact.

And we could reduce that to describing them as literature reviews, but I think they are much more than literature reviews. I think in this field currently we need those, and I think those could be impactful enough to want to draw the attention of Congress to think about issues about early intervention and treatment and diagnosis. And often the perspective of a single research paper I think is too narrow to really encompass those.

I sort of wanted to add that little nuance to either literature reviews or opinion pieces, the idea of conceptual framework that I think you may have been sort of subsuming under literature reviews.

DR. GORDON: Before I respond, I don’t want to influence the discussion too much as Chair. Let me just ask, Sam and Larry, I see your hands up, but if others have direct reactions to Joseph’s suggestion. I see a thumbs up from JaLynn, so she is supportive of that, and a thumbs up from Alice, and two more thumbs up.

Now let me inject my thoughts on this subject and say that if I am overruled by the committee, this is one that I am happy to be. I think there is a real danger here in that we are being asked by Congress to provide them with a list of advances, not of plans, not of perspectives, not of opinions, but advances in the field. And while I certainly recognize that frameworks, new ways of thinking about old results can really alter the course of research, I think to represent them as advances, it is probably going to be pretty rare that those frameworks in and of themselves would, number one, actually represent by themselves a significant change in the way that we approach autism and, perhaps more problematically, run the risk of putting our imprimatur on a concept that might be controversial, that might not reflect, in its early stages, a mature and accepted scientific perspective. That is what I would worry about.

I am trying to think of a way to make this more concrete because I realize what I just said was rather abstract, although I think, Joseph, you also were a little bit in the abstract territory.

But I'm thinking, for example, let's suppose that a review of a set of neuroimaging studies in autism points out the fact that if you look at the data, what it really suggests is that there’s some functional difference mapped onto the brain anatomy that people hadn’t really seen before. And you can characterize that functional difference by thinking about a particular behavior in a new way like, yes, you have done a working memory task and your executive function task, but you haven’t thought about the fact that that function might mean that it is not working memory or executive function but it’s really attention that is different in autism.

It’s a really important framework that one then needs to explore with further science, but I am not sure that that is something that there would be a lot of agreement on amongst all the scientists who did all the original work. So I worry that in putting forward these things we might get ahead of ourselves.

That said, when we bring up a review and we say, hey, we think this is a review or a perspective that doesn’t belong in here, any individual one we could be discussing and saying, hey, yeah, but it represents an important framework, then I probably would just ask the person who is proposing to keep it in for the vote how would we explain this to Congress as being an advance. So that is my thought on it. Joe, do you have a reaction?

DR. PIVEN: Well, in part, I think I would rather hear what other people have to say, and I recognize that you have a much better feel for how we give information to Congress.

That said, I was thinking about issues that were kind of beyond a particular neural structure or system, but really more conceptual issues. So things like early intervention, how we think about diagnosis, that really cross levels of analysis and different domains and require that kind of broad view in order to arrive at the particular point of view or conclusion.

I think those efforts can be extremely important, especially for someone who is not a researcher in the field. If I was an interested congressperson, to read something like that, that was more integrative and broad in scope, I think that would be very impactful. Of course, we don't want it to just be opinion; we want it to be reasoned and based in science. But I think there is a real role for that. I will leave it there.

MS. CRANE: I actually was really hoping to talk about this because I think part of the issue is going to come down to what we see the Summary of Advances is about. My understanding of Congress’ mandate of the Summary of Advances is that this is for the community, and this is for autistic people, family members, practitioners in the field to read these advances and put them into practice and have them have a direct impact on people’s lives. This kind of goes back also to the question of what to do with studies that are interesting science but don’t have a clear application or impact on autistic people’s lives.

I really don’t want us to get bogged down in conversation that assumes that if we are not including something in the Summary of Advances that we think is bad science or we think it shouldn’t have happened or didn’t get the prize -- I don’t think this should be an award ceremony. I think that this should be a resource for people in the community, not necessarily researchers, who want to know what’s going on and want concrete, actionable information that they can use.

So that is what I was hoping, and I was wondering if other members of the committee agree. I think that does tie in a little bit with, Josh, your concern about inclusion of broad framework papers.

DR. GORDON: I agree with you, Sam. I do think you are speaking from the same perspective. Keep going.

MS. CRANE: I also wanted to talk briefly about Ivanova’s point and say that I understand there is a resource issue, but right now our Summary of Advances document with the things to propose for a vote already includes a summary. If I remember correctly, the summary is included by the person who submitted it for consideration, and I want to challenge other committee members to endeavor as much as possible to put that summary in plain language. Because right now, almost none of them, actually none of them, would meet what I consider to be plain language requirements.

I think it would also really help when we get to the point where we’re publishing the Summary of Advances report if the summaries that people already sent in were close to plain language and it’s easier to get the report into plain language so that community members can read it.

DR. GORDON: Sam, I think that is a fantastic point, that second point. I don’t think any of us would disagree with it. If we, when we make the nominations, endeavor to put those summaries in as plain language as possible, that certainly would make it easier. And if that was done, it may even be possible for Susan’s folks to clean it up as much as possible before sending it out.

So I think that is a great idea that we all, when we make these nominations, endeavor to make sure our summaries are meant for everyone on the committee and not just for those with similar backgrounds.

DR. DANIELS: I have a comment. There was a comment made by Yetta Myrick sent to me by our staff asking if there is another way to recommend frameworks and some of these other things that we’re talking about potentially excluding from the Summary of Advances, outside of the Summary of Advances.

The answer to that is there is a strategic plan, and traditionally our Strategic Plan has some reviews of what has been going on in the field. And so there may be things that don’t quite fit whatever definitions we are going to use for the

Summary of Advances that we certainly can be collecting for useful information for the Strategic Plan update. So that and potentially other kinds of documents that we may be preparing we can include those things there.

DR. GORDON: Larry, you are next.

