INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, JANUARY 19, 2022

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 10:00 a.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

PRESENT:

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

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

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

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

SKYE BASS, L.C.S.W., Indian Health Service

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

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

AISHA DICKERSON, Ph.D., Johns Hopkins University

PRESENT: (continued)

ANITA EVERETT, M.D., D.F.A.P.A., Substance Abuse and Mental Health Services Administration (SAMHSA)

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

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

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

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

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

CRAIG JOHNSON, B.A., Champions Foundation

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

ALICE KAU, Ph.D., National Institute of Child Health and Human Development (NICDH), (representing Diana W. Bianchi, M.D.)

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

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

YETTA MYRICK, B.A., DC Autism Parents

LINDSEY NEBEKER, B.A., Autism Society of America

PRESENT (continued)

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

MORENIKE GIWA ONAIWU, M.A., Rice University

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

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

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

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

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

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

ROBYN SAGATOV, Ph.D., M.H.S., R.D.N., Agency for Healthcare Research and Quality (AHRQ) (representing Kamila Mistry, Ph.D., M.P.H.)

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

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 School of Medicine

IVANOVA SMITH, B.A., University of Washington

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

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

HARI SRINIVASAN, University of California, Berkeley

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

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

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University Medical Center

DEBARA L. TUCCI, M.D., M.S., M.B.A., F.A.C.S., National Institute on 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

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

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PROCEEDINGS

DR. JOSHUA GORDON: Welcome. Good morning, everyone, and happy new year. I am Joshua Gordon, Director of the National Institute of Mental Health and the Chair of the Interagency Autism Coordinating Committee. It is my pleasure on behalf of my fellow IACC members and of Dr. Susan Daniels, the Director of the Office of Autism Research Coordination at NIMH and the Executive Secretary of the IACC. It is my pleasure again to welcome you to this meeting of the Interagency Autism Coordinating Committee.

We will proceed in a few moments with the roll call and approval of minutes. But I just have a few announcements beforehand. Before I get there, let me remind all the members of the IACC that when you are speaking, please activate your videos and unmute yourselves. And when you are not speaking, please unmute yourself. But you can leave your videos on at least when there is not an active presentation.

Some brief announcements. We have had some changes in membership since the last meeting even though this is a nascent committee. This is the third meeting of this version of the IACC. We have had some changes already.

As many of you may have heard, my boss and friend, Dr. Francis Collins, has stepped down from his leadership role from his being NIH Director, as of last month. He has always been very supportive of our autism efforts, and we will miss his leadership. Dr. Larry Tabak, who is serving as the Acting Director of the National Institutes of Health, is officially a member of this Committee, acting in that stead, and will be until a new Director is appointed by the President. Dr.

Tabak unfortunately was not able to join us today but will plan to join us at our next meeting in April to introduce himself. In the meantime, Dr. Courtney Aklin will continue to attend meetings on behalf of the NIH Office of the Director. Thank you, Dr. Aklin.

Also, we have a new member from the US Department of Labor, Taryn Williams, the Assistant Secretary for the Office of Disability Employment Policy, is joining us as a member. We appreciated Dr. Jennifer Sheehy’s participation on the IACC on behalf of the ODEP previously and we look forward to continuing collaborations with her, Assistant Secretary Williams and ODEP in the future.

Taryn spoke to this committee at the last meeting to share updates from ODEP. But if you would like to take a few minutes to introduce yourself again, Taryn, that would be great.

DR. TARYN WILLIAMS: Hi. Good morning, everyone. Hello, everyone. I am Taryn Williams. I am glad to be with you here again this morning. As you heard, I am the Assistant Secretary of the Office of Disability Employment Policy. I am looking forward to our continued participation on the IACC. I know we are also joined by a senior policy advisor from our office, Dr. Scott Robertson, who has been actively involved with the IACC for many years. Thanks so much.

DR. GORDON: We know Scott well. Thank you both for joining us.

Lastly, we have a retired departure from the committee. Dr. Valerie Paradiz, who was with Autism Speaks and is a public member of the committee, has retired and stepped down from the IACC as part of that retirement. We expect that the secretary of HHS, Secretary Becerra, will identify another member from the existing pool of nominees that applied to serve, and we expect that that will happen relatively soon. We hope certainly by the next meeting that we will have an additional member to replace Dr. Paradiz. Stay tuned for updates in the future.

Today’s program is really exciting. I am very pleased that we are going to have presentations from the Social Security Administration about their disability programs. That is always interesting to hear about the latest updates. From the CDC about their recent autism prevalence data releases, which I know is of interest to many on the committee and also to many of the public tuning in today and from Dr. Cathy Lord, one of our esteemed autism researchers at NIMH and in the broader community. She is not at NIMH but funded by NIMH. And other institutes across NIH. Dr. Lord will be, however, representing the Lancet Commission on the future of care and clinical research for people on the autism spectrum. As many of you know, the Lancet Commission recently published its report, full of recommendations. We are glad to be hearing from Dr. Lord and we will hear the opportunity to discuss some of those recommendations after Dr. Lord’s presentation.

We also have a lot of work to do as a committee on two of our key assignments, refining and revising the IACC’s Strategic Plan and finalizing the 2021 IACC Summary of Advances. And Dr. Daniels will lead us through those two work items at different points during today. And of course, we will also, as usual, have the opportunity for public comments and the opportunity to discuss those comments as a group.

With that, I am going to turn it over to Dr. Daniels who will do roll call and approval of the minutes.

DR. SUSAN DANIELS: Thank you, Dr. Gordon. In fact, for roll call, we are just going to be looking through the Zoom room and taking notes on who is here. But those who are in Zoom can see the attendance. And then when we are having discussion periods, people can feel free to turn on your cameras if you would like. I know that sometimes for some people, Zoom is a little stressful. If that is the case, you do not need to turn on your camera. You can leave it off. But we still welcome your comments and you can provide those comments verbally, or if you need to do so in writing, use the chat to contact the contractor or staff that we have here to help us with any kinds of written comments that might be needed as a disability accommodation.

I am also going to let you know that today we are going to try for the first time using Zoom polling to get opinions from the committee. Because it is such a large committee, sometimes it is difficult to gauge people’s opinions just by people raising hands because we are a big group. We are going to try the Zoom polling. For those who are in our viewing audience online, just be aware that you will not be able to see the Zoom polls. The people who are in the actual Zoom room will be able to see them. But we will describe them for you. After the fact, we will add them onto our website so that people can see what those Zoom polls look like. But we will tell you about them as we go along. This will be experiment.

For people who are members of the committee or alternates representing someone who is not here who is a member of the committee, you all are welcome to participate in polls and anyone else in the Zoom room who is just observing, please do not participate in the polls.

With that, let us move on to the approval of the minutes. Everyone has access to the October draft minutes that are online and the instructions were sent out to the committee in terms of how to access our materials. We have received a couple of corrections from JaLynn Prince. I do not know if there are any other corrections. But can we have a motion to accept the minutes with the corrections that we have received so far?

DR. SUSAN RIVERA: I move to accept the minutes.

DR. DANIELS: Thank you. Can we have a second?

MS. YETTA MYRICK: Yetta Myrick. I second.

DR. DANIELS: Great. Any discussion that we need to have before we would be able to accept the minutes? I am not seeing a raised hand. All in favor? Can you just hit your raise hand button?

DR. LARRY WEXLER: Susan, where is the raise hand button? Some of us are not used to Zoom.

DR. DANIELS: Sorry. And I should have done this as a Zoom poll actually. I did not think of that. It is in the reactions at the bottom of your Zoom screen. You hit reactions and at the bottom it says raise hand. Thank you. We will do it as a Zoom poll next time. That will probably make it easier. It looks like I have a majority of the committee voting to accept the minutes. You can put your hands down. Is there anyone who is opposed to accepting the minutes? If so, raise your hand on Zoom. That is good. Everyone, put your hand down if you were in favor. Now, we are taking opposed. Larry, I am assuming that you are not opposed, but you are just still putting down your hand. We do not have anyone opposed. Is there anyone who wants to abstain? I have one or two people who want to abstain. With the majority, this passes. We will accept the minutes with the comments that JaLynn Prince sent in. If anyone else has any last-minute corrections, you can feel free to just email us those corrections and we will make sure they get in. We will post the minutes on the website after the meeting. Thank you very much. I will turn it back over to Josh.

DR. GORDON: Thanks, Susan. Thank you, everyone, for participating in that formality and important formality as we want to make sure we get the record of previous meetings correct. And all those meetings are posted on the website.

It is really my pleasure then to get the programmatic aspect of our meeting underway. It is my pleasure to introduce Dr. Jeffrey Hemmeter, the Acting Deputy Associate Commissioner in the Office of Research, Demonstration, and Employment Support in the Office of Retirement and Disability Policy at the Social Security Administration. Dr. Hemmeter is an economist and helps design, conduct, and oversee research, evaluation, and other policies related to disability and return to work. We are really excited to hear Dr. Hemmeter’s presentation on the Social Security Administration and the Autism

Spectrum: Disability Insurance, Supplemental Security Income, and Work. Dr. Hemmeter, thanks for joining us today. We really appreciate it.

DR. JEFFREY HEMMETER: Thank you and thanks to Dr. Daniels also for inviting me to speak with you all today about our programs and policies. My goal in the time I have is to share what SSA is and does kind of level set on that and discuss how some of those policies are related to autism. These programs are vast and complex and I cannot cover all the nooks and crannies of the programs. But I hope that this will provide a good overview about how the program should generally work. If I use improper terminology, I want to apologize upfront. I am intending these terms as SSA uses them. I will touch upon a little bit the current developments with Social Security’s current posture towards the public and COVID. But I will not be saying anything that is already public just because there are negotiations and things going on of that nature.

Of course, I also need to say that anything that I say is not the necessarily opinion of the Social Security Administration or the federal government.

I want to start just by highlighting that SSA is an independent federal agency. It is not part of HHS, Labor, or another department. We have about 60,000 employees and most of these employees provide direct service to claimants and beneficiaries through over 1500 field offices, also payment centers and tele-service centers. In addition, SSA contracts with every state’s disability determination service, funding about 15,000 physicians responsible for making the first disability determinations for any claims that we receive.

SSA has two primary programs, the old age survivors and disability insurance program, typically referred to as Social Security and the supplemental security income program or SSI. Social Security is further split between old age survivors’ insurance program and the disability insurance program for accounting purposes. I will probably refer to DI and SSI a lot in this.

The disability insurance program or DI pays out about $144 billion in benefits to individuals who qualify and those include both disabled workers, which is the category of individuals who is entitled to a claim based on their record, their own history, and then there are also auxiliaries and dependents. Those can be categories as disabled adult children or disabled widow(er)s depending on what the particular roles are. I am not going to get into all of that. But those are the three main disability categories in the disability insurance program.

The SSI program pays out about $56 billion in benefits to children, adults, and the elderly. Children and adults are required to have a disability and the elderly are not. But there are significant differences between these programs. I will point those out a little bit later.

I want to give you a little background about SSA's workload, what those 60,000 people do. SSA fielded about two and a half million initial disability claims in fiscal year 2021. The average claims take about 171 days to adjudicate by the disability determination services. If an individual does not agree with an initial denial, he or she can appeal for a second review by the DDS or the disability determination service and can further appeal that for a hearing with an administrative law judge or ALJ. SSA holds about 400,000 to 500,000 hearings a year. Usually these take about 310 days on average. If a claimant still does not agree with the decisions from the hearing, the case can be appealed to the Appeals Council and then to the federal court, public and supreme court.

In addition to that work, SSA fields about 36 million calls to its national 800 number. It conducts an additional 1.6 million continuing disability reviews, including about 500,000 full medical reviews and over 2 million non-medical redeterminations of SSI eligibility. These are really designed to ensure that people are still eligible for the program after that initial decision.

But there is more. There are OASI claims, old age survivor claims. There are enumerations or the assigning of Social Security numbers, processing earnings reports, forwarding Medicaid and SNAP applications, states taking in death reports and other workloads. All of that to say, SSA has significant workloads touching the lives of Americans from birth to death.

When you file an application for disability benefits, we always check eligibility for both programs with DI and SSI. The same medical requirements apply to both programs. But the nonmedical requirements differ. This chart is just a highlight of the main differences between the programs. Just to cover a little bit of it, the DI payments come from the disability insurance trust fund and are based on past earnings of either the individual or the person they were dependent on and it is funded through FICA contributions. It is a social insurance program.

SSI payments on the other hand, come from the general treasury. They are not tied to past earnings and it is a needs-based public assistance program. DI pays benefits to people who cannot work regardless of their resources and other income. But SSI does have very significant limits on income and resources, and I will talk a little bit about that in a minute.

This slide shows the different steps in the disability determination process. I want to note that financial eligibility such as your asset level for SSI or your insured status for DI generally are determined prior to the disability determination and are usually done by the field office.

There is a three-step process for determining whether a child has a qualifying disability and for adults, it is a five-step process. But they are intended to be very similar. For both children and adults, the first step is actually just to check to see if they have earnings above what is called the substantial gainful activity level. If they do not, then they go on to the second step and that is where they determine if there is a severe impairment.

For children, the third step is to determine if the disability meets or functionally equals the medical listings. Those listings are a list of medical conditions that SSA considers severe enough to prevent substantial gainful activity or causes marked and severe functional limitations.

For adults, the third step is similar to that for children, but does not include the functionally equal check. Instead, a fourth step determines if the individual can perform the past relevant work. Finally, a fifth step determines if an individual can perform any work in the national economy.

I want to return to the definition of disability. These are statutory definitions. They are different in most cases and more restrictive from those used in other programs. I want to highlight the differences between them. For adults, which is the one on top here, it is again the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. It is intended to be something that is both medically determinable, long lasting, or ending in death and needs to prevent substantial gainful activity.

For children, really the only difference is instead of the substantial gainful activity, it is an impairment that causes marked and severe functional limitations. Marked in a sense is the equivalent of the functioning we would expect to find on standardized testing scores that are at least two but less than three standard deviations below the mean. An extreme limitation or severe limitation is the equivalent of a functioning level that we would expect to find if there is a standardized test with scores that are at least three standard deviations below the mean.

The Blue Book, as it is called, describes the process for health professionals and so formerly called the Disability Evaluation Under Social Security. There is a webpage listed at the end of the slides.

It lists specific criteria under which claimants can qualify for specific benefits. I mentioned these before as the listing. It is important to note that these listings are really just shortcuts to making a disability determination. They are not the only way to qualify for benefits. There what has been prior – in many cases, have that level of criteria has been met. Then people have generally been found to be eligible for benefits and if it causes marked and severe functional limitations or prevent substantial gainful activity.

This is a summary of the autism spectrum listing. As you can see, they are very specific. It requires both a qualitative deficit in verbal communication, nonverbal communication, and social interaction and significantly restricted, repetitive patterns of behavior, interests, or activities.

In addition to that, it also requires an extreme limitation or a marked limitation in two of the following areas of mental functioning, which are understand, remember, or apply information, interact with others, concentrate, persist, or maintain pace, and adapt or manage oneself.

I wanted to include this because this or the equivalent of a person with autism and no other condition will need to medically satisfy to qualify for DI or SSI. It is really targeted toward individuals at the end of the spectrum facing most severe barriers. I should note that SSA will look during its determination or DDS will look during their determination at the entire medical history of an individual. It will seek out additional evidence than what is in its folder, including – as long as something is alleged, we will try to find evidence for it. If we cannot find evidence in medical records, there are consultative examinations that will try to obtain a diagnosis because, again, it has to be medically determinable for these things.

The next slides really just show the outcomes for claims of autism through the determination process. These go back to 2019. As I said, the process takes a while to go. These are the – what happens with children on this slide. I think for children applying for SSI, about 75 percent or close to three-quarters of claims with autism are allowed. About 25 percent of those that are appealed to reconsideration are allowed. And then about 42 percent of those that are further appealed to the ALJ level are allowed. But the numbers do drop off significantly at each level.

For adults, the numbers are different, but they are qualitatively similar. And these are subject to any kind of data issues. If somebody did not claim autism as an impairment but they are on the spectrum then they would not be in these numbers.

The next slides I would like to skip. They are just the adult numbers equivalent of that. I think the big point of those is really that it is the volume is less, but the outcomes are qualitatively similar.

This slide is about the SSI payment rules. Payments are capped at a monthly federal benefit rate. It is currently $841 for individuals and $1,261 for a couple. This is reduced by $1 for every $2 of countable earned income above $65 and $1 for every $1 of countable unearned income above $20. Also, an individual is restricted in the value of their assets, $2000 for individuals and $3000 for a couple. Those particular levels have not changed since 1989. That is a very long time and they are very low levels, but that is the legislation.

There are lots of exclusions though to what these are so I use the term countable. We do not count things such as a person’s home or the value of a person’s home, their first car, or their primary residence. But there are also rules about counting the income available from other people. A spouse or a parent, for example. We will count some portion of their income as available to the SSI recipient. There is also in-kind support and maintenance that people might receive with the people that they live with and the like.