DR. LARRY WEXLER: First, I want to reinforce what Sam had to say. All of this is meant for the greater community, and that was I think Congress' intent. I have been on this group for well over a decade and I have said this before. In my world, which is education, we say, except during the pandemic, the school bus pulls up to the schoolhouse door every day regardless of the state of the science. And I think sometimes we have to acknowledge that we can't let science become the enemy in terms of looking for perfection.

And, Josh, I know this is going to irritate you as the NIMH Director, but the CDC and the FDA are about to approve the Moderna booster. The Moderna booster, the data are based on 350 people, and it is likely that it will get emergency approval and will be accessed by 50, 60, 70 million people if not more because it is really important to deal with it. And I think we shouldn’t diminish the importance of what the community is struggling with in terms of meeting the needs of children with autism, adults with autism and their families.

All that is to simply say I think there may be a middle ground here where we in fact have a section of whatever, preliminary studies or studies with small samples, that are in fact interesting and perhaps promising but not put the imprimatur on “this is good science, you should use this; if it’s implemented with fidelity good things are going to happen", but are certainly worth taking into consideration.

I apologize that I used vaccine research as an example, but I do think that there is a level of practicality that we sometimes have to consider in doing this really important work. Thank you.

DR. GORDON: The one qualifier I would put on what you said, Larry -- you didn't irritate, me but I think the one difference here is that what one needs to be concerned with is not the absolute number -- if we had a study of 350 patients with autism actually that would be a pretty big study for most of the clinical stuff that we do -- but, rather, the confidence that we can have in the results based upon that number.

It could be that you have a study of six individuals with autism which is so perfectly done that it reveals something that is super-important, but it is very unlikely. In fact, it’s very unlikely if 350 would actually give you -- say if you were looking for a treatment response -- because of the heterogeneity of the disorder.

But nonetheless, I think you are making a good point, that you do need to consider the significance of the finding. I would just argue that for us to be able to recommend something as a significant advance, it is not just good enough that it has to be exciting and significant and be meaningful, but it has to be definitive, or at least rigorously done.

DR. WEXLER: My only point is maybe there is a subset over --

DR. GORDON: Yes. I think that’s something we can visit at another time. Susan has lots of stuff to do in the next hour, so

I want to make sure to give the next person a chance. But I would be really worried about us as a committee saying this is exciting when we don’t have a lot of confidence in its reproducibility. That is the main issue here, even if it’s super-exciting, because we would then be bringing it up as saying, hey, maybe what we need to do is give everyone the Covid vaccine and their autism will get better.

DR. WEXLER: Don’t put words in my mouth.

(Laughter)

DR. GORDON: I didn’t mean to imply that at all. I just meant that small studies can yield a lot of false hope, and that is the problem. Dena.

MS. GASSNER: I’ll be brief. I just wanted to second everything that Sam said about accessibility. As a national board member for the ARC US, our new strategic plan will be in plain language, and as each policy statement comes up for review, they are also being converted to plain language for accessibility. And so, given that the audience for this is really the community and non-scientific folks sometimes in Congress, I think it would be really good to do more around that.

Larry, I just adore you because I think that what I am also concerned about is the reality that autistic researchers and other neurodiverse researchers are still facing gatekeeping issues regarding admissions criteria that are keeping them out of major universities where these larger-scale studies are able to be done. That doesn't mean that they're not doing good work; it just means that they are unable to be currently placed in a space where their work could be prioritized.

I think what I’m hearing is that this is the basic criteria, and it doesn’t mean that we are not going to be able to look at an exclusion, but it still has to meet the standards for rigor, it still has to be something that is groundbreaking.

I’m wondering, Josh, if there’s a space for something called promising future studies or something that might allow a smaller sample size or a more limited study to be presented such that it could lead to a major university wanting to replicate it or pick it up or to create a collaboration to shift it from a qualitative study to a mixed-methods approach.

I’m just brainstorming, it’s just an idea and you don’t have to answer me. I am just expressing an idea.

DR. GORDON: I appreciate that. Stephen.

MR. WHITLOW: Very quickly, I am way out of my depth here. This is certainly not something I should be commenting on but I have a hard time not commenting on things sometimes.

My perception is that we are talking about two different things. We’re talking about the factual findings of a study and what should be declared as an advancement versus what does it mean to the community, and I see that both in the summary part of it and also some of these other summaries.

I think we need to make a very careful consideration of what it means to the community, and if we are going to create a summary of an article, we either make sure that we go back to those study teams and say does this summary comport with what you actually found, instead of what you propose that it means to the community. Because to me, a specific scientific fact may have no meaning. What I want to know is how does it impact me and my child.

So I think that we’re wrestling over an important idea, but I think we need to very clearly define what it is that’s a factual finding based upon a scientific study and what does it mean to the community and how do we recommend additional studies with regard to those specific findings.

DR. ROBERTSON: I just want to say that I concur with what was mentioned as far as making sure that there is practical value for folks. I don’t know whether that goes in line with having some kind of separate section or separate document in terms of like the research translation in terms of how implementation of research is happening, with findings, because I think it’s that practical service provision kind of end that gets lost in the weeds at times because it’s at the pragmatic end. Like, how is it going to have an impact, how is it advancing folks’ quality of life.

Because I think our charge for the Autism CARES Act ultimately is on the quality-of-life, is improving folks’ health, wellbeing, quality-of-life, access opportunities. I think that is the big picture.

I always see in terms of findings data from studies as being a way to inform and shape that, but it is ultimately the practice service change, the resource development, et cetera. What are we actually doing to improve folks’ lives is I think what should be of utmost importance in terms of that research translation aspect.

I don’t know if that fits into this broader conversation in terms of the section or a new document or something like that, on the research to translation process and how things are being -- like the impact in terms of services enhancement and greater access to opportunity for folks through the services and resources here in the US and what we’re learning from other countries as well, including what we learned from the UK earlier today. I don’t know if you have flexibility for considering adjustment on these things.

I know that the Summary of Advances has been structured as it is for a long time, and I don’t know if that is something that long term could be a consideration in terms of what it looks like for that document or other documents in terms of sections, or new documents that could sort of reflect the impact on services.

DR. MARVIN: I just have a comment about some of the smaller studies. First off, typically what I have seen is that people start off with maybe an R03 or R21, some of these smaller grants, and they use what they have learned from maybe a smaller grant, maybe a K, and they use that to get their R01. So, if something has promising results as a smaller study, it’s already going to be in the pipeline to be used for a major grant. So it will get there eventually if it makes sense. And there is going to be a review process for the R01 from some of the smaller grants they have. I’m thinking a small study might not be there this year but in a few years it will, and then you will have the science backing it up.

My second comment is going back to some of the list of the literature included, and I have to admit some of the biology ones -- I am a statistician, I have some background in physics. Biology isn’t really my thing, and I really don’t know whether something makes sense in that area, so I would really appreciate it if there could be someone who could maybe do some advanced vetting especially in that area which really requires a level of expertise to determine whether something is meaningful and should even be on the list or not.

Those were just my two thoughts.

DR. GORDON: Thanks, Alison. I want to try to summarize because I know we have a bunch of other business to attend to today. I want to summarize where we are now and suggest next steps to hopefully be agreed upon by consensus.

We have had a discussion on these five reasons to typically exclude articles. Again, we don’t exclude articles automatically without bringing them up to the committee. Editorials and opinion pieces, preliminary studies and/or studies of small sample size, literature reviews, expert recommendations and fields related to ASD but without a sole focus on ASD.

I think there were some concerns expressed related to the small studies as being potentially very impactful, and in particular, that excluding small studies might exclude from the Summary of Advances papers that reflect the voices of those with autism and qualitative studies of various kinds.

Similarly, there are some thoughts that reviews, and particularly systematic reviews, might make contributions that individual papers cannot, and where those contributions represent advances, we should be able to recognize them. I don’t think there was much objection to that. In fact, there was further support from many of you that the notion of a paper that presents a novel framework that could be considered in the realm of opinion or review could be considered as well.

Finally, going back to the issue of small sample size, I think there is the notion from many of you that it would be nice to be able to somehow recognize papers that were exciting and provocative but weren’t quite ready for prime time.

So here is what I would like to suggest. One, that we continue to keep these as general exclusion criteria and that we continue to have a process where each paper that is nominated that someone would like to exclude because they think it adheres to these be brought up for discussion in the committee, and obviously we can consider the points raised here before we exclude it for vote. And then, of course, it could be considered amongst the vote and listed in the list of papers that are considered for inclusion in the Summary of Advances that occurs at the end.

Secondly, the issue of small sample size could be treated similarly; that is, if there is a small sample size that nonetheless is substantial, that we can potentially include it in the vote. I have to tell you that I am going to be very, very vocal about papers that I feel are underpowered because I think it’s irresponsible of us to put our imprimatur on those.

As to the idea that for any of these kinds of papers that we wouldn’t want to include in the Summary of Advances but we would like to recognize them as things that we want the field to be aware of for follow-up, I think Susan and her staff can consider how we might do that, whether we would publish an additional report, an addendum to the report, include it in the website somewhere under interesting research. I would ask Susan and her folks to come back with some ideas for what we might do with those kinds of studies to make sure that we have an opportunity to bring them to attention.

I would argue that by just discussing them here in this forum we are bringing it to the public's attention, but nonetheless, I think having a place to put those is something we can look forward to.

Are there any objections to that plan going forward? Okay.

Finally, we were going to try to discuss some of the nominations, but I think, Susan, you probably have to move on at this point, and we should carry on those discussions either at the next meeting or possibly via email so that we have the opportunity to move forward.

DR. DANIELS: We should not do it by e-mail, so we should probably bring it to the next meeting then to have everyone look at the list. If anyone is having trouble deciphering what is in that list and you want a staff member to talk through it with you, I think that is going to be a more efficient way than asking for us to write lay summaries of every single item on the list. I think that would be pretty labor intensive, but I think we could easily sit down and talk with you about studies that you have questions about. Let us know and we can do that prior to the meeting.

DR. GORDON: That was the other thing that I wanted to recognize, is that I heard from a number of you that we really need to do a better job at this stage where we are actually looking at these papers and considering whether they belong and considering what we might vote for, of providing some degree of lay summary. Susan has proposed that for now Susan is available as a potential resource for the papers that you’re really interested in learning more about as a discussion point. I don’t think in the long term that is really going to work, but we’ll see. If there is not tremendous demand, then we might be able to accommodate it.

I think, though, as several of you have pointed out, it is incumbent upon us as nominators to write a summary when we submit a paper for nomination that is, as I said earlier, meant to be read by everyone on the committee, as inclusive as possible.

We do note who the nominator is, I believe, when we send this information around, so I think another resource for you is the nominator. If any of us here would like to know more information about why -- the nominator is sending is because they think it’s a significant advance, so it is to their advantage if they provide additional information to any other committee members about why they nominated it in a way that would encourage those committee members to consider it when they vote.

So I think the other resource you have is the nominator. You can reach out to them and say I didn’t really understand that paper about Mint signaling, or I didn’t get why this qualitative study or this small sample, is important enough. Can you explain it to me so that I can vote in an informed fashion?

So we will keep these five but we will continue to discuss papers that are excluded, and I appreciate all the points about why some of these exclusions shouldn’t be automatic, and they are not necessarily automatic.

Two, Susan is going to work with her staff to figure out whether there is a way we could note exciting advances that don’t quite make the cut in some way, shape or form.