One important note again that I want to point out is basically everything on this slide is determined by legislation, not by SSA. There are regulations that will adjust the federal benefit rate, but other than that, everything is set by legislation.

The DI program on the other hand pays people based on a primary insurance amount. This is calculated based on past earnings and has some complex formulas that I am not going to go into, that makes it more progressive in its structure.

As I mentioned before, there are auxiliaries that can – dependents who can receive benefits based on somebody else’s account. It is a family-based payment, but there is a family maximum. But in general, the beneficiary will receive their full benefit no matter how high their earnings are during what is called a trial work period.

That is the first 9 months in a rolling 60-month window where earnings are greater than $970 this year. That is the level, the trial work period level.

Once those nine months are used up, the benefits are suspended and if the beneficiary performs substantial gainful activity or SGA. SGA, while it is not technically a dollar value, it is taken to be $1,350 for non-blind beneficiaries and $2,260 for blind beneficiaries. Again, while there is a regulation that changes the levels per legislation, those are generally set by law.

If after 36 months in this extended period of eligibility, the beneficiary is working above SGA, benefits will be terminated. That is the gist of the SSI and DI programs. Go to the next slide, please.

This slide just provides some numbers of how many people are receiving SSI and DI with a primary diagnosis of autism. There are about 215,000 children receiving SSI who have a diagnosis of autism. That is about 20 percent, a little less than 20 percent of all the children who are receiving SSI. Comparatively, only about four percent of adults receiving SSI have a primary diagnosis of autism and only one percent of DI beneficiaries have a primary diagnosis of autism. But that does vary by entitlement category with over 6 percent of what is termed disabled adult children receiving DI benefits having a primary impairment of autism. I was not clear about this, but disabled adult children – they are adults who first had a diagnosis before age 22, and generally are not married unless they are married to another disabled adult child, but they are receiving a benefit based on a parent who is also receiving a Social

Security benefit, which could be retirement or disability of their own.

In general, SSI payments to people with autism are above the average SSI payment while DI benefits to people are below average. But, again, it varies by eligibility category.

I should note that these counts likely underestimate the number of people with autism in each program because of the way SSA data is collected. While full medical history is considered, the main data systems just record a primary and secondary impairment and official statistics just go by the primary impairment listed. Autism of course could be the secondary impairment listed or it could not be listed at all if it is the third impairment or the fourth impairment. But it all just really depends on how the disability examiner records the findings.

Next slide please.

The bulk of the rest of the presentation is really about working. And the big point I want to drive home is that, yes, DI beneficiaries and SSI recipients can work. There are a lot of program rules to support work and they are summarized in what is called the Red Book. If you can see my picture, it literally is a red book. It can be found also online and in addition to hard copy formats that could be mailed out if requested. There is a link to it also at the end of the presentation.

Next slide, please.

I want to cover some of these work incentives. There is a lot that are listed on these slides, but I am only going to cover a couple of them at a very high level. On this slide, this talks about the continued payment under VR or a similar program. It is also called Section 301. If you are receiving benefits and have a medical CDR or an age 18 redetermination and you lose your eligibility for DI or SSI, you can continue to receive benefits for the duration of any vocational rehabilitation program or similar program, which also includes an individualized education plan.

This requires a specific application, and it is actually superseded by other program policies such as statutory benefit continuation, which would be the continuation of benefits during an appeal in general. It is not widely used, but it is something that is available.

Also, for SSI, if you are under age 22, most earnings will actually be excluded from SSI calculations. It is up to a little over $1,800 a month, up to almost $7,400 per year. But it should be automatic. It comes before the different – all the other things that is supposed to come off right at the top. It should be used more than it is, I think.

Next slide, please.

For DI and SSI both, we also do not count impairment-related work expenses for work. Things like transportation costs, service animals, medical devices, and lots of other things that are needed for an individual to work are excluded from both the SSI monthly payment calculation and the SGA determination.

Also, if an individual leaves DI or SSI because they returned to work, they can return through an expedited reinstatement process if they need to come back to the program in five years. They will get immediate payments for at least a period of time, but there are some conditions. They must have the same medical condition and meet a few other conditions.

All of these work incentives are designed to mitigate some of the risks of going to work and some of the concerns about returning to work that individual may have if they are receiving benefits and they are not able to continue to receive to stay off the program.

Go to the next slide, please.

In this slide, I really only want to talk about the second set of bullets there of Section 1619(b). That is the provision of the SSI program that allows an individual to continue to receive Medicaid even if their SSI eligibility ends due to work. There are different state-specific earnings thresholds. It is up to $40,000 I believe in Connecticut - it varies a lot. But it is - one thing that we do hear a lot of is that people are interested in SSI a lot for the connection to Medicaid. There are ways to continue to receive Medicaid even if you are working.

Next slide.

The only one I want to talk about here – the first two are a little bit more complex. I am happy to go into them if there are questions. But I really want to note the Achieving a Better Life Experience or ABLE Account. Those are not SSA policies, but they are similar to 529 plans for colleges. But they have a broader expenditure allowance. But an individual can have up to $100,000 in these tax preferred accounts. And it will not count toward SSI purposes. It does help mitigate some of the limitations on participating in the SSI program by that $2,000 limit that an individual has in terms of their assets.

We know that these policies are complex and that really reflects the laws that they are all based on. In each SSA field office, there is a work incentive liaison who can provide information about work incentives. There are also area work incentive coordinators or AWICs, who are responsible for work issues over a broader geographic area. These are SSA employees whose job it is to help provide information and support work incentives and issues. I do understand that not every SSA employee or field office technician will really understand all the depths of these rules. They have help internally.

But SSA also funds external organizations called work incentive planning, assistance providers. They provide benefits counseling and outreach to beneficiaries and to people interested in work or who are working.

SSA also funds agencies under the Protection and Advocacy for Beneficiaries of Social Security or PABSS program to help protect the rights of persons with disabilities related to work.

SSA has two major return-to-work programs, independent of the actual policies. Many beneficiaries are likely eligible for location or rehabilitation services and SSA will reimburse state VRs for successful outcomes defined as nine months working at that SGA level.

A beneficiary who does not want to work with VR or who can’t because of selection or a waitlist or any other reason, has the choice if they are over 18, to work with what are called employment networks in our Ticket-to-Work program. In the Ticket-to-Work program, SSA will reimburse these employment networks for specific beneficiary outcomes and milestones related to work. They are generally levels of employment or months without receiving benefits. But VRs have an option to get paid under the traditional cost reimbursement program or they can be ENs, it is their choice. But the ENs – I think there is about 600 or so of them now, that are private or nonprofit. Multiple other government agencies, state agencies can be ENs and support their budget by helping SSA beneficiaries.

Next side.

The next three slides highlight some of the limited research out there on SSI and autism. There really is not a lot related to DI and autism. I know I have missed some. I am not going to cover these, but I am really hoping that the slide deck makes it out to everybody. There are links there for all of these and a brief summary of each one of them.

The one that it is on right now mentions the Promoting Readiness of Minors or our PROMISE project. The Promoting Readiness of Minors in SSI was a joint work between Education, Labor, HHS, and SSA, to offer services to individuals who are receiving SSI and their families. The individual had to be ages 14 to 16. There were 11 states that were involved. We are getting ready to do the final report now.

But one of the reports that we did was or that came out, was just on how the services that were provided - what the impact was on individuals with a diagnosis of autism. There is some interesting research out there, but I am not going to go through each of these.

In the interest of time, can we go to Slide 26? How to Apply. Yes. That one. I want to just highlight how to apply for SSI and DI. Right now, field offices are closed. I am not sure when they are going to be open. If you are reading the newspapers, you probably know as much as I do. The only way to really apply is really by going online or by phone. Unfortunately, for children under age 18, you cannot apply for SSI online. You do need to call for that. The phone numbers are on the slide. The links will also take you to some instructions on applying.

SSA, also because of the pandemic and knowing that the field offices were closed, did really step up its information and its outreach efforts. There is a website that is dedicated to information for helping people helping others. This includes additional information about how to apply, what the programs are, other resources, how to help somebody apply, what you need to do, what you are not allowed to do as you are helping them apply, and what you can help them do. But it is a good resource for people to be aware of.

There are two other things that are not on the slide that I want to highlight, and a couple other things as well. I do want to note that we have a new research program called the Interventional Cooperative Agreement Program. This is a way to partner with SSA to test or demonstrate a new policy or program. We announced the forecast of the funding opportunities on grants.gov. If you are interested or if you can spread the word about that, that is great. It will be something where we can change SSI program rules. We can test new services. We can partner with people who are helping provide benefits counseling or assistance applying, all new ways of trying to test new policies and evaluate them to make sure that they work right.

Another thing, again, I want to reiterate is that much of the complexity of the program is based on legislation. SSA includes legislative proposals as part of its budget. If you never read our budget, it is a thrilling read, but there is a section on legislative proposals. And recent ones have included things like giving SSA the authority to refer beneficiaries to VR, which surprisingly, we do not have the authority to do. Allowing SSA not to count any earnings of youth. If you are receiving SSI and you are under 21 or maybe 24, we will not even count the earnings.

We have proposed changing the DI payment structure to a tiered structure of an all or nothing. We have proposed eliminating the complex in-kind support and maintenance rules for SSI. There are a lot of other changes.

But I want to highlight that changes like that cannot be done by SSA alone. They do require legislation as well as changes to those earnings limits or asset limits. I know this is a lot of frustration to a lot of people so I did want to mention that.

I also want to mention that as a result of the more recent – the pandemic and other kinds of things that are going on and recent executive orders, we are working on a better customer experience. We are working on a better internet option or online presence and online options for people to do things so that they do not need to come into the office. The field offices are not going anywhere. But we do want to make sure that we are meeting people where they are and giving them the services that they need and are accessible in that way.

And also, part of that is – part of our rules and regulations have historically required wet signatures. We are working on ways to eliminate the need for wet signatures on a lot of our forms, and that will go a long way towards helping us be more accessible in the 21st century.

The rest of the slides really are just a lot of resources, the Red Book, the Blue Book, a number of other fact sheets on disability determination, resources for professionals, and both medical and school professionals, and other things like the Ticket to Work program. We have a specific youth portal at ssa.gov/youth. It has a lot of information for youth receiving SSI and preparing for the age 18 redetermination of benefits where about I think 40 percent of children lose benefits at that age. We have a lot of resources out there. I hope you can all look at these. If not, please free to reach out to me directly. I am happy to share.

Again, I want to thank you all for your time. I am sorry if I went too long. I am able to answer questions too.

DR. GORDON: Thank you very much, Jeffrey. We appreciate all the information. We have just a couple of minutes. It looks like we have a couple of people waiting to comment. One of them I am going to read, but we will start with Paul Wang.

DR. PAUL WANG: Dr. Hemmeter, thanks very much for a really detailed presentation. I especially appreciate you mention of the ABLE Act and the ABLE Accounts, something that I hope as many individuals as possible will be able to take advantage of.

I wanted to just comment on the ASD listing. You showed a slide early in your presentation giving a summary of the ASD listing. It looks like it very closely parallels diagnostic criteria for autism. But it looks to me like it parallels outdated criteria. Specifically, the newest addition of the DSM-5, the diagnostic bible, if you will, includes sensory symptoms. Sensory symptoms can be very impairing for individuals with autism. It is now a part of the official diagnostic criteria. I suggest that the ASD listing should incorporate that.

DR. HEMMETER: Thank you. I will take that back to our Office of Disability Policy. I do not know what their schedule is for updating this particular listing, but I will note that. Hopefully, I copied the right one and not an outdated one. I will bring that back. Thanks.

DR. GORDON: Thank you. I am going to go ahead and read a question and comment from Morenike. I want to thank you very much for your comment. I am going to go ahead and read it word for word. Dr. Hemmeter, thank you for this informative presentation. I am writing to you as an adult on the spectrum, who is a parent of several disabled children, two of whom have DSM-IV-TR diagnoses of autistic disorder and one of whom was a previous SSI recipient. I want to share with you from a family perspective that whether or not it was intentional, communicating with the SSA can be very burdensome, speaking for myself. I sincerely doubt that I am alone. Your processes are often intimidating as well as cognitively inaccessible. My child was dropped off of SSI during the previous administration a few years ago before the pandemic despite still very much qualifying and very much still needing it. For whatever reason, at some point, you all sent new requests for a huge slew of documentation to "determine whether the child remained eligible". Most of the things they asked for are things I did not have and do not even know how to get. Several were not necessarily applicable to my child.

There was no concession to the fact that I am, myself, disabled and have difficulty with executive function and navigating the process of determining that you needed, requesting and requiring them, submitting them, et cetera. There was no way offered at all for me to communicate with a human being beforehand to gain clarification about what other items might be acceptable or whether it was okay to provide some and not all the items requested. None had to do with income or assets. They were various requests for records. Plus, do you have any idea how intimidating it is dealing with correspondence from the SSA?

Feeling helpless and uncertain how to proceed, I opted not to send the documents in and my child's SSI lapsed. My child also lost Medicaid as a result. Again, the diagnosis has not changed. The only difference was now you are all asking it again for documentation even though we had already gone through the evaluation process with SSA and it already had been approved upon initial application. No denials nor appeals. My child is autistic and is getting older and SSI Medicaid could have been a critical resource for them in young adulthood. Now, they will not have it despite still needing it. It is a problem and I know I am not alone. It needs to be fixed.

I do not know, Jeffrey. Do you have any comments or responses to that?

DR. HEMMETER: I do want to say -- I am sorry to hear that the experience was not good. I do think – I will take back the comments, particularly about making sure that things are not always accessible to the parents of individuals. For everybody who is involved, who was listening, what was described was a medical continuing disability review or an age 18 redetermination. This is part of what SSA does is when somebody is awarded benefits, we need to review the continued eligibility by law. These are CDRs or age 18 redeterminations depending on the – and we are looking for in most cases is medical improvement is the standard for most of them, not the age 18 redetermination, but for childhood disability reviews and adult ones. Congress has actually appropriated a significant amount of money for what are called, program integrity activities. They are one of those things where they are legislatively required. I am sorry that it turned out that way.

I would encourage you to reapply at this point. Again, I think this is one thing that also might be lost for many people that even though at one point, you are determined not eligible. You may still be eligible in the future. There are technical reasons for denial and things like that that can be appealed, but also new applications can be taken for claims like this.

But I will take back - I will note to the policy office - communications - operations components the concern that you expressed about the communication. What I am also hearing is an explanation might be needed about why we need certain documents and I will take that back as well.

DR. GORDON: Thank you very much. Again, thank you for your presentation. My apologies to the three people who have questions or comments that we are unable to get to. We do have to move on to the next segment of the program. I really appreciate SSA coming today.

I also really appreciate hearing from members of this committee about the challenges and negotiating the system and pleased that SSA will at least be able to take those comments back and see what they can do to ameliorate them. Thank you.

Next, I am going to turn it back over to Susan Daniels, who is going to be giving us an update in her role as the Acting National Autism Coordinator.

DR. DANIELS: Great to see everyone. I am going to give you an update about some of the activities going on around the federal government, as well as our recent Report to Congress. The purpose of these presentations is just to get everyone on the same page and share information that you might not hear otherwise through people who are on our committee.

First, I am going to talk about the Report to Congress that was recently submitted and then go through a few updates. You have more detailed information in the materials online. There is a National Autism Coordinator update packet that has a lot of information and links. And the information is also in the slides if you want to go back to them later.

First, as I mentioned in the fall, our office was involved in coordinating the 2021 HHS Report to Congress on Health and Well-being of people on the autism spectrum. This is a report required by the Autism CARES Act of 2019. The report was submitted in the fall and it is now available on the IACC website. We placed it on the website. You can access the PDF there so if you would like to read it in full.

The purpose of this report as assigned by Congress was to look at physical and mental health outcomes, access to autism-related services and supports, and access to an inclusion in the community.

There were four elements required by Congress in this report, including looking at demographic factors, the policies and programs at various federal agencies, comprehensive approaches that are being used to improve health outcomes and well-being for individuals on the autism spectrum, and they also asked departments and agencies to make some recommendations on how to improve health outcomes and ensure better coordination between relevant agencies and service providers. The report covered those things.

There were 22 federal departments and agencies that we reached out to and that contributed to this report. I am not going to read all the names and acronyms for you, but they are on these slides, and they are in the report as well. There was a lot of participation from across the government, including some agencies that are on the committee and some that are not on the IACC as well.

The main thing that I want to highlight for you – we have information in the report about the activities of all these agencies and departments in the report. But we also have 23 recommendations that were developed as a part of this report. And the Federal Interagency Workgroup for Autism, which is an all-federal workgroup with representation from the agencies listed in those slides ahead of this one, contributed to producing these recommendations. I do not know why 23 is the magic number. We have 23 recommendations in the current IACC Strategic Plan and there are 23 recommendations in this report.

The recommendations cover seven areas that were asked for in the law and those are listed here, including interdisciplinary coordination of federal resources, screening and diagnosis, behavioral and therapeutic interventions, primary, preventative, and emergency/acute care, treatment and understanding of co-occurring physical, behavioral, and mental health conditions, caregiver supports, and quality of life.

The 23 recommendations – I am not going to read them all out for you as I know that we have a lot to do today. But I did want to list them on the slides so that you can go back and read them if you are not able to access the report right away.

But briefly, the recommendations cover developing best practice guidelines for interdisciplinary coordination across service providers, increasing understanding of and access to systems that provide services and supports, creating coordinated systems of mental health supports in various settings, developing interstate and intrastate health care information exchanges, tracking and collaborating with and learning from efforts that are happening across the nation and around the world through various organizations, enhancing delivery of community-based services, developing effective approaches for early identification and also identification in adults, developing behavioral interventions and mental health supports to be used in educational settings, developing and validating measures of social and behavioral functioning, professional programs to train educators, health care workers, and service providers, research on communication needs of individuals on the spectrum and improving access to tools for communication, developing and disseminating health literacy resources to empower autistic individuals to take charge of their own health, engaging state agencies to increase awareness of existing federal policies so they can take advantage of to help autistic individuals, developing best practices to reduce gaps in mental health services and primary care, addressing health care disparities, increasing provider awareness, tools, and training, increasing understanding of co-occurring physical, mental, and behavioral health conditions and creating tailored supports for people in these areas, developing and improving behavioral, mental health, and pharmacological interventions for people who are experiencing major challenges, best practices related to person-centered approaches for wandering, enhancing supports and services for caregivers, activities, research, and resources that contribute to improving the overall well-being of people on the autism spectrum from across different areas that contribute to well-being, strategies to prepare adolescents and adults for gainful employment and foster access to career pathways, which we know does help with overall well-being, and gathering additional population-based data to help better understand, prevent, and reduce causes of premature mortality.

That was a really quick rundown of the 23 recommendations. There is more information in the report. But we welcome you to access that. This is available online on our website.

Next, I am going to move to federal activities, just to share brief updates from several different parts of federal committees and federal agencies and entities that are working on things that you might not be hearing about in other places.

Just briefly to mention that at the White House, President Biden this fall appointed Sara Minkara to be the US Special Advisor on International Disability Rights, which reinstated this role to work on foreign diplomacy and assistance to protect human rights of people with disabilities around the world. And President Biden also issued a Proclamation in December on the International Day of Persons with Disabilities. The links are provided here and are in your materials.

As our office was looking at information for our portfolio analysis, we learned that the Defense Advanced Research Projects Agency or DARPA, which is a part of the Department of Defense, which is on our committee, but DARPA specifically is not on the committee, funded a recent project that was on autism. We have added them to the portfolio analysis and just wanted to give you an update on their recent project, which was applying machine learning to early screening and tried to provide another tool that could be used to augment screening and increase its ability to identify people on the spectrum as well as potentially reducing disparities.

The National Science Foundation, which is not on our committee, has a couple of recent or current funding announcements out. I just want to make you aware of these. The NSF Convergence Accelerator Program has named

Enhancing Opportunities for People with Disabilities as a theme for this year. They are accepting applications. This theme also includes communication and assistive technologies, workforce accommodations, and robotics.

NSF is also calling for proposals for their National Artificial Intelligence Research Institutes. And they have a theme on augmented learning to expand educational opportunities and improve outcomes that focuses on artificial intelligence technology to enhance education and outcomes, including for those people with disabilities. I just wanted you to be aware of those.

The National Council on Disability did a couple of things. They have a new report on the impact of COVID-19 on people with disabilities that you will want to take a look at. That was issued in October.

And they also send a letter to the leaders of the National Institute on Minority Health and Health Disparities at the NIH, as well as the Agency for Healthcare Research and Quality to ask them to consider designating people with disabilities as a health disparity population.

The Federal Partners in Transition, which is a working group that is managed by the Department of Labor is working on their new strategic plan. That work is ongoing.

The Interagency Committee on Disability Research has a new toolkit on health care access and quality for people with disabilities. There are three new themes that they have identified for future activities include equity and disability, COVID-19 and disability, and disability statistics. They also host a number of events. We have listed a couple of recent Lunch and Learn Webinars that are available.

For those who might be interested in caregiver issues, the RAISE Family Caregiving Advisory Council met, and they will be holding their first joint meeting with the advisory council to support grandparents raising grandchildren in January so on January 25. We provided the link in case anyone is interested in that.

The Interdepartmental Serious Mental Illness Coordinating Committee discussed their recent Report to Congress at their last meeting in December.

The Federal Communications Commission has a disability advisory committee as well and they recently produced a set of recommendations from their Pandemic Communication Access Working Group that is called Concerns and Lessons Learned Regarding

Communication Access for People with Disabilities During the Pandemic. And that can be accessed online as a PDF.

And then just briefly, three other nongovernment activities I wanted to point out. One is that the Patient-Centered Outcomes Research Institute or PCORI had 2019 legislation that asked them to include research on intellectual and developmental disabilities as a priority topic. They have recently hosted a couple of workshops on this topic and they have a current funding opportunity announcement called Comparative Effectiveness of Interventions Targeting Mental Health Conditions in Individuals with Intellectual and Developmental Disabilities. And they also have an open public comment period right now on their proposed research agenda. Anyone who is interested in commenting on their research agenda can access it with these links. You are welcome to provide your comments.

The American Academy of Pediatrics just issued a report on promoting the participation of children and adults with disabilities in sports, recreation and physical activity in the Journal of Pediatrics in December. I wanted to point out that out to anyone who may be interested in that.

Last, the National Academies of Science, Engineering, and Medicine hosted a recent workshop called Challenges and Opportunities for Creating an Optimal Care System for Individuals with Intellectual and Developmental Disabilities. I wanted you to be aware of that in case you want to access that online. They have the videos available.

This was a very quick rundown of a lot of activities that may be relevant to us as we are working on the Strategic Plan and for you all in your different agencies and organizations working on things. I wanted to bring that to you, and I am happy to answer a couple of questions if anyone has any.

DR. GORDON: Thank you very much, Susan, for the update. I really appreciate it. I think in the interest of time, what we will do is we will go to our planned break. We are going to take a ten-minute break. We recognize that Zoom all day can be grueling. We encourage everyone to use this opportunity to get up, walk around, get yourself a drink, take care of yourself, and we will see you back here at 11:13 when we will resume with Susan with IACC committee business.

(Whereupon, the Committee took a brief break starting at 11:03 a.m., and reconvened at 11:13 a.m.)

DR. DANIELS: We are going to talk about IACC committee business now. For business today, we are going to give you a brief presentation on the autism research database. This was requested as something to help our committee members understand how they can access information on the projects that our office collects on research. We will have someone from our team. Dr. Katrina Ferrara is going to present that.

We also are going to talk about the IACC Strategic Plan update today and as you know, we did a public request for information to get opinions from the community about what they would like to see in the new Strategic Plan. I am going to go through what we received in response. And our office did some review of that and then put together some of the major themes. We will talk about that.

We are also going to talk a little bit about the budget recommendation for the Strategic Plan. We are working step by step through getting the Strategic Plan done. And later in the day, we are going to talk about the Summary of Advances. We have the 2020 edition to work on as well as the 2021, which we will just touch on today, but we are going to mainly work on the 2020.

First, I am going to turn it over to Dr. Katrina Ferrara from my office and she is going to present the office’s Autism Research Database that shares information about research projects collected for the IACC portfolio analysis. Katrina, welcome.

DR. FERRARA: Today, we just want to provide a really brief introduction to our Autism Research Database, the ARD, as we call it. And we want to highlight some of the ways that we think that it might be useful to you.

The ARD is a publicly available resource that provides comprehensive information about the status of autism research funding among both federal agencies and private organizations. It is a tool that the IACC can use as they are thinking about research and priority areas to highlight in the upcoming Strategic Plan Update, which we are going to talk about in a bit.

The ARD is available on our website. From the IACC homepage, you can find it under the tab for Funding that is shown here with the red arrow.

Whenever we put out an ASD Research Portfolio Analysis Report, the complete dataset that went into creating that report gets uploaded to the ARD. For every single project that is included in the report, the following are listed in the ARD: the funding amount for the project, the funder, the principal investigator of the work, a description of the project so you can learn more about the aims and the methods of the research, the institution and location where the project was carried out, and also the Strategic Plan question, objective, and subcategory that that work aligns with.

Here is just an example for you to see what an individual project page looks like when you are within the ARD. You can see all those details there on the side, including links to the external funder for the project.

Just to illustrate the amount of data that goes into each Portfolio Analysis Report can be pretty substantial. For the year 2018, this included data from 23 different federal agencies or organizations. This totaled over $394 million and over 1500 different projects. These cover all the objective areas in our Strategic Plan.

The ARD is really a user-friendly and interactive way to view and understand all this big amount of data. We have data that goes back over a decade. On the website, here you can see – you can select what fiscal year you are interested in looking at, going all the way to 2008.

In the slides coming up, I am just going to show you a few more key features and tools that you can use in the ARD. As I said, the ARD aligns projects with objectives in the IACC Strategic Plan. It provides an account of how much funding has supported projects and it highlights trends over the years. This has been used by the IACC to help in their efforts to monitor ASD research and track funding progress that is made from year to year.

Here, you can see in the tab for Strategic Plan Questions that is shown with the red arrow. You can see the proportion of funding that is aligned with each of the different question areas. Here, in this pie chart for 2018, I am showing you how that $394 million was broken down among the different question areas.

There is also information broken down by funder in the ARD. If you click on the tab for Funders shown here, you can see the total amount and distribution of each individual funder’s portfolio across all the Strategic Plan question areas. You might look here if you wanted to see what certain research areas were, priorities for different funders.

And then you can also get a breakdown of the proportion of funders and what they are contributing across all ASD research dollars. Again, that is what I am showing you here for 2018 for that $394 million.

Also in the Funder tab, we have historical data. For the funders that have been participating in the report for a long time, we have data that goes back to 2008. Here, I am showing you in this bar chart the funding history for NIH. You can look at this and see how funding has progressed over the years.

To get even more detailed, we have a tab for Strategic Plan objectives. These are important areas within each question area. Here, I am showing you the table for Question 1, which is about screening and diagnosis. And then you will get a listing of the different objective areas. You can click on the projects here and that will populate a list of all of those individual projects with their descriptions and funding amounts, et cetera. You will also get a pie chart that shows you the breakdown of the proportion of the different objectives and how they contribute to the total funding for that question area.

Another neat thing that we have in the ARD is data broken down by geographic location. You can see where projects are taking place. You can click on this map. You can click on each state. You will get the total funding in that state and a list of all the projects that are happening there.

And then in addition to a map of the US, we also have a map of the world because there are research investments that we have to other countries, supporting international research. And you can click on those countries and get a list of the projects that are happening there.

Another really cool feature of the ARD is that you can search by any key word of your choosing. You can type in the search box up at the top. You can type in a key word that you are interested in looking for. And then within that fiscal year, you will get all the projects that have that term in their title or also in their project description. Here, I am showing you the results for a key word search for epilepsy for 2018 and you can see we get a list of 36 different projects that have that term. And then you can either download this to your computer and in Excel or a PDF file.

You can also view projects as they are organized by principal investigator. Here, I am showing you an example of Joseph Piven. You can click on their name and then you will get a list of all their projects that they conducted in a given fiscal year. And then again, you can export this to an Excel or PDF file.

Lastly, I just want to draw your attention to another tab that we have in the ARD. Everything I have been telling you about has been in the United States data tab. We also have a tab for international data. This is based on our report that we put out in 2016 where we partnered with the UK, Canada, and Australia. We got data from other countries to learn more about their own investments in ASD research. Here in this tab, we have the data organized in a similar way with alignment with the Strategic Plan questions and objectives, et cetera. In the future, we hope to put out another report like this and have information from even more countries reflected in the dataset.

I just want to note this is a really brief introduction to everything that is in the ARD. I just want to draw your attention to the fact that in 2022, we are going to publish our 2019-2020 Portfolio Analysis Report. We are working on that now. Once that report is out, we will upload all of that new data to the ARD and it will get updated.

Thank you very much for your time. Apologies for the technical difficulties. If you have any questions about the ARD or the Portfolio Analysis Report, you can just shoot us an email here. Thank you.

DR. GORDON: Susan, I do see a couple of questions.

DR. DANIELS: Yes, and I see that the host has stopped my video so I cannot turn on my video, but I am here. We do have a couple of questions. Katrina, you and I can also answer these. First, Alycia.

DR. ALYCIA HALLADAY: Hi. Thank you for putting this together. I know this was a labor of love. I do have a question for use of this that you may not have anticipated but

I can see being very helpful is tracking grantees over time. Is there a way – everything is selected by year. Is there a way to make it so that you have a field for all years so that funders can track where grantees have also received funding, not just in a particular year, but across years? If I do a search for one of our grantees, it is only found in the year that that person was funded. Does that make sense? Can there be a field added for all years or something like that?

DR. FERRARA: Yes. We do not have that capability in there right now, but we could think about building it in for the future. If you wanted that information right now, I would suggest exporting to the Excel file each year and then you could combine the data across the years. That would be the way to get that information quickly. But it is definitely something we can work on incorporating in the future.

DR. DANIELS: We are happy to take suggestions on new features that we could add. Our senior web developer is in this meeting as well and can listen to that feedback. We will see what we can do. But feel free to send us suggestions.

Larry.

DR. LARRY WEXLER: Thank you. Katrina, thank you. Having supplied some of the data that was used for this, I do not know if a labor of love is quite the right description. It is a daunting task and it looks like you all have done a terrific job.

I only have one suggestion and there is nothing worse than putting a database out to the public and then receiving every possible iteration of everything that could possibly be done. For the major slides that you put forward and since some of this will be public facing and I referenced the one you did on the funding for NIH that NIH provided over a period of years. I am wondering if you could not do an inflation adjustment for that especially given our inflation level right now. It can be extremely helpful to put things in perspective. If it is not a totally robust increase in funding, it may look really good, but in reality, it may not be a whole lot. Running a funding discretionary grant program myself, I know based on inflation, we have had some really significant losses over the last ten years. It is just a thought for your consideration. Thanks.

DR. FERRARA: Yes. Thank you. That is a good point now that we have over a decade's worth of data. We need to start, considering how that changes over time as well. It is likely a calculation that we could work in and then present the data in two different ways.

DR. DANIELS: Something we can consider for a future report. It looks like we do not have any other questions. Thank you so much, Dr. Ferrara, for sharing this information with the community and with our committee. Hopefully, you will feel more confident about logging onto the ARD and checking what we have. We will let you know of course when we update it with the latest, the 2020 data, which just to let you know, the reason that it takes us a while to get all the data in is that every fiscal year, it takes a while for agencies to close out their data set and then we start working with the agencies to get all of that aligned and verified. And it takes a while to do that step. By the time all that happens, it takes some time before we are able to have the analysis done and publish it. But we do get it out as soon as we can and we look forward to getting you a new data set this year. Thank you.

Now, we will move into the next set of items. We are going to talk about the Strategic Plan Update. And the first item on the agenda here is talking about the recent RFI. We really appreciate the input that we received from the public for this RFI. It is really valuable to help us know what the latest needs and emerging concerns are and priorities that people feel would be really helpful to include in the Strategic Plan.

We got a robust response. We had 403 individuals and organizations respond to the RFI. We put out our first ever Spanish version of the RFI and we received two responses on that. We hope in the future we can do even more to get the word out that we are welcoming responses that may come from the Spanish-speaking community. We welcome all communities but that was our first venture into expanding in that direction.

We also want to share with you that our team went through and read all of the responses, reviewed them, and then identified major themes and topics within each question area with the goal of identifying things that we may want to include in the new Strategic Plan and having a special lookout for anything that might be new that has not been included in the Strategic Plan before.

Each of the responses that we received was assigned to one or more themes. If you want to just read the list of the themes that are detailed, there is a document in the materials on the website for this meeting and we provided the URL for that in this slide. We also have the full text responses to the

RFI available on the website for anybody who wants to go there and read the responses in detail.

Our team was able to identify some cross-cutting themes, themes that kept popping up across the different question areas for the Strategic Plan. We summarized them here in this slide. The themes that we identified were accessibility to services and treatments and interventions. There was a concern about making sure that all of these things are accessible to the whole community.

A theme of disparities in detection/diagnosis and service access and utilization to address these disparities and to close gaps. A theme for acceptance of autistic people, having a reduction of stigma, more understanding of autistic people and their priorities and interests.

Inclusion of autistic voices and underserved groups in both research and services. Lifespan issues that affect adults on the autism spectrum from childhood through older adulthood, including the aging process. In the past strategic plans, we have talked about the transition period in early adulthood, especially with regard to things like initial employment and so forth. In this set of comments, we noted that people were talking about wanting more emphasis on later adulthood and what happens next.