Three, we are all going to work together on ensuring that all of us have the capacity, capability to be able to understand to the extent possible the papers that are being nominated so that we can make informed decisions. And Susan is going to be, for now, a potential resource for that.

DR. DANIELS: And the entire OARC team, so we can help out with that. Keep in mind that there is the whole Strategic Plan, which is usually a pretty big document, and we do talk about promising practices and other things in that document, so the Summary of Advances is by no means the only document that the committee has. As you go along you will see that we work on a lot of different things, and there are definitely places where we can put different ideas.

If we are ready to move on, we wanted to have some time to talk about the Strategic Plan, and this will be our first discussion of several. With the Strategic Plan Update we have a few issues to talk about: the request for public comments, the structure of the Strategic Plan, budget recommendation, statement on duplication of effort, and language considerations, if we have enough time to get through all of these items today.

Just as a brief update, at the last meeting you all let us know that you were fine with OARC going out with a request for public comments to bring in public input for the new Strategic Plan Update, and so that request for public comment has been issued.

It is on the IACC website now and it is open until November 30th. It has seven questions that relate to the seven questions of the current Strategic Plan, and you can see on this slide what those categories are. There are also a couple of additional questions covering the COVID-19 pandemic and the needs of underserved populations that we discussed at the last meeting.

And so we welcome comments from the public. You are welcome to go into that request, and it is in a web format. We will be looking forward to bringing that information back to the committee. OARC is going to take that feedback, compile it, organize it and do some analysis of that information and bring it back to the committee.

And I wanted to let the committee know that we also are going to be collecting written information from you all, but we would like to prepare a special form that is going to be a little more detailed for you. And for those of you who like to have a little more time for processing and thought, I think that form will also give you a chance to provide your input across the Strategic Plan. So stay tuned for that. That will be coming shortly.

The first item on the Strategic Plan I wanted to bring to your attention is thinking about the structure of the new Strategic Plan. We currently have a strategic plan that is organized around seven topic areas that are related to seven community-focused questions, and this is the way the IACC's Strategic Plan started out years ago. Those seven questions are listed here.

The topics roughly that are covered by these seven questions are screening and diagnosis, biology, risk factors, treatments and interventions, services, lifespan issues, and infrastructure and surveillance. These seven questions have been followed from 2008 up until now and we have been tracking -- Even the research project data that we collect annually is categorized according to these seven questions and we have been tracking that since 2008.

One consideration for the structure would be the continuation of being able to track, but, at the same time, we also want the Strategic Plan to be up to date for the needs of the community and what new input there might be from the committee.

And so I wanted to open this up for feedback about the questions as they are stated right now and these topics and how you feel about continuing either with this structure or if you have ideas for anything that would be a change in the structure. That is pretty foundational to developing the plan, so I wanted to get that out on the table.

Are there any comments about the structure that we have in place now and future considerations?

DR. WANG: This is a very basic question and forgive my ignorance. Is this a strategic plan for research, or is it more broadly a strategic plan for supporting the autism community?

DR. DANIELS: It started out as a strategic plan for research because the initial Combatting Autism Act asked for a strategic plan on research. However, in 2014 Congress expanded that mandate to cover services and supports to the extent practical, is how they said it in the law. And so the structure that was there already had sections on services and lifespan issues and some of the infrastructure and surveillance that are related to those services for the community, and those sections of the Strategic Plan have been built out further in the last several years. That is how it has been covered.

It did initially start out with research but now it covers the span of research, services and policy. Paul, do you have a response based on that?

DR. WANG: No. That is helpful to understand.

MS. GASSNER: You will have to forgive me because I don’t think in categories; I think sequentially, so sometimes I have ideas that may fit in a box, and I just can’t identify it.

On Question 5 around what kinds of services, I’m wondering if a more enhanced version of that question could also include what quality of supports and services that people are experiencing, especially as they try to navigate governmental agencies for support.

The second one I wanted to bring up is -- and I am not sure where it would fit or if it fits, but -- the implications of interactions between first responders, law enforcement and the autism community.

And finally, I don’t see anything specific to marginalized intersectional communities and the huge disparities both in regard to race but also gender, also identities, that might have more repressive experiences because of the multiplicity of identities they experience.

DR. DANIELS: To answer your questions, in terms of the quality of services, that is certainly something that could be incorporated into Question 5. With law enforcement it is included in the area of services, so we do have some information on that area. It certainly can be expanded beyond what it was stated in the 2017 plan, which was our last completed plan, with a brand-new set of objectives.

In terms of marginalized communities, that has been a crosscutting issue and it cuts across all seven of the chapters of the Strategic Plan. However, it never became a crosscutting objective of its own, as the last committee created a crosscutting objective on women and girls that cuts across all seven, and so the marginalized communities part pops in and out of all seven questions but could be further delineated by the committee if this is an area that you all are interested in seeing more strongly highlighted in the plan.

MS. GASSNER: Considering that only 80 percent of US doctors ever experience working with a woman with high support needs, I think women, as one of the later-diagnosed, marginalized populations, still need to be part of the dialogue, but then when you start layering those intersectionalities on, I think it deserves its own attention because we are seeing significant research demonstrating long-term consequences in those arenas. So that is just my bug. Thanks for listening.

DR. ROBERTSON: I concur in terms of the focus on intersectionality as far as race/ethnicity, gender identity, sexual orientation, socioeconomic status, et cetera, and I think that also dovetails with our federal priorities as far as what has been of major focus for us at federal agencies for the intersectionality, racial equity, social equity. So I think it is very much in alignment with our priorities in that area right now in terms of how that could be weaved throughout the Strategic Plan and given heavy emphasis.

I would add secondary conditions and, for instance, communication usages. I think it would be great to enhance the narratives around, for instance, augmented alternative communication use.