Personalized approaches that include all autistics, including those who have very high-support needs. That popped up in various places across the question. These were the cross-cutting themes we identified and we have noted them for possible weaving into the next strategic plan.

I wanted to go through each of the questions and some of the themes that we identified per question. The major themes that we found in Question 1, which is on diagnosis, screening, early detection, were reducing disparities in early detection for girls and women as well as ethnic and racial minorities or other underserved populations and also for adults.

The need for more practitioner training to ensure timely and accurate diagnoses and access to diagnosis and screening services. We listed a number of themes. I just chose a few to highlight here that were major ones that came out in Question 1.

If you see these little flags that say new, there were a few new themes that we did not have in our previous strategic plans, that we noted as well. Education and stigma was a topic that was new and has not appeared in previous strategic plans, so we noted that.

Dr. Gordon, did you have a question? No, okay. I will continue.

Question 2, biology of underlying autism. This question area had major themes that included the need for more research on several areas, including co-occurring conditions, physical, mental, and behavioral health that contribute to quality of life for people on the autism spectrum. And inclusion of autistic individuals in the research process and planning were two major themes that came out. But I have also listed the other themes that we identified. If you look in the full text, you will see what kinds of responses we got on these various areas. The inclusion topic was a new one in terms of including autistic individuals in the planning of research and conduct of research.

Risk factors. This was Question 3 that talks about environmental and genetic contributors to autism. In this, the major themes that were reflected in the RFI, included that some members of the community expressed that they value the research on genetic and environmental causes of autism while others felt that they did not feel this was a really important priority for focus. And some of the comments advocated for research on how social factors and social determinants of health shaped the autistic experience and that was a new theme these we identified.

In Question 4, which is treatments and interventions, there were a number of themes that were highlighted here, including providing personalized and targeted interventions for those with a variety of needs, including improved supports for people with high support needs such as communication supports, reducing potential negative effects and experiences that may be associated with some interventions, and improving access to interventions. Two of the new themes included inclusion of the full autism spectrum when thinking about treatments and interventions, and also reducing any negative effects that might be experienced with certain interventions.

For Question 5, which is about services, the major themes that were highlighted in this area, included increasing community acceptance and they talked about increasing acceptance among care providers and other people in the community who are serving the autism community or autistic individuals and their families, the development of services that meet the needs of underserved groups, such as girls and women and minorities, access to services and services that promote community integration, as well as services for adults.

Question 6 on lifespan issues. The major themes for Question 6 included employment for autistic people, ensuring services and research continue across the entire lifespan of people on the spectrum all the way through the aging process, services for people with high-support needs, and adult services for community integration. The new area here was inclusion of older adulthood in thinking about lifespan.

Question 7 on infrastructure and surveillance. The major themes were about including autistic voices in research and services, developing a strong workforce that is needed to support research and services and promoting collaboration across agencies and organizations. Again, in Question 7, acceptance and inclusion were two new themes for this particular question.

In the RFI, we also included special questions about two other areas that we know the committee was interested in and that are timely. One was a question about COVID-19 and the effects of the pandemic on the autism community. What we heard back from the community about this – I have listed the themes here that were shared. The major themes related to COVID-19 and its impact included services disruption or concerns about service disruption during the pandemic, ensuring that benefits that have emerged during the pandemic such as remote options and other accommodations will be able to be continued after the pandemic, and also about the mental health impacts of the pandemic, including isolation, loneliness, depression, and other issues that have emerged. Those were the major themes that we heard about in the COVID-19 section.

We also had a question about disparities and underserved communities. We have listed some of the themes here. Disparities in underserved communities have always been a part of the strategic plan. It has been a growing part of the strategic plan. But in this particular RFI, the major themes that we identified related to disparities in underserved communities, included access to services and supports for underserved communities, reducing disparities in services, access, and health outcomes for underserved communities, and inclusion of autistic people of diverse genders, racial and ethnic minority groups, and other underserved communities in research, services, and policy.

Those are the main themes that I heard. I want to thank everyone again for contributing all those who took the time to access this form and send us your feedback and your thoughts. It will be really valuable for the committee and for our team as we help to prepare the draft of the Strategic Plan.

I have a couple of questions for the committee, but I wanted to give a few moments for any thoughts that the committee wanted to share about what I have discussed about the RFI here today.

Alycia.

DR. HALLADAY: Sorry. I have a quick question. How did you determine what was a new theme? Was it two or more people identified that as a need? Was it ten or more people? How is that defined as a new theme or how did you define grouping the themes together?

DR. DANIELS: It was not based on numbers. But some of them were new in that we can look back at all versions of the Strategic Plan and if these issues were not mentioned. For example, the word stigma I do not think appears in any previous Strategic Plan. But this was a word that came up in some of the responses. We noted that.

Of course, this type of analysis is a qualitative analysis. You have a team of diverse people looking at it. We all looked at it from our own lens and tried to identify what were some of the emerging themes. But I think any individual who looks at the same information may come up with different conclusions. This was our attempt to boil down some of the main points from a large set of information.

Dena.

MS. DENA GASSNER: Hi. I apologize for my late arrival. I missed the message that we were starting at a different time, but I think I am up to speed now. One of the things that I saw that was of great concern to me was the actual language that was in the prior document. I was wondering whether we were going to have an advisory team or some collaborative group contribute insights into how we are using language throughout the Strategic Plan.

And I was also wondering too. When we talk about accessibility issues as it applies to services, were we able to delineate the difference between access to health care services versus access to social service systems versus diagnosis. I am kind of seeing all of those things in my practice. I am just wondering if there was any delineation or any clarity there. Thank you.

DR. DANIELS: Sure. With the language, our team has been paying careful attention to changes in thoughts about language. We are going to be – our team is going to be taking the first stab at a draft. You will see what we come up with for language. But then the committee is going to have a chance to reflect on this. And if you see anything that is still a concern, we certainly can try to address it. But we will be trying to be sensitive on language, to be as inclusive as possible, and also clear and accurate as possible to make sure people understand what we were talking about. We have taken in a lot of feedback that we have heard from various committee members and around the community. For the sake of time, we are going to give a first stab to this, but we will welcome your feedback on it.

In terms of accessibility, I saw that throughout the comments there were different uses of that, and many other terms, and people have different nuances. Our team will be trying to weave some of those different themes in in different parts of the Strategic Plan Draft. But we will give the committee a chance to reflect on it too, and share if you think that there is something important that was missed.

It is always a challenge of trying to put in all the details as much as you can, but also not making it so detailed that you can’t understand it anymore. We have to keep it at somewhat a high level so that it is understandable, but we will try to reflect some of the different diverse opinions from across the community.

MS. GASSNER: I guess my primary concern is that so many individuals in recent qualitative research have communicated, especially PCORI-funded programs, just navigating access through systems is such a huge determinant of health. I do not know, I guess I am looking for a little element of policy in here as it applies to systems navigation, which has actually been magnified by COVID for certain. Thank you for taking my question.

DR. DANIELS: Sure. Question 5 is where we would talk about systems. In the comments that you provide as an IACC member for the Strategic Plan, if you want to note that, we will take note of that.

Next, Helen, did you have a question?

DR. HELEN TAGER-FLUSBERG: Since I can’t do my video, you will just have to imagine me. Now you can. Thank you. I do want to say. I think this was an enormously helpful piece of work that you and your team did, Susan.

Identifying the themes, that is really a tough job and I think the summary is quite exciting.

I actually was going to respond to your questions for consideration. What I want to recommend is obviously the last two years has been enormously difficult, particularly for our community. But I think since we are talking about a strategic plan, not thinking about it in the context exclusively looking back to COVID-19 and what the last two years was like, but strategically thinking about what can we put into the plan that will get us ahead of what it is likely to be the next pandemic. So being more future looking rather than rehashing the terrible times that we have been through as a group. That was what I would like to recommend. Thank you.

DR. DANIELS: Thank you. Thank you for sharing that perspective. There have been a few reports also talking about planning for future emergencies and situations. We can certainly look at that. But I appreciate that comment about trying to keep it forward looking.

JaLynn.

MS. JALYNN PRINCE: Yes, thank you. Am I on? I want to thank you so very much for emphasizing things with adulthood. It is an area that has been sorely neglected in so very many ways and we need to address it. I would like to also comment too, on the sociological aspect of things. We do need good science and how that goes along with the human body, but also how people participate in community and how communities can put things together within their own confines that can help with inclusion and also help people have better mental health.

But it also has one component, and I am seeing that this is missing, and I would like to have more of a conversation at some point and it could be offline about the impact on families. Because if you consider two parents and two siblings as people are growing up, that makes it five times the number of people that we are working with or in our numbers. I am seeing a great number of parents and siblings who are suffering as well, because their lives are changed. It does not mean they have any less love or concern for the individual on the spectrum, but an entire family is impacted when somebody is on the autism spectrum, and how we can address those mental health issues.

Also, the aging process for the parents of adults that are also aging and the implications of what that could be even on homelessness, because if plans are not made by families, then an individual may be subject to losing the family home and the structures and the financial support to be able to remain in the home, and we are seeing alarming statistics in conjunction with homelessness across the country.

I hope we can maybe put some of those things into play as well, but you have done a beautiful job of putting things forward for us. Thank you.

DR. DANIELS: Thank you. We certainly do plan to include caregiving issues, and that is a whole family issue. There was a theme of caregiver supports that are needed. I think that that will be captured.

I am aware of the homelessness situation. I hope that we might be able to get someone to comment on this in the future. I have been in touch with a partner in New Jersey who has been telling me about issues with young autistic people ending up homeless. But there are also older autistic people who are ending up homeless. I would love to share about that in a future meeting. It is on our radar and there are some discussions going on and hope to be inclusive of those issues. Thank you.

Matthew, do you have a question?

DR. MATTHEW SIEGEL: Yes. Thank you. Just getting my video on. Thank you, Susan, for the presentation and the work your team has done. My question is responding to the two questions here. Are these our only options for cross-cutting objectives? There was one cross-cutting objective, I believe, in the prior strategic plan on females or sex. These are two potentials that you have put forward. However, in my comments, I put in that I would like us to consider a different cross-cutting objective or an additional one, which is to focus on communication. Being one of the two core domains in autism, it is obvious that communication drives many aspects of quality of life, development of mental health conditions, challenging behaviors, and the ability to access education, medical care, family and community life, the workplace, and interventions.

However, I think it is fairly well-recognized that communication has really received as a topic very little research attention or policy focus or services in terms of both the underlying biologic challenges and genetic. I wanted to propose that as a potential cross-cutting objective that the Strategic Plan could address. Thank you.

DR. DANIELS: Thank you. We certainly did hear a lot about communication. With the cross-cutting objective part of the purpose of it is it allowing our team to do separate tracking on that issue in terms of the dollars and so forth. We are tracking as subcategories some of these other topics. Communication is already tracked in a different way. But we will certainly give some thought to how we can highlight communication. It did come across as a strong theme. We are planning to talk about communication in our April meeting. Stay tuned.

Josh, do you have a comment?

DR. GORDON: Thanks. Matt, thanks so much for bringing the issue of communication up. I think it will be important for - it will be helpful actually for you, Matt, and others to take a look at where communication is in the current plan. I think it certainly should appear in multiple places whether it is truly crosscutting, as Susan suggested, something that I would appreciate some further opinions on. But I absolutely agree that it is crucial that we ensure that we are covering it in multiple places in the Strategic Plan.

I do want to take one objection to the notion that communication is inefficiently represented in the research space. Actually, my colleagues from the National Institute on Deafness and Other Communication Disorders fund a great deal of research in communication and autism as do we and NICHD and others at NIH. I know it is a focus of several other initiatives as well.

I cannot argue that it is sufficient. I cannot argue that there are sufficient resources being put into research in any of the spaces in autism. We are doing what we can. We can always do more. But I do not think it is underrepresented in the grand scheme of things.

DR. DANIELS: Thank you. We have, I believe, a couple of polls just to see what people think about this. What our team was thinking about was trying to create a section that would address COVID-19 issues in the new plan. That is not necessarily a question area that would be ongoing forever, but something that could be highlighted in the next Strategic Plan since it has been an issue of interest and a lot of concerns in the community. I appreciate the idea of thinking about it as a forward-facing objective thinking about – not an objective, but forward-facing discussion about how we can also be thinking about the future now that we have been through what we have and we have learned some lessons and some things that are even helpful for the community and what can we do about those.

We would like to see what the committee’s thoughts are about considering whether disparities in underserved communities is a cross-cutting themes that we would like to be tracking similarly to how we are tracking the research on women and girls. It is something that is overlaid on top of the other objectives because women and girls pops up in every category. It is just an additional tracking. It is not a double counting. That is something our team is interested in potentially doing, but we wanted to see how the committee feels about it.

If the team can put up the poll, I would like members and this includes federal members so federal and nonfederal members can vote in the polls. This is just an opinion poll. It is not an official committee vote for an action. If you could just respond to the poll questions, we would like to get a temperature read from you about what you think.

(Poll)

DR. DANIELS: We will take a minute to do that and then with the team, once you think that everybody has put in their opinions, you can go ahead and show the poll on Zoom. I will describe it for viewers on videocast. We have results. Those of you who are on Zoom, you can see this. And those for you who are on videocast, we will create a slide about it after the fact. But I will tell you what the response was.

The question was would the committee like to see a section of the plan devoted to COVID-19 response. Seventy-five percent said yes, and 25 percent said no. It sounds like the majority is that you would like some sort of discussion of COVID-19. We will plan to do that.

Number two. Would the committee like to consider a second cross-cutting objective to track activities related to disparities and underserved communities? It was a 95 percent yes and 5 percent no. That is also a majority of the committee. Our team will take that in consideration and plan to include those in this first draft. Again, we are just doing the first draft to make it easier for the committee because with such a large group, if we were assigning writing to lots of people, it would take a lot longer I think to get it done. We will come to you with a draft and then you will have a chance to share your feedback on it. Thank you. That worked really well. I am glad that worked out.

Next, I would like to talk with the committee about the budget recommendation that Congress requires us to include in the plan. In the 2016 and 2017 Strategic Plan, the committee decided to call for a doubling of the 2015 ASD research budget, which at the time, this was the amount that our team had calculated from across both federal and nonfederal entities who were funding research on autism. The doubling would have resulted in a $685 million level and they wanted to see if we could reach that by 2020.

In this figure that is shown on the slide, you will see where we are right now. We have tracked what the actual spending was compared to the Strategic Plan budget recommendation. The budget recommendation is in the yellow bars or the bars that are to the right and the bars to the left that are blue are the actual. We have not included the 2019 and 2020 numbers in there because we have not finalized them yet. But they are somewhere above $400 million. You would see that there is a gentle slope there. But it is not anywhere near the top of that budget recommendation.

The IACC’s recommendation was basically a 15 percent annual increase in ASD research funding across combined federal private funders and the reality was that it was not at such a steep level. However, there has been a continuing increase.

My question for the committee is what should we do about the next budget recommendation in the new plan? We have come up with two options and then another if neither option is appealing. Option 1 would be we could just extend the timeline on the current recommendation that was based on the 2015 budget and see if we can reach $685 million by 2025. Or Option #2 would be recommendation a doubling of the research funding amount for 2020, which is going to be in the neighborhood of $430 million to ask for a doubling of that to $860 million by 2025. And Option 3 is neither one appeals. If the majority of the committee thinks that then we might have to go back to the drawing board for other ideas. But we are going to poll you on this as well so if the team could put up the poll.

Julie, you have a question.

DR. JULIE TAYLOR: Hi Susan. I already voted in the poll, but I was just wondering if you could remind at least me how this recommendation is used. I am not sure that it does not behoove us to be really ambitious in requesting what we would like to see for funding or to be a little bit more conservative where we would hope for things to go. I am not sure what makes the most sense. Obviously, I think probably everybody would love to see Option #2, but just thinking through how this information would actually be used. I would love to hear if you guys have any thoughts about what might be the most influential, the most impactful between these options.

DR. DANIELS: Sure and I will give it to Josh to talk as an agency had about his thoughts about this.

DR. GORDON: There are two parts to your question, and I want to try and address both parts. I encourage others who have opinions and knowledge about it to chime in as well. I do not have a definitive answer to either of those parts.

How is this used? The budget recommendation is requested by Congress. We have chosen, as Susan has articulated, to give a budget recommendation specifically about research as opposed to about the sum total of autism care because it is so hard for us to figure out even what the sum total of costs of care and services for individuals with autism at the federal level. That has been essentially accepted by Congress in the past.

How does Congress use it? Well, there is actually some practical impact of these numbers. There have been, for example, authorization bills introduced into Congress that authorize the federal government or the NIH or other agencies to spend that amount in research by the year 2020. I am not aware that any of those have actually passed although, Susan, you may know. If Phyllis Ampofo, our legislative director at NIMH, has any input, I would be happy to hear from her if she is on the line. But they have been introduced with the explicit recognition that the IACC has recommended it.

Now, before you get too excited about the introduction or even passage of an authorization bill, the authorization just gives the authority to spend that money. But we cannot actually spend the money until the appropriations have been made and appropriators have not responded with a similar increase in the appropriation to any of the research agencies that would enable a budget of that size. That is an answer in terms of how it is seen.

It is absolutely seen by Congress as an advisory opinion with weight and they use it to attempt to increase the resources available for research in autism across a number of different federal agencies. It is having an impact from that perspective.

I think the second question is a lot more challenging to ask, which is what is the magic number. What should we be shooting for from an advisory perspective? Is it inappropriate or problematic even more so to shoot for the stars so high that it becomes unrealistic, or vice versa, is it problematic or we set a more modest number because that does not adequately speak to the needs of the community?

My own opinion is that we should look at what we are doing and what we are not doing from a research perspective and make a reasonable and educated guess in terms of what we could do with more resources and try to match the resources to what we are doing. The doubling in 2020 was cognizant of that. Many of individuals have commented. Just a moment ago, we heard that we need more resources put in communication studies. The increased resources for adults with autism was a big push at IACC several years back. It has been heard. We have been putting resources into at NIMH and in other agencies.

I think when we think about that initial doubling that was sort of what most of us had in mind, I think. That is my best shot at saying, yes, I think there is a cost for reaching too far and there is a cost for not reaching far enough. But it is really hard to know exactly where to put the number. Not at all that helpful, but I will turn it back over to Susan to moderate. I see lots of hands up, which is great.

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

MS. GASSNER: I just wanted to provide some background. As I remember the last time that there was conversation about the budget, we did reach for the stars because of the historically manifested underfunding of research and we were trying to gear up to catch up.

I think though given that the vast majority of people under 65 that are experienced COVID outcomes that are negative, most of them were people with IDD and many of them are people of color. And of course, autism would be included in that population.

I think also if we provide a caveat that we are going to be flipping that imbalance between causation research versus outcome research and our funders can see the potential for research that actually can enhance outcomes in real time as compared to historically a lot more emphasis on causation, I think it would be easier to justify the bigger ask to be honest.

I think that Option 2 also communicates how dire the need is. Even if we go in with the big ask and they come in with a lesser amount, at least they are aware of just how much the need is, especially in light of the implications of COVID. I do not know. I obviously voted for Option 2. But I appreciate your insights, Joshua, about going too big.

DR. DANIELS: Thank you, Dena.

JaLynn, do you have a comment?

MS. PRINCE: Yes. A few years back, we were involved with the public comments to defend something with adult autism to increase the proportion of funds I believe coming through NIH. You can help me with my verbiage on some of this. To go from 2 percent of the autism budget to 4 percent of the autism budget, which is not a huge amount of money.

Can we get in on even more the granular level with this type of recommendation to say that we would like to see a larger percentage of the funding that would be granted to go into this research that is sorely needed and sorely neglected?

DR. DANIELS: So a larger percentage of -

MS. PRINCE: Of the funding that comes through the process of NIH to be directed toward the issues facing adults with autism. That is what we had talked about in the public comments. I believe it was four, almost five years ago as we were asked to address things to increase it from 2 percent to 4 percent of what the NIH budget was that was directed toward adult autism.

DR. DANIELS: And remember that this recommendation is not just for NIH. It is for all of autism research. But Josh, I do not know if you have any comments on that.

DR. GORDON: I have opinions. I would like to hear from others as well. We are not tasked with that level of granularity by

Congress. It does not mean that we cannot as a committee if we come to agreement on it make such recommendations.

I want to caution though the difference between understanding that you are making recommendations and the decision-making power of this body, which is – this body does not have the power to make those decisions, only to make recommendations.

And the second thing I think – this would speak to something Susan and I have talked about trying to do for this committee in the future, which is really give you a better understanding both from the federal and from the nonfederal partner perspective about how decisions are made about funding because funding decisions are not made at that level of decisions. It is not like we say we are going to spend X percent on adults with autism and Y percent on communication disorders in autism or communication function in autism or enhancing communication in autism. But we do absolutely listen to the recommendations of this committee in terms of trying to increase the availability and demand for resources for research in areas where we recognize gaps occur.

If we were to get into the business of trying to make more specific recommendations about specific areas, I think this committee would get quite bogged down in a lot of different and potentially competing recommendations for additional resources.

But what has been exceptionally useful both from the congressional perspective and from the perspective of federal agencies is hearing the generalities and you can see the results of those generalities. Should we make specific recommendations about the percentage of autism? My own personal opinion is I do not think that is going to be very productive and I think it is going to lead to what could be a quite complicated and challenging discussion about potentially competing priorities.

Should we make a budget recommendation overall? Absolutely. And should we tailor that with recommendations or observations for informed hopefully by what we are actually doing for emphasis changes? Absolutely.

DR. DANIELS: Thank you, Josh.

Julie, I think that you have a question as well.

DR. JULIE TAYLOR: Yes. Sorry to prolong this discussion. But now, Josh, you have convinced me that this number is actually an important thing for us to think through. I was thinking through. How can we justify Option 2 because I think probably everyone on this call would love to see more – us justifying more money for autism research as opposed to less.

I do think that potentially with this focus on really engaging underserved groups and groups that are underrepresented in research, if that is something that becomes a real focus of this plan and a cross-cutting theme, that may give us some really good justification for Option B because this is not easy work to do. Engaging people who are – I think all of us, myself included, would love my samples to be more diverse. But I do not necessarily obviously I have the tools to make that happen. And sometimes groups are hard to engage to do that. I think if we really wanted to see a change in terms of really having our samples be more representative of the population at large, I think that will probably take a significant investment for that to happen. Perhaps sort of a focus on really engaging populations that are more representative of the population of autistic individuals and their families could be a nice rationale for us to say this is a big endeavor and it is really important and we are going to need additional funding to really make this happen.

DR. GORDON: You know, Julie, I like that. Sorry for interrupting. I know there are other comments. I will just say very quick. I like the formulation of identifying specific areas that we want to expand by increasing resources available, including reaching underserved populations, including in reference to the earlier conversation, increase the amount of research in adults with autism in communication so we can identify. That would be a very productive activity, identifying areas that we like to see expansion and using that to justify a recommendation for a budget increase. Sorry to interrupt.

DR. DANIELS: Sure, no problem. Also, just as a reminder too that when we are making this budget recommendation, this committee is authorized to be able to make recommendations regarding autism. But I wanted you to keep in mind that there is an entire body of work being done on all disabilities and many agencies that focus on disabilities as a whole and do not necessarily specify very many things specifically for autism. There is other funding that is also being spent on things that would be useful to the autism community. But the budget recommendation that the committee is authorized to make would have to do autism spending specifically. Keep in mind that it is not like this is the only research money that benefits autism. There is also research money that is being spent on disabilities more broadly that is beneficial.

Susan, do you have a question?

DR. RIVERA: I do. I had a comment. I just wanted to say that I really appreciated and felt that we have benefited from the comments that we have heard after the poll was launched. I was personally very surprised to see the results of the poll. I wonder if we could have comments and discussion before the poll is launched. That way we can go into those answers with more informed opinions.

Personally, I was also very surprised by the overwhelming 75 to 25 percent on adding COVID-19 as a separate section of the report, which I obviously personally disagree with. But I wonder if we could benefit from talking to one another about that before we have the opportunity to vote.

DR. DANIELS: Sure. And I am going to ask to rerun this poll because we have had a significant discussion. This is the first time we are using polling in the meetings here. It is an experiment.

DR. RIVERA: And I think it is a great idea and we are learning as we go. But I would like to request that.

DR. DANIELS: Yes. I was planning to do that again.

JaLynn, your hand is still up and I do not know if you had another comment before we can move to the poll or if that is just left from before. It is down.

The poll has been put up again. If you can go ahead and just respond to that then we will see where we lie with this.

(Poll)

DR. DANIELS: The poll results are in. And those who are on Zoom can see it. But for those who cannot see it - this poll said how should the budget recommendation be updated in the upcoming Strategic Plan. Option #1 was to extend the timeline by 5 years. It is what is on the slide to reach $685 million by 2025. And Option #2 was recommending doubling the research amount from 2020, which is around $430 million to $860 million. And Option 3 was neither 1 or 2 or something else. It looks like we came in at 60 percent saying they would like to extend the timeline so Option 1. And 40 percent at Option 2. That is a clear majority. We will work with that in the draft of the plan and bring it back to the committee to look at it once we have drafted it.

But there is a Part 2 to this. What we talked about a couple of minutes ago about thinking about what areas we might want to think about in terms of what we would do if there were a budget recommendation. Is there something that underlies this? And last time the committee identified three areas that are – that they felt were priorities for intensified research efforts and the three areas they identified were treatments and interventions, evidence-based services, and lifespan issues.

This one – I think the way I have set up the poll is just for you to first look at this. There is another slide after this that has another poll to see if you still feel that these three areas are top areas that you would want to consider. And just keep in mind, of course, we do not want to have 25 different areas to highlight. We really want to keep it small and focused so that when Congress sees it, they see that we have a direction. I know it is challenging because it is a diverse committee with a lot of different opinions and thoughts. Should we have a discussion about it before we have the poll?

DR. GORDON: Yes. Susan, I am wondering if we need to do this now. We have just a few minutes left before we need to break. It was a desire to have a discussion, including some other areas nominated. Can we afford to wait until the next meeting to discuss the areas that we are recommending increasing or do --

DR. DANIELS: Are you talking about the summary of advances?

DR. GORDON: No. Talking about the budget recommendation that you just had, other areas, emphasis for increase. We heard at least two nominations so far of communications in addition not the lifespan, the other two issues. And then the other one being reaching diverse populations. I am just wondering whether that would benefit from a longer discussion than we could have in the next three minutes. Could we come back to that at the April meeting?

DR. DANIELS: I think we can. We can work with the initial budget recommendation. You will see that my next slide and my next poll was whether services on disparities in underserved communities should be added as a priority area. But there may be other ones. Perhaps with the committee giving us feedback on the plan, if you have thoughts about priority areas that we could consider, you could just send those in and we can use them in a poll at the April meeting.

I think before we break here – if we are going to do that and table that discussion for the time being to talk about the Strategic Plan update process, there are a couple of hands raised. We are skipping these polls and moving on.

Yetta, did you have a comment?

MS. MYRICK: Yes, good afternoon. Is it the afternoon? Yes. Good afternoon, everyone, who is on the East Coast. I am thinking when you present the priority areas, it would be great if we can see a list side by side because it is difficult for me personally to – what are all the areas that we have talked about like we are seeing on multiple pages and seeing what the proposed list is? I think that would make it at least for me to make a determination.

DR. DANIELS: That is a great suggestion. Sure, we could easily do that. That would be a way we could do that. Thank you.

Dena.

MS. GASSNER: And similarly, if we could define how we previously reference those categories. What were the definitions of interventions, for example?

Since we are wrapping for lunch, I just wanted to ask. Several of us arrived very late for the meeting because we did not register the shift in the time. We missed the opportunity to participate in the SSA discussion. From what I understand, we were not able to ask a lot of questions. People were left with a lot of questions. I just wanted to ask if we could invite that individual to come back so we have opportunities to ask those questions maybe in the April meeting because frankly, I prepared a lot of questions because my dissertation is on SSA. I do not know. I would just like to pose those questions and I think other people have questions and comments that we just did not have time for. I just wanted to make a pitch there. Thank you.

DR. DANIELS: We do have a full agenda already for April. We have a number of different things. I am not sure if we can reinvite the same speaker again. But we can talk about it. Dr. Gordon, do you have any thoughts about this?

DR. GORDON: I think we will take that suggestion to heart. I was disappointed with the relative small amount of time the speaker left for us this morning to ask questions and make comments.

I do think though that we want to make sure that the comments and questions that we make that are going to be pitched towards the needs of the general audience that is listening if we are going to go through that. Let us confer.

Dena, if you would not mind just emailing me a little bit about what your questions were. Maybe we can figure out a way to tailor a session around some of the needs. If others had questions as well that they wanted to ask and did not get the opportunity if you would send that along to me. Susan and I can confer.

MS. GASSNER: That would be great.

DR. GORDON: We will report back to you in April about what we decided and when we can schedule it.

I think we do need to move on but I see Alison, you have been wanting to make a comment. Go right ahead and then we should break for lunch.

DR. ALISON MARVIN: I do not want to interrupt the lunch schedule, but I just I wanted to mention one option, which Jeff and I have been discussing because we wanted to catch those questions that he was not able to respond to. I know there were three people who had raised hands. But I already sent Susan a note to try and get that information of some questions and writings that we could actually respond. I already mentioned that to Susan. Maybe if we could send those questions off to Susan and the team, maybe we can draft some kind of response and send that out that way so that way people can also get the response sooner than later.

DR. GORDON: That is not a bad idea. We do have to figure out a way to make sure that it reaches the audience. This committee is not about answering the individual members of the committee's questions and concerns, but rather providing them an opportunity to ask questions that are of broad interest to the autism community at large and allow those individuals to hear those answers. Perhaps we can broker a document, maybe a Q&A document that we can put on the website, et cetera. Susan, I will leave that to you and Alison to figure out what we can do and then we will solicit questions and comments from the committee and figure out whether we cannot get a document up on the website for the public and/or repeat the session at a future meeting.

I want to thank everyone for their tremendous activity. I know Susan really appreciates all the comments that we have heard. We have made some progress on the Strategic Plan process, including the budget, and we will make more progress at the next meeting. I am really pleased at the active nature of this group today.

I also am pleased that people have been feeling comfortable voicing their opinions even when they are not necessarily agreeing with the previous speaker. I want to continue to encourage that. Everyone is being incredibly respectful and I really appreciate that.

We do need to take a break. We need to take a break for our own mental and physical health. We cannot be on Zoom from 10 a.m. to 5 p.m. without it. We are going to take a half an hour break. We will be back at 1 o’clock when we are going to commence with the public comments. Please do come back on time. We want to make sure to be able to hear from all the commenters and also hear about the written comments. See you all at 1 o’clock.

(Whereupon, a luncheon recess was taken at 12:33 p.m., to resume at 1:00 p.m.)

DR. GORDON: Welcome back everyone. It is 1 o’clock. I am going turn it back over to Susan, who is going to be orchestrating the public comment session. I will be back to help with moderating the discussion after the comments.

DR. DANIELS: Great. Thank you, Josh. I would like to take a few moments just before we start the public comment session this afternoon to give an opportunity to Dr. Anita Everett to introduce herself from the Substance Abuse and Mental Health Services Agency. Can you please come to the screen, Anita, and introduce yourself?

DR. ANITA EVERETT: Sure. Can you hear me?

DR. DANIELS: Yes.

DR. EVERETT: I think my video is turned off. Thank you. It was a really nice morning. I am Dr. Anita Everett. I work at currently as the director for the Center for Mental Health Services within SAMHSA, a federal agency within the HHS, a family of agencies that is called Substance Abuse and Mental Health Services Administration. Prior to my personal time in the federal government, I worked in Baltimore at Johns Hopkins where I was a division director of community psychiatry program and we had a dedicated clinic to adults with autism, many of whom have aged out of services at the Kennedy Krieger Institute in Baltimore. I am familiar with the clinic – with the population through a clinical lens and very interested in supporting what we can to ensure good services of good quality for the array of situations that come up clinically with individuals with autism and also recognize the value of course, the discussion we have been having this morning of research so that we get better answers to the questions that are out there with regards to working with the population that has autism.

I also wanted to call attention to Mitchell Berger, who is a representative from SAMHSA that works with me. When I am not able to attend, Mitchell is there to assure that SAMHSA is represented. Thank you very much and I am looking forward to participating more actively in the group over the next year. Thank you.

DR. DANIELS: Welcome, Anita. Glad to have you with us. Now, we will go on to the public comment session. Today, we are going to hear from five oral public commenters, and we are going to talk about the written comments and then have time for discussion. With our oral commenters, I will just call on your name and if you can turn on your camera and then go ahead with your three-minute comment to share with the committee and we have the full text of all the comments, as a reminder, on our website. If you go to the meeting materials, you will see the public comments packet and you can use the index in the front or the table of contents to find the specific comments from each person.

First, I would like to call on Russell Lehmann to give us a comment. Welcome, Russell.

MR. RUSSELL LEHMANN: Hello. Good morning. Good afternoon. Thank you for having me. My name is Russell Lehmann. I am a motivational speaker and spoken word poet with a platform of autism and mental health. I happened to have autism myself. I would like to just offer my brief comments on the shock treatment at the Judge Rotenberg Center.

As somebody who has been in-patient in psychiatric wards three times in my life and has always left worse off than when I entered due to very traumatic experiences, this sits close to home for me. This school advertises its behavior modification program as safe and effective and backed by science. But the science is that the graduated electronic decelerator, GED, the shock devices they use – when they give a shock, they produce 90 milliamps of electricity that lasts 2 seconds. 90 milliamps. That is the strongest device they have. Now a cattle prod produces 10 milliamps for just a fraction of a second. The ones on humans, 90 milliamps, 2 seconds.