And I think one of the other things that we should be considering is how the Autism CARES Act has changed. With the reauthorization in 2019 of that law it emphasized quality-of-life across the lifespan, so it may be good to consider, for instance, revising Question 5 with some different wording, because I would argue that quality-of-life should be embedded across all the questions.

It should also be a crosscutting focus in addition to health and wellbeing in terms of physical and mental health and wellbeing because that’s a major priority in terms of quality-of-life, access and opportunity for children, adolescents and adults across the entirety of the life course and is in the law now. And it refers repeatedly to life course, 20, 30 times. I don’t remember the exact number in the statute, but I know they added it a lot when they did the reauthorization in Congress in 2019. So I think that should be a major consideration.

And then maybe it’s a possibility that the committee should consider other adjustments to the questions just to make sure they are modernized in terms of how we are looking at autism right now from the research end, from the services and resource development end, and how they align together and cohesively flow together.

I think one example of that is, if you look at services and you look at lifespan issues, there is a lot of overlapping focuses there. I know that, for instance, employment and some of the other adult focuses tend to be in both areas. I don't know if there are ways to be, strategic, for lack of a better way to put it -- a strategic plan on what goes in what area and how it goes, and how these questions interconnect to each other, too, so there's consistency across the Strategic Plan and thought out really carefully.

I know that the process with the development of the Strategic Plan allows us to be thoughtful on that.

I think the final point I want to make is inclusive language. I know we touched on that in the January meeting of the committee, and I think that should be of major consideration. I don’t know if that means guidelines or some other way not only now for this Strategic Plan but for future strategic plans, too, in terms of how that is looked at to make sure that the language is inclusive.

I would argue strength-based where possible, make sure that it also aligns with the values that are emphasized in the Autism CARES Act and what our community wants to see in terms of autistic people ourselves, family members, service providers who are stakeholders across the country who would be reading the Strategic Plan, not just researchers, what their values look like and what they are seeking for us to be supporting -- again, improved quality-of-life for folks across the lifespan.

DR. DANIELS: Thank you for those thoughtful comments. We are of course, taking notes on all of this.

For the committee, when you get your specialized form to provide input, you are welcome to make suggestions about rewording of some of these questions, if there’s a way to modernize them, and areas that you think need more clarity, et cetera. I know that in a short discussion here on Zoom we won’t have time to get into all of those details, but we will be eager to get input from you in writing and, of course, we are going to continue these discussions. But thank you for those thoughtful comments. Susan?

DR. SUSAN RIVERA: I am struck by the absence of anything around psychological processes in the Strategic Plan, things like sensory processing, language, anxiety and other kinds of mental health issues. I’m wondering about the restrictiveness of Question 2. What is the biology underlying ASD. I suppose it depends on how you define biology. I think of psychophysiology and some of the things that we look at and other researchers look at as a type of biology.

But it really strikes me that the basic psychological processes and sensory processes that are important for understanding and phenotyping and ultimately treating autism are missing from this Strategic Plan as an emphasis.

DR. DANIELS: Just in response, on Question 2, actually, all of those areas you mentioned are included in Question 2 when we actually flesh out the Strategic Plan. It may be that we want to reword the question to make that more clear, but in terms of when we collect research projects from across the country for the portfolio analysis, all of those types of science are included in Question 2.

DR. RIVERA: That’s great. I think that rewording Question 2 then might be valuable. As people are looking at these shorthand versions of these questions that are part of our Strategic Plan, I think expanding that would be a service.

DR. DANIELS: Great. And in terms of mental health services, they are more in the later part of the plan, in Questions 5 and 6. But that is a great suggestion so we will keep that in mind.

DR. RIVERA: Let me just clarify that when I spoke of anxiety, I was speaking about understanding how that presents and how it interferes with cognition, et cetera, not so much the acquisition of mental health services. So I do see that as distinct from that. Thank you.

DR. DANIELS: Helpful comment, thank you. Jennifer.

DR. JENNIFER JOHNSON: I just wanted to go back to the comments Scott was making about the plan itself, and being really forward thinking and about quality-of-life and really being mindful of the language that is being used to really move the Strategic Plan forward in that way.

In particular, just looking at these questions, Questions 3 and 4 I think are the ones that really need to be addressed, and I understand we won’t do that here. But I think we really want to think about the language that we are using and that it’s empowering and, again, forward-thinking, that ASD isn’t something that we necessarily want to be preventing or preempting but certainly we want to understand it so that people can live full lives and quality lives.

And also, the idea of treatments and interventions that will help. Again, I understand the idea there, but it just makes it sound like people with autism have to be helped, and I don’t think that is what we want to be communicating through the Strategic Plan. So I want to support Scott’s comments on that.

DR. DANIELS: Thanks. We probably at a later meeting may have more time to go into more detail about some of that, but if you have anything to share in writing that would be great.

I also have in the slide set here to talk more in detail about language if we get to it, so I hope that we will, but we do want to have a more nuanced conversation about language. Matt?

DR. MATTHEW SIEGEL: Thank you, Susan. I would suggest that perhaps we look at

Question 1 because it strikes me as written with a fairly somewhat narrow focus, likely focusing on young children, but I think there is a lot of research that this question is really broader.

I would consider the question perhaps being more how is ASD identified, defined and expressed, because, for instance, there is now increasing research on how ASD is expressed in females and many other populations. So this question feels very 2008 to me in its focus -- and it is wonderful -- in its focus on I think likely young children and early intervention, and I think it’s really getting at a broader set of questions. So that would be my suggestion.

DR. DANIELS: Thank you. We have that noted here. Helpful suggestion.

DR. WANG: I just want to support the idea of retitling Question 2 along the lines that you and Susan Rivera suggested. I don’t know the words but something to incorporate cognition, language, sensory processing, et cetera.

DR. DANIELS: Great. So we will look forward to hearing more from you in detail about suggestions for that. That would be great to get that input.

This has been really helpful. I am going to move to our next question to see how much we can get through here, but very helpful feedback. Hopefully you will take some time to think about this, as this is not the only time we are going to talk about this. We will be coming back.

DR. ALICE CARTER: If possible, also thinking developmentally. Each of these questions -- we think about what is -- I don’t like this question either, but what is the biology underlying ASD. It’s like at this point we are not thinking there is a static biology but there are sort of cascading developmental processes, and so I think somehow building that in, because that is important for each of these questions. So maybe having something that somehow, like intersectionality, that really need to be addressed always are some themes that sort of are not embedded in one question but are crosscutting but that are named as essential for doing this kind of work.

DR. DANIELS: Thank you. Another thought-provoking idea. Mercedes.

DR. MARIA MERCEDES AVILA: Just briefly I wanted to also echo what Jennifer said and others, the concerns with Questions 3 and 4 and possibly looking at anything that has to do with causes more from a social determinants of health framework rather than looking at it from a witness-based framework.

So, looking more at the structural system conditions in our society that can lead to some concerns and not so much looking at prevention and preempting, because that has been a concern. As a parent that's a concern when I hear those questions.

So, just echoing what other people have said, that hopefully we can reword them or change these questions in a different way. Thank you.

DR. AISHA DICKERSON: I just have a question about the process. What will happen is there's a list of questions and we will have time to think about better ways to rephrase them. Is that how it will work?

DR. DANIELS: More than rephrasing them. You will have an opportunity to reflect on the content in each of these areas, give us suggestions like the ones that you have given. We are taking notes on what you're saying here so we will have that, but you can take some more time to think about each of these areas and what you think are major advances that have been happening in these areas, major gaps in these areas, if you want us to reframe how we're thinking about some of these questions.

I think this has been an incredibly rich discussion so far in just a short time and is very helpful, but you will have an opportunity to reflect. And we will try to make sure that your windows for the web form are big enough that you can provide feedback on these different areas.

From Hari: "My comment No. 1, Questions 5 and 6 has to consider access issues from across the spectrum, race, gender, et cetera."

I think that is just saying that those issues need to be considered. Yes, they could be considered for 5 and 6 and they also could be considered across the entire Strategic Plan, which also has been discussed.

"Aging autistics is a crisis waiting to happen, so needs lots of looking into. We will be coming into aging with health conditions, a higher risk of dementia, Parkinson's, according to NIH studies, overuse of psychotropic medications over lifespan for behavior management which can cause their own long-term side effects, the lower level of family supports as family members die, and plus, all the issues that neurotypical aging populations face." Thank you for that input.

And then, "Question 1 assumes the diagnosis only during early intervention age, but not everyone has equal access to diagnostic resources and diagnosis can happen later." The previous committee put issues related to adult diagnosis in Question 6 and wanted to keep Question 1 focused on the pediatric population at the time, but we can change some of those things, although that would impact some of the tracking if we start lumping all of the diagnosis together, so we would have to think about some of those things as we shift things. But there were some other suggestions, too, for that.

Thank you so much. If it’s okay, I am going to move on because there are some other questions that I want to ask the committee to weigh in on regarding the Strategic Plan.

Congress requires the Strategic Plan to have a budget recommendation in it, and the 2016 and 2017 IACC Strategic Plan called for a doubling of the 2015 research budget that covered both federal agencies and private partners because that is what the IACC tracks.

The reason we track it that way is, at the very beginning when the IACC was first starting, the committee, being made up of members from the public who are parts of various organizations that are conducting or supporting important research as well as federal agencies, did not want to ignore the important contributions of nonfederal organizations, and so we look at all of the federal and nonfederal organizations in our counting. That is why this considers not just the federal budget but all of the organizations that we're tracking together and use that as an initial estimate.

And so, with that, if it actually doubled from 2015, we would have gotten to $685 million by 2020, and this would have been about a 15 percent annual increase in ASD research across combined federal and private funders. At the time they did discuss in the committee that this was an ambitious goal, but they felt they wanted to set a high goal and not undershoot on that goal.

With the data that we have collected so far -- and right now our team is working on the 2019 and 2020 data so they are not in yet, but with the trend that you can see, of course, the funding has not been at the 15 percent annual increase level. It has been increasing but at a slower pace.

We wanted to get any suggestions about what we should do with the budget recommendation for next time. If you would like to just extend it for more years and stay on the same track of trying to reach $685 million, or if you have a different idea about where to go with the budget recommendation. I would like to open that up. Stephen?

MR. WHITLOW: Just a quick question with regard to counting. How do we go about counting and identifying funding that's going on in non-governmental entities? How is that tracked?

DR. DANIELS: Our office collects that information from non-governmental organizations that have partnered with us, many of whom have representatives on this committee and others that are not represented on the committee that have been very kind partners to us and they provide us with their research project data. So all of that is in the autism research database which is on the IACC website. Right now it is updated through 2018, but we are in the process of analyzing the 2019 and 2020 datasets.

MR. WHITLOW: Thank you.

DR. DANIELS: Any other comments about what you would like to do with the budget recommendation? Helen?

DR. TAGER-FLUSBERG: I think, given the expanded, ever-expanding needs that the IACC is focusing on and is going to be incorporating into the Strategic Plan, it seems like to go in with a recommendations that remains static would be to undermine the perspective that, in our view, the needs are increasing and the scope of what we need to be doing is larger.

DR. DANIELS: I was not completely clear. What is your suggestion?

DR. TAGER-FLUSBERG: My point is no, we should not remain static in terms of our budget, but our recommendation ought to reflect the expanded scope of what we anticipate will be going into the Strategic Plan. New needs need new funding.

DR. DANIELS: Thank you. Next, we have Dena.

MS. GASSNER: First of all, Helen, I agree with you 100 percent, because we haven’t even begun to unpack the implications of COVID, and I think we are going to see significant needs happening during these transitions in the many months that people have gone without services. They have regressed in terms of access to that kind of support.