My first experience in a psych ward was age 12. I stayed there for five weeks. They used to tackle kids from behind if they were just wandering down the hallway. I remember one time my mom came to visit and I started crying because I was so happy to see her. And they pulled us apart because they thought she was enabling me. They told her to leave. My mom leaves. I started running down the hallway. In the back of my head, I am like they are going to tackle me. It is just that it was so traumatic. That hurts to this day. It is like when we traumatize these kids, these young adults, they are not just doing it in the moment. That lasts a lifetime. It has a ripple effect.

But thankfully, I never even got to close to these GED devices. And some of the traumatic experiences that occurred in these hospitals – sure, they might have helped my OCD. They might have helped my depression, my obsession, my autism. But at what cost in the long run? Because now I associate that improvement with traumatic experiences and that takes a hell of a lot of work to heal. It really does.

My question is what are we going to do about this? I know my time is coming to a close, I just want to end it with I have been looking at some of the drawings from these kids at the Rotenberg Center. There are drawings that these kids draw and they are just heartbreaking. It looks like something out of the Spanish Inquisition. What are we doing? Are we just talking the talk or are we actually going to take some action behind this? I know it is up to the FDA at this point. But let us actually act on our sincerity of helping individuals with autism and developmental disabilities. Thank you.

DR. DANIELS: Thank you so much, Russell, for sharing those comments. We are going to have a discussion period for the committee at the end of the comment period. We appreciate your comments, Russell, and we will give people a chance to respond at the end of the session.

Next, I would like to invite Nicole Corrado to share some comments if you can turn your camera on. We would like to hear from you. Do we have Nicole Corrado on Zoom?

PARTICIPANT: It does not look like she is on.

DR. DANIELS: Okay. We will move forward. But if she appears on Zoom during this session then we can come back.

Next, I would like to move to Karen Heffler.

DR. KAREN HEFFLER: Hi. I am Dr. Karen Heffler. I am an autism researcher at Drexel University and mother of an autistic adult son. I ask you to please listen carefully to the research that I will briefly review and that you discuss this and act on it urgently in the Strategic Plan.

While autism prevalence rates continue to rise, there is ample research findings of an association between early-life digital screen exposure and autism outcomes. Additionally, there are growing reports of intervention, including turning off screens and focusing on social engagement strategies in children 4 years old and younger with a history of high exposure to screens, resulting in more rapid and extensive improvements in autism symptoms, than is typically seen. Our work is additionally showing a decrease in parent stress related to the intervention.

These findings are consistent with child development literature. Infants and toddlers learn through parent-child interactions. Digital screens in the background, as well as parent-focused, and child-focused screens all interfere with these critical parent-child interactions. A landmark 2021 Australian study showed that parent-infant social communication training decreased autism outcome in infants who were showing early signs of autism.

Higher screen time is also associated with language delay, social impairment, attention problems, cognitive impairment, challenging behaviors, and dysregulation, all of which are co-occurring in autism.

In the US, toddlers average 2.5 hours per day of screen time and 50 percent have their own mobile devices. In Romania, 97 percent of children presenting with an autism diagnosis had screen exposure of at least four hours per day since infancy.

What can be done by the IACC? Provide an urgent recommendation in the Strategic Plan to provide a focus on research to study first, parent education to expecting parents and new parents on digital screen time and social engagement strategies with autism and child development as outcome measures.

And secondly, parent education and support to decrease screen time and focus on social strategies in young children with autism and high screen exposure, with autism symptoms and child development as outcome measures.

As a parent of an adult son with autism, I understand the need for services for all impacted by autism. With rising autism prevalence, the need for lifelong services is astronomically increasing. Addressing this environmental risk factor from both the prevention and intervention pathways has the potential to significantly improve outcomes in the youngest children with this exposure, thereby leaving greater resources for other children and adults with autism.

Extensive research references are in my written comment. Thank you for your attention.

DR. DANIELS: Thank you, Karen Heffler, for those comments. We really appreciate you being here and sharing with us.

We will next hear from Alison Singer.

MS. ALISON SINGER: Hi. I am Alison Singer. I am the President of the Autism Science Foundation and the mother of a daughter with profound autism. I served as a public member of the IACC for 12 years.

In December of 2021, The Lancet published a special report titled The Lancet Commission on the Future of Care and Clinical Research in Autism. You will hear more about this later today from Commission Chair Dr. Cathy Lord. In the report, the commissioners introduce the term "profound autism", which is defined as autistic people with intellectual disability, who are minimally verbal and who are likely to need 24-hour support throughout their lives.

The goal of introducing this designation is to provide more specificity to the extremely broad autism spectrum and to equip our community with the language necessary to ensure that all individuals with autism receive the accommodations and interventions that they need. Concise and meaningful terms like “profound autism” will simplify the process of determining appropriate care, leading to quicker and more forceful interventions. For those who bristle at the use of labels to describe autism, it is vital to understand that the term “profound autism” does not seek to demean individuals in this group, nor does it seek to invalidate the experiences of those not in it. Instead, “profound autism” is meant to call attention to the unique needs of this vulnerable and underserved community.

Based on review of several international databases, The Lancet estimates that up to 48 percent of the autism population falls into this category of profound autism. In other words, for nearly every autistic person trying to get a job at Microsoft, there is also one who is nonverbal and struggling to get through the day without peeling the skin off her arm. Furthermore, these data indicate that for every high functioning adult with autism sitting at the IACC table, there should be a parent representing the needs of a child or adult with profound autism.

Since the publication of The Lancet report, I have heard from countless parents of profoundly autism children who are scared about their children’s futures and feel bullied into silence by higher functioning self-advocates who often have a fundamental misunderstanding of what having profound autism even means. These parents tell me they are exhausted both physically and emotionally by the work it takes to keep their children healthy and safe each day and by the difficulties in securing quality care.

In closing, I urge this committee to add additional public members who are parents of individuals with profound autism. And I urge this committee to focus on the traditionally excluded population in the annual Strategic Plan for autism research.

The current list of IACC Strategic Plan themes published on the IACC website grossly overrates neurodiversity themes and relegates 48 percent of the autism population, the people with profound autism, to a footnote. The current list reflects a huge disconnect to the suffering that a tremendous portion of the autism population lives with every day. Thank you for your consideration and I appreciate all the work you all do to support the needs of all the members of the autism community.

DR. DANIELS: Thank you, Alison. Next, we have Michael Ha. Are you in the Zoom room?

MR. MICHAEL HA: Thank you. My name is Michael and I have a 4-year-old son named Ryker. He was born in the modern world of technology and social media with the physical and intimacy of bonding from birth separated by nothing more than a Wi-Fi connection.

So many of today’s parents rely on lights, sounds, and lots of visual aid from devices that requires a power source to act as our babysitter while we busily continue on our days, doing laundry, cooking, cleaning, shopping, fixing things, earning income for the family, and tending for other children, or just having some alone time to recharge our own batteries. We did this too until about two months ago.

My goal here today is to convey a message of hope and bring awareness to the detrimental effects of tech time, which takes away the time from naturally occurring communication and social bonding, both of which is the core definition of autism diagnosis.

To illustrate my own experiences, Ryker was diagnosed early, around 18 months old. We had him started on early intervention with OT, SI, and speech. Then on his third birthday, we added some more hours including ABA into his daycare routine, all of which seemed to have helped his gross motor skills and fine motor skills and to some degree his receptive and nonverbal language. Despite intensive therapy for most of his waking hours, none of these services significantly increased his social response to others. He had poor eye contact, no spoken language, played by himself, and did not engage with others.

However, about two months ago, we were introduced to a Drexel researcher who compassionately suggested that we try some of the techniques that seemed to have benefit in a recent pilot study. The researcher taught us how tech devices disrupt interactions between children and parents and guided us on strategies and techniques that involve intense social connections, including strategies for eye contact and getting our child’s attention.

And one of the strongest suggestions was to remove all tech and screen time cold turkey so that all available moments spent with Ryker was dedicated to social interactions. Within one week, we noticed that a change in his attentiveness to his family and his environment. Within three weeks, his receptive skills took a quantum leap. And two months into this program, he has begun showing consistent signs of social engagement, parallel playing with his peers and some direct play at day care. He is producing some vocal approximations of words and now saying several actual words with meaningful intent. He giggles. He looks at us, loves the attention from his parents, and points to objects he wants. He has shown remarkable improvement since following these recommendations. This intervention is noninvasive, non-drug induced, scalable and is teachable therapy that has tremendous potential to help others like it did for my own son.

What I am asking for is not to - I am not asking for help for my son. He is now making rapid improvements. I am asking you that you improve the funding and focus on this type of intervention so that other children and families can benefit from replacing tech time with social engagement strategies based on what we have experienced. This is very important to us. Thank you.

DR. DANIELS: Thank you, Michael.

Did Nicole Corrado join us? Can the team let me know if she is available? I am not seeing Nicole. Her comments are included in the packet. You can read them.

Then if I can get help with going to the slides, we will share something about the written comments. Great. You can see now the summary of written comments that we have shared here. We have listed for you the written comments that we received from the community and tried to put them into categories so that you could understand the types of topics that people wanted to write to the committee about. They include addressing the needs of autistic individuals with high support needs and/or profound autism, and there are a number of people on that list.

There were concerns about medical practices and potential causes of autism from a few members of the public. There was a comment on the role of the IACC and the federal government. We had some comments on research and services needs, resources, and policy implications from a few people. Comments that were directed toward the Strategic Plan. Services and supports for adults with autism or on the autism spectrum and safety, elopement, and interactions with law enforcement. I believe those were the topics that we heard about through the written comments and the full text is available on our website.

At this time, we would like to open the floor for discussion from members of the committee to talk about the comments that you have listened to in the oral comments as well as what you have read in the written public comments.

Dena, you have your hand up.

MS. GASSNER: Yes. I cannot start my video and I know some of us need both. Thank you.

I want to thank everybody for their commentary. The public always does such a phenomenal job of keeping us in the loop. I examined all the public comments in advance of the meeting. I feel like there are some things that need clarity. While I would agree 100 percent that the level system in the DSM is not adequate largely because they are very subjective, and they are observational. Personally, I would like to see us go back to the global assessment of functioning that looked at adaptive and behavioral supports.

I do believe that there is some information that needs to be clarified. While nearly 60 percent of children with autism have intellectual or borderline intellectual abilities, many of that 60 percent do go on to enjoy at least part-time employment, positive school opportunities when high-quality supports are provided. Not everyone who is in that borderline range is really profoundly affected as the word was used today.

I did want to say too that IQ and language are not protective factors preventing and inhibiting self-harm. IQ also does not mitigate functional limitations for many autistics. In fact, this is why many autistic individuals are identified as autistic and identified for social services. Throughout the continuum, autistic individuals engage in NSSIB, non-suicidal self-injurious behavior, self-harm. Many of the things that are described as symptomatic of people who have high support needs are really not able to be used in that way because it is not just limited to that community. Research by Cassidy, Hrabowski have addressed non-suicidal self-injurious behavior. Burke and Stoddart's research and Chrone and Nicolaidis and Benevides have talked about barriers to health care and mental health. Dewinter, Strang, and Graham have done the heavy lifting on LGBTQ issues. And eating disorders even have plagued our community. I think we need to continue to look at autism as a continuum of issues.

I personally just want to thank all the autistic adults, especially the high number of autistic women who continue to present themselves for research that can offer insights into helping the entirety of the community.

Lastly, in terms of having a parent representing the needs of a child with profound autism, I think we continue to demean the reality that many of the members on the IACC have been people, are people with high-support needs. Many members of the IACC are also individuals who have parented individuals with high-support needs. And to suggest that somehow this community is not represented when we are all charged to represent the entirety of the community, it is really very distressing. It is keeping us from the most important work we do, which is to unify our community such that we are able to push for the policy changes that are so critically needed for the entirety of the community. I hope that we can continue to work toward eliminating fractures.

I was blessed to participate in policy advocacy with a pal who has a son who is non-speaking, very high support needs, 24/7 needs and yet we were able to partner together to bring policy changes in DC that represented the needs of both of our loved ones. I think we need to find a way to unify and move forward so that we can get better services and supports for the entirety of the community. Thanks for listening.

DR. DANIELS: Thank you, Dena. Can we have a comment from Martine?

DR. MARTINE SOLAGES: My name is Martine Solages. I am the alternate representative to the committee from the Food and Drug Administration or the FDA. I am here because our representative, Dr. Tiffany Farchione, was not able to attend. I did review the public comments and I want to just to acknowledge specifically Russell Lehmann’s oral comments and concerns about the Judge Rotenberg Center and the use of electrical stimulation devices. I know that this issue is working its way through the courts. I do not have any specific updates today. But I am taking notes and will be bringing back any comments, including Russell Lehmann’s comments, to the agency. Thank you for having me.

DR. DANIELS: Thank you, Martine.

Next, Scott Robertson.

DR. SCOTT ROBERTSON: I am Scott Robertson. I have been on the meetings before, but I am the alternative for DOL and representing us right now during this afternoon period. I want to first comment on the oral comments as far as the Judge Rotenberg Center, and I think it gives a lot of concern in terms of the high level of the nuance that were mentioned and that makes me think in terms of the need as far as human rights focuses. I do not know whether that is something that could go more in the Strategic Plan or in other documents. But I think it is something different for us with the Autism CARES Act versus other laws like the DD Act, for instance, that talk a lot more about human rights, self-determination, independence, community living, and inclusion. I do not know whether we can either strengthen that through the Strategic Plan or other focuses in the future. But I think that that sort of helps spotlight something that is even broader. Obviously, it is horrible in terms of the electric shock, but I think there is a broader focus in terms of human rights.

I do also want to concur in terms of what has also already been said as far as supports and services should be tailored to the individual so that folks can have the supports and services that they need in order to be successful and be able to have the high quality of life that is emphasized a lot in the Autism CARES Act. I hope we continue to have other discussions on that on how it should meet the individual in terms of individualized. I do concur that sometimes we make generalizations about functioning on a global scale and I think a more modern understanding from the research literature and from promising and best practices is to tailor and to individualize it to meet the needs only for autistic people and I think most folks know that I am autistic myself.

But I think for folks overall with significant disabilities and other folks in life is having the individualized, customized nature for supports in services is crucial.

Obviously, I also concur with some of the focus that has been mentioned as far as employment, et cetera, that folks need better access to that. I am glad it is a major emphasis here for the IACC Strategic Plan and other focuses. Thanks.

DR. DANIELS: Thank you, Scott.

Morenike, I do not know if you would like to speak. I do not have anything written. I see something in the chat. You would like me to read this.

MS. NICOLE CORRADO: I am an oral commenter. I signed up. But I am sorry that I was late. My email has been really acting up.

DR. DANIELS: Yes. Can we take this next comment and then come back to you?

MS. CORRADO: Sure.

DR. DANIELS: Thank you. I was about to read for Morenike. Her comments. Morenike says, perhaps it bears repeating yet again that being an autistic adult and a parent are not mutually exclusive. It is presumptuous as well as a sweeping generalization to make a declaration such as for every "high-functioning autistic IACC member there should be a parent of an individual with profound autism appointed." First, how do you know that such a ratio does not already exist? Have you done some type of inventory on our family compositions in our wombs?

Second, intersectionality exists. Please note that it is very possible to be an individual who wears a lot of hats and occupies a lot of roles. It is very possible to be "high-functioning autistic adult" and a parent and/or sibling of someone who meets the criteria that has been outlined at the exact same time. You have people right here on this committee like this.

Third, you do not know what the functioning level of any IACC member is. Only what you presume. This is part one out of two. I only have part one. If there is something additional, maybe we can come back to that.

Nicole Corrado, you can go ahead and give your comments.

DR. GORDON: Susan, can I just interrupt? And I apologize. Ms. Corrado, we will absolutely get to you. I just want to respond because there have been a couple of comments along the same lines. I think it is important. My hand is raised on this specific topic. But I think it is important for the committee that I mention this.

I really appreciate the perspectives that Morenike and that Dena have brought, noting that the subtleties and intersectionalities that people can play multiple roles and people need to represent multiple opinions.

But I also think it is important that we give all of our speakers, including the public commenters who have commented so far, the respect and not to assume that they are impugning the current members of the committee. I think what Alison and frankly others have voiced to me over the intervening six months is that a lot of the dialogue on this committee has been around issues of centrality to adults with autism, self-advocates, and those – and I agree. We have self-advocates on this committee with very wide levels of functioning. And Ms. Singer and others have been giving voice to what they perceive right or wrong to be a relative neglect of issues that are plaguing many members of our community that affect individuals and families where people with autism are so profoundly affected that they are unable to communicate for themselves. We have some of those advocates here around the table. We have some advocates in our community. Those voices are not absent from the table. But I think what I have heard frankly from many in the community is that they are concerned that this particular iteration of the IACC, has not yet addressed those issues and that is the voice that Alison was raising at that point.

I want to reassure everyone that I consider very important that this committee address issues of importance to the full range, to the full spectrum of autism and that we will be addressing the issues of importance to parents and families for those who suffer with such intense needs that they are I think incorrectly perceiving that this committee has not dealt with those problems or is not dealing with those issues. I want to make sure that, number one, we hear Alison and others' perspectives as being important reminders of the issues we have not yet gotten to. I want us to take up the charge that is behind the words, not to discount of course they have the right to their opinions about the makeup of the committee. But I think the message we should be hearing is let us make sure to take those concerns and issues to heart. I just wanted to respond directly. I really appreciate everyone speaking up on this topic and I am sure more will have more to say. And with that, I will cede it back to you, Susan, and I think we do need to give Nicole her minutes of public comment. Thank you.

DR. DANIELS: Thank you. I will circle back to Nicole now to give her public comment.

MS. CORRADO: I will just say that I fully agree with what Dr. Gordon was saying. Yes, we do need to be looking at the entire spectrum. I have a neighbor who has profound autism and she is a friend and her needs are very different from mine. But her needs are just as important as mine. Her needs are much higher. I cannot say what it is to live her experience because I am not her and autism is a spectrum. I care about the entire spectrum. I consider myself neurodivergent because autism is a big spectrum, and it is a part of a wider neurodivergent community. Thank you for saying that.

I would like to just read out what I have written. What I wrote is I am autistic and have experienced wandering/elopement behavior. I have written an article based on lived experience regarding missing autistic persons. There is a link on the government website.

I do not agree with tracking devices unless they can easily be removed and are consented to. There may be cases in which a non-consenting person, an adult with dementia, or a person with very profound autism, or a very young child may wear a removable tracker. But the point of any tracker must be to improve independence. That will of course look different for every person. And some people – it will be a joint decision between caregiver and individual. A tracking device should not be used to further restrict a person. Therefore, the default for tracking device purchase must be self-sign-up and self-purchase for adults. That is adults who may have moderate to lower support needs obviously.

I am autistic and live in Toronto, Canada. I am interested in the topic of elopement and Kevin and Avonte’s law from the perspective of an autistic person. I am involved with an upcoming research project on elopement behavior.

While tracking devices are one tool to reduce search and rescue time in finding missing persons, they are controversial and do not always prevent elopement or drowning deaths. The funding from the Kevin and Avonte’s Law grant program should be used to support swimming lessons, other sports programs, (persons often run or swim to get rid of anxiety or other pent up energy), education programs to teach autistic persons the dangers of elopement in a way that makes sense for each individual, and healthy alternatives to the behavior, mental health programs for autistic persons with various support needs and communication methods, including an autism specific crisis phone line that accommodates spelling for communication, relationship support for autistic persons, including sexual education and consent education, a safe place for autistic persons fleeing abuse, mandatory autism education by autistic persons for all first responders, and housing/funding supports for persons who want to live independently.

DR. DANIELS: Thank you, Nicole, for sharing those comments. We appreciate you being here.

I am going to circle back and just finish the comment from Morenike and then we will move on to Jenny Mai Phan. Part two for Morenike. Please note that there are many individuals who are presumed to be cognitively impaired until they gain the ability to use AAC in late adolescence and adulthood. This clearly is not going to be the case for all people. But it is yet another reason why a one size fits all approach does not fit anyone or help anyone. The ICD-11 does provide more description than the levels in DSM-5 and could be a possibility.

Lastly, I am not necessarily opposed to the term “profound autism”. A name is a name. What I am opposed to is assuming that such individuals do not matter to those who are different than them. That is the end of that comment. Thank you, Morenike, for sharing.

MS. MORENIKE ONAIWU: That is actually not the end. I had to push send because you all were asking me, and I did not have a chance.

DR. DANIELS: Okay. Is there more that --

DR. GORDON: Monica sent it to me. Let me read it. I did not get a chance to finish typing. Again, some of us have those individuals in our very own families and therefore of course we care about such issues. They are erasing our loved ones before our very eyes. If a non-autistic parent can have a profoundly autistic child, why is it impossible to think that an autistic parent can have a profoundly autistic child? This makes no sense at all. What makes anyone think when I or anyone is sharing a perspective that we are only sharing our own? Because we are on the spectrum that means that apparently, we are somehow incapable of also caring about and advocate for the perspective of our children, our siblings, our colleagues in the community who might differ from us. Thank you, Morenike.

DR. DANIELS: Thank you.

Next, we will hear from Jenny Mai Phan. Jenny, are you still there?

DR. GORDON: Jenny, I think you are muted.

DR. DANIELS: Maybe Jenny stepped away. We will move to Sam Crane.

MS. SAM CRANE: Hello. Sorry. I had to get myself off of mute and back on camera. I just wanted to add. I believe that Dena’s point and Morenike’s points are very important. I think that what we are missing here is the fact that perceptions aside, the autistic members of this committee have often consistently been the ones bringing up the need for more supports, more services, more research into long-term supports, more research into communication supports and more research into co-occurring medical conditions. I think that we really need to start moving beyond just saying autistic people versus non-autistic parents. Many of us are both, as Morenike pointed out.

I think one of the things that we need to think about in terms of the profound autism label is that it often obscures what we are actually talking about. One of the things that – I am not concerned about talking about people with significant support needs. But let us talk about people with intellectual disabilities, people who self-harm, people who have significant independent living challenges, people who need AAC. Those are not always seen together. There are a lot of people with many different combinations of these. And sometimes when we talk about just one axis, profound versus high functioning, we are not capturing the people that we want to capture and we are not necessarily addressing all the people that we want to address.

DR. DANIELS: Thank you, Sam. We will take three more comments and then we will try to close this session out.

Next is Paul Wang.

DR. WANG: I am unable to start my video but I think you can hear me. I wanted to register my support for the thrust of the remarks that Alison Singer made. I should acknowledge that I was a co-author of The Lancet Commission piece where this term “profound autism” was introduced and discussed.

I think the thrust of Alison’s remarks is – the thrust is something that we can all support. It is essential to ensure that supports and services are made available, are accessible to those with these extensive support and service needs that are appropriate research – as well is focused on this particular group.

This point is independent of whether IQ is a good predictor of who needs extensive support needs. It is independent of what the present composition of this committee might be. It is independent of whether you really like the term “profound autism” and want to use that extensively or not. In fact, the recognition of this group should be considered part of the neurodiversity perspective because diversity does not just refer to those who are more functional, but diversity is diverse. It includes this very important group where we really have to ensure that supports and services are made available. Thank you.

DR. DANIELS: Thank you, Paul.

Next, Alycia Halladay.

DR. HALLADAY: Hi, everyone. I will not take up too much time because I think that there is some misunderstanding about the term "profound autism". And we are very lucky to have Cathy Lord, who led the commission to explain what exactly this label is and how it is to be used.

I will also say that while I just joined as a member, I have been going to IACC meetings before COVID and watching IACC meetings for years. And some of the issues around things like employment and housing have been debated on these IACC meetings. In fact, this label of profound autism seeks to maybe resolve some of the controversy around appropriate housing and appropriate employment options.

Also, just quickly, I want to address the comments that were made about screen time. I want to plug in for something called Autism Navigator and Baby Navigator. This is a project led by Florida State University and it actually provides webinars twice a month to families and also professionals about not just detecting early signs of autism but providing one-on-one support from parents to infants and toddlers about how they can incorporate skills around things like communication, following directions, social interaction. It is done mobilely, but it does not rely on screen time. Perhaps we can have a further conversation about it. I wholeheartedly agree that perhaps some of these preemptive moves may alter the trajectory.

DR. DANIELS: Thank you, Alycia.

And our last comment will be from Ivanova.

MS. IVANOVA SMITH: This is Ivanova Smith. I am from Washington State. I wanted to say I’m an IACC member, self-advocate. I am very passionate about making sure all autistics are treated equitably and treated with respect. My concerns with the comments about promoting this profound autism idea is that it be used to restrict people’s lives and it will be used to justify institutionalization and restricting people’s civil rights based on that diagnosis.

When I was born, I know firsthand how diagnoses are used to restrict people’s lives and put people in institutions, segregate people in their work, segregate people from the community. That is my concern with the profound autism idea is it would be used to restrict people’s rights. How would we make sure that profound autism would not be used in that way to restrict people’s rights and make it so people are not institutionalized? I do not think any autistic no matter what label you put before them should be institutionalized and restricted in their daily living. That is the main concern many autistic people have is these terms being used to restrict people’s lives because that is how these terms have always been used historically. These functioning labels have been used to segregate people, put them in institutions, not give them an equal education, saying people do not need an equal education, say people do not need this or that. I do not think that is how we should use that term. And if that is the reason we want that term then it is going to hurt people and it is going to hurt the profoundly autistic.

I would much rather we make sure any term we use, any functioning label we use would not restrict people’s civil rights and it would not force people to be put in an institution. That is my concern is we do not want this language to be used to restrict people’s rights and not just institutionalization, but guardianship, education, even like education on how our bodies are. I do not want profound autism to be used to say that you are mentally a child so you do not get to do adult things because you have this label. I want to make sure that that label will not do that. Thank you.

DR. GORDON: If I might, I just want to inject here. Thank you very much, Ivanova, for that perspective. It is really important that we not use labels improperly. However, and please if someone else from the committee would like to say something on this topic, I think we should extend this for just a moment longer. I think, Ivanova, with all due respect and the others on the committee, your comments actually bring to heart really Ms. Singer’s comments in that there are some individuals on the spectrum, and it is quite a lot of individuals, I do not know if it is 50 percent. I do not know if it is 20 percent. But there are many individuals who need to be in places where they can get the supports to enable them to live their lives. They need to be in places you might call institutions. They need to be under care, including at times need to have trustees to watch after --

MS. SMITH: I am sorry, but I will respectfully disagree. They said that about me – I do not think that --

DR. GORDON: Ivanova, please. I gave you the opportunity to speak. Please give me the opportunity to speak. Please respect me enough to give me the opportunity to speak as well.

I am not suggesting that you are one of those people. I am suggesting that there are people around this table, including some of the self-advocates, who are caring for individuals who do need that level of care and that those voices need to be able to be expressed around this table.

And to say that no individual with autism should be institutionalized misses the point that there are individuals on the autism spectrum whose deficits are significant enough, whose care needs are significant enough that they do need that level of care. I do not know what percentage. I am not pretending to tell you what percentage it is. And I certainly am not suggesting, Ivanova, that you are one of them. But I am suggesting that that is a voice we need to be able to hear around the table. If we do not allow that voice around the table, we are not doing our due diligence.

MS. GASSNER: No one is preventing them from being heard, Josh. We are disagreeing very respectfully and very politely, and we are the only ones that are getting negative feedback from you about us speaking our truth.

DR. GORDON: I do not mean to be giving you negative feedback about you speaking the truth. As I have tried to say, I value these opinions tremendously and it is important. But I am pointing out that of the voices we have heard today, we have not heard that other side and it is not because it does not exist.

MS. ONAIWU: You are assuming you have not heard the other side. Can we take a break?

DR. GORDON: Let me just say that anyone who needs to take a break should feel free to do so, but I do not want to cut this conversation short.

MS. CRANE: I want us to understand that this is not about who has different experiences. Many of us have direct experiences with people with extremely high support needs. This is a political disagreement that is being recast as a disagreement between people with different experiences. I do not think that it is about different experiences. We have many people who have supported people with extremely high support needs in the community, using home and community-based services, 24/7 supports in the community. Saying that these supports have to be delivered in an institution, that is, I think, a policy disagreement, not a disagreement over whose needs are being represented.

DR. JENNIFER JOHNSON: Hi. This is Jennifer Johnson with ACL. I just want to echo Sam’s comments that what we are talking about is really the – we lack the adequate the home and community-based services and supports for individuals to not only be able to speak for themselves and communicate in a way that people can understand them. I think we make the mistake when we say that while we might want to characterize people as being non-verbal, they are still communicating in one way, shape, or form and we do not necessarily at this point in time truly accept the various ways in which people can communicate. This committee is not structured necessarily in a way that allows for that kind of communication to occur.

I do think we need to be careful about how we are characterizing these things and also acknowledge that the way we are characterizing this is in the current context of the services and supports that are being made available to people to be able to live independently in the community and that is very different in each state. It is different in each territory. It is, as Sam said, very much driven by politics and what we are willing to invest in terms of institutional care versus home and community-based services. I do think we need to be very careful when we are trying to characterize the individuals that we are talking about, the way they can participate and represent themselves in these conversations as it relates to the current level of services and supports that they are getting and that is also driven by the research. I just want to add that in and echo Sam’s comments on that regard.

DR. GORDON: Very good, Jennifer. Let me just be very clear. I was careful not to suggest that there are individuals who “need” to be institutionalized, but that there are many individuals who need the level of care that Ivanova was inferring by the term institutionalization.

DR. JOHNSON: Just to respectfully disagree, the reason they need those institutional services at this point in time is because we do not have adequate home and community-based services. As Sam said, people can be served in the community and we have seen people with intense needs.

DR. GORDON: I am not disagreeing with you.

DR. JOHNSON: But that is the way – I am just saying that that is the way it is coming off and that is the way it is being heard.

DR. GORDON: I apologize if that is the implication. I was trying to be very careful to say that it is the level of need that I am discussing and not the venue of care. Perhaps we should take Matthew and Yetta and then move on to the presenter.

DR. DANIELS: And we had Jenny Mai Phan who had sent in a comment, and I have that one as well.

DR. SIEGEL: Thank you, Josh. Returning to the research, which is the charge and focus of this committee, is advising the federal government on the research portfolio and where it should head, which then relates to service and policy and ultimately politics.

I think that it is important that The Lancet Commission, which spent almost three years working on this. One of the few very clear recommendations they made was this distinction about profound autism, and the purpose I think was to drive more research and ultimately more services. I think it is important to point out that the autism research world has really turned on its head in the last 20 years. We published a paper in 2018 in JADD. Steban(ph.) is the first author, where we analyzed all the treatment studies in autism that we could get our hands on from 1990 to 2013. There were 367 studies. And we very carefully analyzed them for inclusion of people who had either intellectual disability, minimal verbal ability, which is how we defined it at that time, or lower adaptive functioning, which is very similar to the profound autism definition proposed by The Lancet.

And the finding was simple, which is that it went from almost all of those treatment studies, including that group to about a third in 23 years, including them. In other words, two-thirds of the research, treatment research studies done did not include individuals with what would currently be called profound autism. That is, I think, a very important context to have in mind and perhaps why we see some of the reaction of people feeling that there needs to be some greater, that this has now become an under researched and underrepresented group, which is really a great irony given where autism started and so therefore, a need to focus on this group. I would suggest an objective in the new Strategic Plan should be on research services and policy for those with profound autism. Thank you.

DR. GORDON: Thank you, Matthew.

And last but not least, Yetta, please.

I am sorry, Nicole. This discussion period is reserved for members of the committee itself. My apologies.

Yetta.

MS. MYRICK: Thanks, everyone, for your comments. As a parent of a young adult who has autism intellectual disability, this is very emotional. I am not going to pretend to know what it is to be someone who is autistic. But I think at the root of all of this is access to services, making sure that autistic individuals get the level of support that they need and that is why we were selected to be on this committee to give that voice to take our lived experience and make sure that we are thinking about the community as a whole. I value everyone that is here. I value everyone who is either a parent or an individual. We all have these experiences, and they are valid.

The challenge is making sure and again what we were charged with is making sure that the research is reflective of where the needs are. Where do we need to be focused? Who is high functioning, who is non-speaking? It gets to be overwhelming and frustrating to be quite honest for me specifically because I do not do this work to support my son, to support others and/or to work in community and partner with autistic individuals for there to be this fighting. I really want us to take a deep breath, which I am doing right now, and want us to really figure out where we need to be focused, focusing our attention of what it is that we need to get done because I want to ensure that when I close my eyes that my son is safe, that all of you are safe, that you feel like you are a meaningful part of society, that you feel included just like I am someone who is not and want that for myself. That is why I serve. I believe that is why we all serve. I just want everyone to bring it back and focus on what is it that we need to do. It is healthy to agree and disagree. But I do not want us to lose focus. I appreciate your comments. Thank you for giving me a moment to speak.

DR. GORDON: Thank you, Yetta, and that is wonderful way to conclude this. There were a lot of powerful statements and a lot of emotion, but I think a lot of points were well said. We need, unfortunately, to transition now to the next session.

We were meant to start at 1:45. We are about 15 minutes late. With an apologies to those of you who would like a break between this and the next session, we are going to move right into the next session. Later on, we are going to come back to The Lancet Commission Report. That will be in just about an hour. But for now, we are going to turn to a presentation from Dr. Matthew Maenner, I hope I am pronouncing that right. Please correct if I am not, who is from the Centers for Disease Control and Prevention, their Surveillance Team. He is going to share the latest updates from the CDC on autism prevalence. Dr. Maenner.