Anecdotally, I know my son is still unemployed 24 months after leaving college, not because he is not employable but because of Covid. He is healthy and emotionally well balanced and stable in that, but that is not the case for everybody. So I agree with you. I think as we start to recognize more and more the under-diagnosis of so many populations, suggesting that there is a need for greater research around intersectionality and the implications of COVID, I think a higher rate would be appropriate.

But I was wondering if we might be able to delineate in this particular chart or the subsequent chart, the portion of money going to research that looks at biology versus service delivery. I know we made strong recommendations for more funding for service delivery and life course outcomes, but we didn’t get the money we had requested, so can we do something like further inform that?

DR. DANIELS: That has been analyzed. In the 2017 and 2018 portfolio analysis report you will see a pie chart that shows you the distribution of funds. But something that is important to understand is it’s not like there’s a giant bolus of autism-labeled money that just comes in and everybody decides what they are going to spend that money on. In federal agencies, each agency gets its own appropriation and then, within the agency, they may have certain programs that are already funded, and so if there is an increase in appropriations, they have some flexibility about what to do with that. But not too often do they want to really take away from existing programs to focus on something different.

It is challenging. It’s not that all this autism money is there, and it’s not being divided differently; it really is being parceled out to different agencies according to their own appropriations. And with the private organizations they each decide based on their constituencies and so forth how they are going to allocate their funding. But everyone has different strengths and mission areas.

That is more explained in the Portfolio Analysis Report. Sam, do you have comments?

MS. CRANE: I want to reinforce what Dena was saying about addressing not only the total level of funding but the re-balancing question. I respect that agencies generally don’t want to stop funding things they are already funding, but then we need to make sure that new funds go toward underserved topics of research that have not been getting adequate funding. If we can’t do that, if we don’t get enough additional funding or the additional funding isn’t adequate to achieve that re-balancing, then we do have to recommend that agencies reconsider their portfolios. Our role is to make recommendations about what the priorities are for research and to identify areas that are not being funded in relation to their importance to the community and I think we would be neglecting our role if we didn’t consider addressing that.

DR. DANIELS: You are correct that it’s the role of the committee to make recommendations that go out to the agencies and to the community about what these priorities are, so the committee, as you deliberate, will be making recommendations about what you think are the priorities. Actually, on my next slide I have a question about that. Scott?

DR. ROBERTSON: I just want to say that I concur with what was being shared earlier about some of the other focuses of research and making sure that there is an alignment with that, but it is not just about the numerical value for the money, it’s not just about the numbers, it is also about the priority focuses that are at hand.

I think part of our charge for this should be also again looking at the Autism CARES Act with the reauthorization in that priority focused on quality-of-life and that it should crosscut across all new research foci.

But at the same time, as was mentioned, the underrepresented population in terms of race/ethnicity, gender, gender identity, sexual orientation, socioeconomic status, et cetera, which AAC use is very heavily under-researched, especially inclusion of AAC users and access to AAC and impact on health and wellbeing. There are a number of examples of focuses that just have not received a high priority from research.

And I know this is challenging. I appreciate especially what you laid out, Susan, as far as each agency has their own appropriation in terms of money they are given by Congress and they have their own priorities internally and then discussions, and there are complex activities that happen that we may not see that happen internally where they have to balance things out. And similar work happens in the private sector as well, and industry, in terms of foundations, et cetera, that are funding research.

But at the same time, I think it is definitely our priority as a committee, to lay out strong recommendations and to be bold about that, to emphasize, in alignment with changes to the Autism CARES Act and lifespan focus, what would be good to see with research as it is moving forward and as research priorities are increased.

If I remember right, the Autism CARES Act, the reauthorization in 2019, also increased the amount that could be authorized by Congress, and then, obviously, Congress will appropriate what they choose to appropriate. So you are already seeing those increases at times I think; you’re just not always seeing it explicitly tied back to the focuses in the law and that are important to stakeholders for quality-of-life, health and wellbeing, access and opportunity.

Basically, the focus that we have been bringing up already across this meeting and in prior IACC meetings is that the research should align with that. I think our recommendations will be considered in some kind of form across the agencies and private organizations, and I think the bolder we can be about emphasizing, as I say, making sure the research is actually empowering folks to have greater opportunities in life and live a quality-of-life and have self-determination and have the access and opportunities that fit what they want to have with their own ambitions, dreams, skills and talents in life and access to the community, I think we should strive to do that with the recommendations that we have through the Strategic Plan as sort of a way of helping inform what happens at agencies and outside of government as far as the research funding.

I would say as strong a signal as we can say with what we have already been discussing, to try to work that into research. I think in that way we can build upon what the last strategic plan did as far as the increase. I could be wrong, but I gather that part of their reasoning for that increase is, again, these under-focused topics that haven’t been research that well historically but could be in the future.

And one of the reasons, just a last quick point so everyone knows here in the committee and elsewhere, just to elaborate that one of the reasons that researchers often don’t study things is because they are not being funded, right? It’s a business, too. Research is just like any other form of work.

So I think as the funding increases in certain areas you will see more researchers jumping in to study them, and researchers would value it more. Some researchers, obviously, are also doing it because they think it needs to be studied, but I think you have a significant portion of folks in the research community that, once you fund it, it will get studied. Just to put that out there.

DR. DANIELS: Thank you, Scott. Of course, we do want the committee to be thoughtful and bold, and we expect that will happen. Really appreciate the comments.

DR. GORDON: I don’t want to derail the thread too much, but I feel it’s important that people understand the appropriations and authorization process. Consistently, Congress has authorized expenditures for autism care and research to increase, but consistently they have not appropriated the dollars at the levels that have been authorized. I think there is a disconnect between what is authorized to be spent versus what is actually appropriated to be spent.

I recognize this graph is $600 million and represents a doubling of the total research budget, but if we were to spend $600 million of NIMH’s budget on autism research, that would be one-third of the NIMH budget when we’re supposed to be studying lots of other things. The NIMH budget did not double from 2015 to 2020, and so the amount of resources available for autism research, at least federally, did not double over that period, even though the authorizations might have.

One other quick point here is that the recommendations about focusing more research dollars on more of the quality-of-life issues, as several people have suggested, that is certainly within the purview of the committee, so I don’t want to suggest that you can’t do that. That would be a recommendation that would absolutely have impact. That is all I wanted to interject.

DR. DANIELS: Thank you for those clarifying comments, Josh. Next, I will go to Ivanova.

MS. SMITH: I would just like to say I think it would be really good to have some research on the impact of institutionalization on autistic people and how that affects trauma response.

DR. DANIELS: Thank you for that input. I have a comment from Hari. Hari says, "In the biology group we need more focus on comorbidities as these really impact quality-of-life, lifespan, than just a drive with genetics with respect to funding." I think that is the last comment. These are very helpful, and again, we are taking note of them.

It sounds like you have answered some of the questions I have on my next slide. Maybe this is something more you can answer when you get your questionnaires in the committee. For people out in the public you can share your opinions through the request for public comment.

If there are areas that should be a focus in terms of any changes in the budget recommendation, let us know what you think. The last time, treatments and interventions, evidence-based services and lifespan issues were three areas the committee wanted to emphasize, but those might be different in the next strategic plan. So, we can bring back what you hear from you all next time.

I will talk about the statement on duplication of effort. In the law it also says that we need to have a statement about the duplication of effort, or lack thereof, in the Strategic Plan. It says they would like to see recommendations to ensure that the autism spectrum disorder research, services and support activities, to the extent practicable, of the Department of Health and Human Services and of other federal departments and agencies are not unnecessarily duplicative.

To address this in the last Strategic Plan, the committee did the following. They talked about cooperation and collaboration more as a conceptual or abstract idea, but the idea that cooperation and collaboration are not the same as duplication, helping define that. Talked about the scientific process requiring replication or reproducibility, and talked about how, in looking through the portfolio, didn’t see instances of duplication but did see gaps in research. So that is what was summarized basically from the statement of duplication of effort last time.

So for this time, I want to hear any suggestions you have for what should go in this section this time and some thoughts where we could talk about any duplication that is identified, if there is any, or the lack of that duplication. We could give examples of gaps in autism research, services and support activities. We also could potentially give some examples of interagency coordination and public-private partnership efforts that are sort of the opposite of duplication because they create synergies and help us to collaborate and avoid duplication.

But I wanted to hear your thoughts and see if you have any other ideas for what should go in this section.

MS. GASSNER: Based on my practice experience at the grass roots level, I am actually leaning in a different direction in that there doesn’t seem to be a unified partnership on hardly any surfaces. It is very difficult to navigate people through these systems because they are so disenfranchised from one another. I have clients that apply for Social Security, then they have to apply for housing over here, then they have to go there for SNAP, instead of there being some kind of means where these agencies could collaborate, or we could create master systems of information that would examine eligibility for services with a single application. I would love to see that kind of interagency collaboration, and that could have an immediate impact on the lives of autistic people.

On the other side of that coin, however, we see a trickle-down of implications when something isn’t going well with one agency. For example, if you get an overpayment from Social Security, SNAP taps you right away for having too much money. So the punitive part is interagency, but the accessibility part doesn’t seem to be functioning that way in my practice settings.

I would love to see something involving that kind of collaboration.

DR. DANIELS: Thank you for that feedback. Alice.

DR. CARTER: I agree with what was just said, and what I was going to say is sort of prioritizing evaluations of services that enhance current delivery systems. I feel like there are a lot of intervention grants that are done outside of existing service systems, and that I think may promote more lack of coordination; whereas, if you try to implement evidence-based practice within existing services or the focus of the intervention is actually to promote coordination and communication, I feel like if it works, you need to show that it works, but if it works, I feel like you could have really dramatic impact quicker because then you don’t have the whole 17 years or whatever it is of dissemination to get it to the sites you want the evidence to be impacting.

DR. DANIELS: Thank you for that suggestion. We have some other discussions that we wanted to have on language, and I know many members of the committee are interested in that topic, and perhaps if we have any extra time tomorrow, we could come back to it, or else we can come back to it in another meeting. I think at this point, though, we probably should wrap up for the day.

MS. GASSNER: I would like to vote for this being a priority tomorrow, because I just don’t want to hear disorder all day tomorrow again, to be honest about it. Thanks.

DR. DANIELS: We can try to find if there is some time toward the end of the program tomorrow. We have time for a round-robin, which we could defer and talk about language if we want to, or we could save that for the next meeting. I know that might be an extensive discussion as well. We really appreciate all the thoughtful comments.

Josh, do you have some closing comments for the group today?

DR. GORDON: I really appreciate the free exchange of ideas and opinions and thoughts. This is clearly a group that is not shy. I do notice, though, that the discussion today has not been uniformly distributed throughout the group, so I encourage those of you who have been shy, to participate to speak up and to let us know overnight how we did in terms of facilitating communication for those of you who have challenges. Looking forward to seeing all of you tomorrow.

DR. DANIELS: Thank you so much for the robust discussion and all the useful input and notes that we have been able to take on today’s topics. We look forward to having you back tomorrow. We are going to start at 1:00

p.m. Eastern time and go until 5:00 o’clock, and we have some exciting presentations on wandering and law enforcement-related issues on mental health, and we will be talking about the public comments, and please refer to the public comments that are posted on the website before the meeting.

Thanks so much for being here, and we hope that everyone has a wonderful afternoon.

(Whereupon, at 5:04 p.m., the meeting was adjourned.)