DR. MATTHEW MAENNER: Thank you and good afternoon. We appreciate the opportunity to provide an update from CDC’s Autism and Developmental Disabilities Monitoring Network or ADDM Network for short.

DR. GORDON: We can see but it is not in presentation mode.

DR. MAENNER: It always gets me. Last month the ADDM Network published two surveillance summaries on the prevalence of autism and another on early identification of autism from participating communities in 2018. I will review some of the main findings of these reports and then describe the current state of the ADDM Network.

The ADDM Network is a population-based surveillance system that monitors autism among children living in multiple geographically defined areas. The ADDM Network has reported autism prevalence among 8-year-old children every 2 years since the year 2000. Highlighted in green are the areas comprising the 11 participating sites for the 2018 surveillance year. While this is not a nationally representative sample, it covers a large population and is composed of geographically and demographically diverse communities.

The activities supported by ADDM have changed a little over time and this table compares the current ADDM Network to the 2016 ADDM Network. There are still 11 sites overall. It is a competitive funding process so not all the same sites. CDC expanded the tracking of early autism identification among 4-year-old children to all of the sites while previously it was in subregions of only six sites. This tripled the total population monitored for this activity. All of the sites track autism prevalence among 8-year-old children and a new activity hopefully coming out later this year is following up on children at age 16 that were previously ascertained by ADDM at age 8.

The latest reports use a new autism case definition, which as in the past, is based on information collected from health, education, and service records from multiple community sources. The child was considered to have autism if they lived in the surveillance area in 2018 and ever had documentation of a written autism diagnosis, a special education classification of autism, or had an autism ICD code, which is a medical billing code.

New to this year and just for the 4-year-old children, the ADDM Network also ascertained instances where children did not meet the autism case definition but had a documented suspicion of autism in the records.

These changes were the result of intensive planning, evaluation, and analysis and are described in a paper in the American Journal of Epidemiology from last April. The paper compares the new case definition to the previous one for the prior two surveillance years. In almost all situations, autism prevalence and other indicators were very similar, sometimes even unchanged, using either case definition. By the way, this would not have been the case twenty years ago when ADDM began. The paper shows how things have changed over time but the new case definition requires considerably less data collection, and it simplifies the process for managing and reviewing information. This allowed the ADDM Network to disseminate results faster to fund more sites doing these activities than would have been possible under the previous methods. And in retrospect, it was much more robust to barriers accessing data caused by the pandemic.

Perhaps most important, the new approach more transparently reflects that children are being evaluated and served in their communities, which aligns with the purpose of public health surveillance to inform and ultimately improve practice.

With that background, here are some of the findings from the report on autism prevalence among 8-year-old children. This chart shows the overall autism prevalence for every ADDM surveillance year and the 2018 result is represented by the rightmost bar. It is corresponding to 2.3 percent or 1 in 44 children. While there is a general upward trend over time, it is important to remember that some of the participating communities change from year to year.

These bars show autism prevalence observed at each of the 11 sites. As in the past, there is considerable variability ranging from 1.7 percent in Missouri to 3.9 percent in the California site. The green areas of the bars indicate children that have a documented autism diagnosis in the records. The blue represents children that did not have a diagnosis but were classified in an autism special education program. And the purple are children that only had an autism ICD code. As you can see, the ICD only group is just a small percent of all children, which is reassuring.

The reports have more information showing how children were ascertained in each site in different break-downs. That can provide some context in evaluating site-to-site differences.

This figure shows autism prevalence by race and ethnicity. There was little differennce overall between white, black, Asian, Pacific Islander, and Hispanic children. However, several communities within the communities reported lower prevalence among Hispanic children compared to white or black children. For the first time, the ADDM Network included an estimate among American Indian and Alaska Native children. It was a little higher than some of the other groups. But it is also a really small population. It has a bit less precision than the other groups.

The ADDM Network also collects IQ or adaptive test information. Of the children that had cognitive test information, about 35 percent were classified as having an IQ less than 70 or intellectual disability. This year the proportions among boys and girls were similar. But there continues to be a higher proportion of black children with autism that are also classified as having intellectual disability compared to white or Hispanic children with autism. The reason for this is not fully understood and it could be influenced by inequities and ascertainment for access to services.

This figure – it is just a simple analysis comparing autism prevalence by neighborhood-level income. Previous ADDM studies have shown a robust positive association between neighborhood socioeconomic indicators in autism. But as you can see here with all the sites, there is not a consistent pattern that we would have seen in the past. A more focused analysis on why this might be different would be helpful.

One thing that really was not emphasized in this report that maybe has a little bit in the past is the statistic about the average age of the first autism diagnosis. And this figure shows the overall median age of the earliest autism diagnosis over the years in ADDM. There just has not been much change and people have interpreted this to mean that perhaps there has been no progress.

However, that might be a misleading interpretation of progress just due to the metric that is being used. In a paper that came out the week before Thanksgiving, which was the week before the other ADDM reports, Dr. Kelly Shaw compared different metrics of measuring early autism identification. To summarize, the median age measured that was used in the past shows very little change over time where representing this as cumulative incidence of autism identified by 48 months has quadrupled over the same time period.

Furthermore, reporting cumulative incidence reveals racial disparities that are masked when examined with that median age measure. There is a lot more in the paper, but it outlines the reasons why we chose a metric that is sensitive to both showing change over time and important disparities. And the article up in the corner – it was accompanied by a really thoughtful commentary by Dr. Sheldrick, they didn’t bury the lead, it is time to move beyond the median.

Therefore, the ADDM Network focuses on early identification in a separate report, featuring children aged 4 years. And these are some of the findings from that report. This is a bar chart of autism prevalence among children aged 4 at each site. It is analogous to the one I showed you a moment ago for the 8-year-old children. At 10 of the 11 sites, autism prevalence was lower in the 4-year-old population than among 8 years old. And California was the exception, where prevalence was actually a little higher among 4-year-olds.

This figure takes the bars from the previous charts. Those are now gray. And then on top of them in orange is the children that were only suspected, but not yet identified as having autism. There is some site-to-site variability, but it is small compared to the amount of children that are identified with autism.

While in the data on 8-year-olds, we see that many children are not first identified until age 5 or later. It was a little surprising to some that these suspected children did relatively little to make up the gap overall between the 4 and 8-year-old prevalence.

This figure shows autism prevalence by racial and ethnic group again among the 4-year-old. And it shows a different pattern than among the 8-year-old children. White children have among the lowest autism prevalence compared to the other groups. And the finding for higher prevalence among Hispanic children is not only due to California. It was actually observed at five sites. It will be interesting to see if these patterns – if this is what we will see in the future among 8-year-olds or if this reflects different factors associated with autism identification at young ages.

Here is our cumulative incidence figure showing a higher cumulative incidence of autism identified by 48 months among children born in 2014. They were 4 in 2018 compared to the 8-year-old children who were born in 2010. Through age 4, the younger cohort in orange is up facing the older cohort in blue.

This actually might be the single most informative figure in either report. This is the same chart as the previous slide. But not each site is shown in its own facet. Most sites show more early identification among 4-year-olds, but a few do not. Again, it will be interesting to see if these trends continue into the future.

I just wanted to mention a few other things that the ADDM Network is working on this year. As I mentioned earlier, for the first time, the ADDM Network conducted a follow up of children at age 16, looking at health conditions and planning for a transition into adulthood. There is also a paper estimating how many children might meet the description of profound autism. The goal is to contribute population data to these conversations and to better understand who the term might apply to. Maybe these data could be used to inform how it could be useful.

There is also a pilot study that some of the sites are doing using data linkages for efficient statewide autism prevalence estimates. This is not to replace the core ADDM activities, but to explore ways to efficiently generate data for communities that have never had local data.

The ADDM Network is also continuing to conduct surveillance for the 2020 surveillance year and should be well situated to observe any disruptions in evaluating or serving children with autism during 2020.

These are just the references to the four articles that were in these slides. There are also resources in addition to the scientific reports. There is a nicely designed community report that summarizes the findings for people that might prefer that to the scientific papers. It is also available on Spanish on the web. There is a slide deck with the latest ADDM findings available, including many of the slides that I used in this presentation. Our division here, also creates easy read summaries for the MMWR reports. And we maintain and update an interactive website, showing ADDM data and autism data from three other state-based data sources. You can look up what is available for whichever state you are in. We hope you find these helpful.

Finally, I would like to acknowledge really an amazing group of scientists and public health professionals that make this work successful. It is a lot of work and hard work especially with the challenges of the past couple of years. It is really a privilege to have such passionate and brilliant colleagues. Thank you for your attention. I am happy to respond to questions or comments if there is time.

DR. GORDON: Thank you very much, Dr. Maenner. Did I get the pronunciation by the way correct?

DR. MAENNER: Yes, you did. It was good.

DR. GORDON: We have a number of questions, and we are going to start with Joe. Dr. Piven. Joe, please.

DR. JOSEPH PIVEN: Thanks. Thanks for a really clear presentation. I just thought I would take this opportunity to ask you a question. Not meant as a criticism. I think there is always the potential for confounders and biases. But can you speak to the issue of ascertainment bias when you ascertain the samples through the school system? There are lots of ways to do these studies. In the old days, I am old enough to remember and psychiatric disorders, the ECA studies where ascertainment at least in some of the sites were door to door. As a child psychiatrist, I know the pressures that we have to make a diagnosis of autism to get services for kids.

I think it is notable of the variation of prevalence rates from California to Minnesota to Maryland. I just wanted you to speak to the issue of how that ascertainment scheme might be affecting these numbers.

DR. MAENNER: It is a big issue to consider. Really, it should be a core part of the interpretation of any of these in terms of your question about identifying a target population for a public health surveillance system like this. The population is every child that is in an area so it is not just children being served in school or participating in a service system, which is why it is so critical, to link multiple sources of medical and educational professionals with service providers to try to cover the population as best as possible and the ability to do that I think at the sites is continuing to improve. Kind of behind the scenes, we actually have been working – had a really nice collaboration with the Office of Special Education Programs Privacy Office to help draft a template to better utilize education data for public health surveillance in a way that meets all of the privacy requirements both on the health and education side.

There is differential access that the surveillance systems have which I think is lessening over time. But I think the big thing is just what services are in the communities. I think there has always been variation from site to site. There has been variation by wealthy and poor neighborhoods. I think it would seem most likely that these variations are just reflective of who is being identified and what the practices are and which children may or may not be getting served. I would take that as the primary interpretation of what we are seeing.

DR. PIVEN: Do you think there is a need for an all-time, door-to-door study to validate these rates and take out the issue of service as the confounding factor?

DR. MAENNER: That would be an interesting study to do certainly. I think it would probably be extraordinarily expensive. It would not fit the rubric of what public health surveillance is though. I think that maybe the most useful thing would not be to say like is ADDM getting the right numbers but are community providers effectively identifying children. The goal of our program is to inform practice and the focus should, I would argue, be on using these data to examine issues related to practice or ways that things could be improved. That kind of door-to-door study – I think as an additional thing if people are able to do that, I am sure people will find it interesting. But as you know, the question of what is the gold standard would be tough, as would differential participation. It is hard question.

DR. PIVEN: Okay. Thanks. It was meant to be.

DR. GORDON: Sorry. Go ahead, Yetta. You are next.

MS. MYRICK: Good to see you, Dr. Maenner. Thanks for presenting. Quick question. How are the ADDM Network sites selected? Because I do not think I have seen that information anywhere or if you could direct me to that. And then are there any plans to expand the network not that you do not have enough on your plate already, but just thought I would ask.

DR. MAENNER: Great questions. Nice to see you as well. It is a competitive process. The ADDM sites – however many cycles are funded in four-year cooperative agreements. It is an open competition. We fund as many sites as we have resources to support. We were able to do more than we would have in the past based on the efficiencies that we have been able to implement.

Would we expand? Yes. We would love to be in every state. It is just the opportunity and resources to do that. But we would definitely want to, of course. But it is more about how could we support it.

MS. MYRICK: Thank you for that.

DR. GORDON: Dena.

MS. GASSNER: Hi. Thank you again for your presentation. I do appreciate it. I just wanted to ask two questions and I will be brief. The first one is when you look at these 16-year-olds, is it the same people that you have already identified previously or is this a new random sample?

DR. MAENNER: It is going to be children that were identified previously that had at least some indication that they might have autism. It could be children that were never diagnosed and still do not. It could be most of the children did have autism. It is possible to pick up some children that were formally identified in the community after age 8 or maybe as teenagers. It is sort of seeing what has happened since this group was ascertained at age 8.

MS. GASSNER: I would love you to respond to a question again about selection bias. Given that many children who have intellectual disabilities or who may have co-occurring Down’s syndrome, may have been previous underdiagnosed and not assigned an autism diagnosis. Many autistic individuals are in schools under 504 plans where they do not even categorize the nature of the disability that determines eligibility. What have you done to eliminate those aspects or at least try to be preventative about those aspects of the bias?

Lastly, what are we doing to identify this in adulthood because so many people did not even get identified in early childhood? Thank you.

DR. MAENNER: Thank you. Those are good questions and those are things that we spend a lot of time thinking about. It is hard because we are – we base our work using the existing service and education infrastructure and it varies from place to place. If children might not be identified as having autism because they have 504 plans, we are trying to find them maybe in other systems.

Maybe they are receiving autism services through state-funded Medicaid programs. Maybe they are diagnosed with autism at the doctor’s office. We try to link all of the sources we have available and just say what we can find.

In terms of co-occurring conditions, we do track when those are documented for select things. It is an interesting idea for an analysis to look at whether the proportion of children with certain conditions like Down’s syndrome or other established conditions that would have been ascertained over time whether that their representation is changing among children with autism.

For adults, that is another really important – many years ago in my – when I came to the fellowship program at CDC, I said I wanted to lead the agency in doing something with adults. It is hard to change things. But we are taking steps to start looking at adolescents. We have some great scientists within the network that are thinking strategically based on our current activities. Can we link forward after high school to start looking at outcomes? We are intensely interested in doing more with that. But, again, it comes down to the resources and the opportunities that are available to us right now.

DR. GORDON: Thanks. Larry, you are next.

DR. WEXLER: I am sorry. It said the video is stopped by the host.

Matthew, thank you. Can you just talk a little bit about how or if you use the OSEP data, the Department of Education's data?

DR. MAENNER: When you say OSEP data, do you mean data that OSEP holds or data that is covered by FERPA policies? Because the way the surveillance system works is it is all data collection from state or local entities. We did have a really nice consultation and collaboration with your privacy office that helped us outline a data use agreement between local entities to incorporate special education data and to do it in a more formal way that meets all the legal requirements. But we do not get any data from a federal source at this point.

DR. WEXLER: Our data are public. There are not FERPA issues with our data. Any state data that you want to reference to, we have those - it is on our website. We would be happy to - I oversee all the data. It is one of my side jobs.

DR. MAENNER: Oh, cool. You mean like the child count data and stuff like that.

DR. WEXLER: Yes.

DR. MAENNER: That is a slightly different thing. In our surveillance work, we do need identifiable information to do securely within the states make linkages to know if a child in school is the same child that is receiving Medicaid services for autism. Then that identifiable information is destroyed and then as an analytic extract then it is de-identified and moved on.

The child count data – you are right, it is great. We actually do use it. We have a data visualization site for different autism data sources. And once a year, we do try to put the latest child count data so people in every state can compare for whatever state they are in, what is the special education prevalence of the autism category versus Medicaid or the surveys or ADDM if there is ADDM.

DR. WEXLER: Just two things very quickly. One, just be aware that any of our data about 3- to 5-year-olds is usually oddly skewed in the sense that states are allowed to report children as developmentally delayed as opposed to putting a disability category on them. There is a large group that are in fact in that category. It under-counts specific – results in under counting of specific disabilities.

And the other thing is just an offer that if you want to get together with our data team who are pretty terrific, we would be happy to help you facilitate anything within your analyses to explore our data. It is an offer.

DR. MAENNER: That sounds wonderful. Thank you very much. We have a couple of really excellent scientists on staff that I think will be eager to get in touch with you and your team. Thank you.

DR. GORDON: We are going to take two more questions. JaLynn and then Scott. Go ahead, JaLynn.

MS. PRINCE: Thank you very much and thank you Dr. Maenner for that excellent presentation. It is nice for us to know what is coming up through the pipeline. I still have some questions with the CDC and looking at adult statistics. I know there have been some extrapolations and things that have come out. I am glad to say. I was so sorry to find that your data had been hidden in the middle of the COVID epidemic because you could not bring things forward when you had to work on just COVID things. It is helpful information to us.

I do have a 32-year-old son who is kind of on that edge of the tsunami wave. But we are seeing so much more within our circles of working with adults with autism. But we do not have really accurate data and I do not know how one goes into do that to find things because there is not the school. There is HIPAA. There are all sorts of things. Some people have not been diagnosed before. But it is hard for advocacy to go in and ask states to help put things together for adults without having that information about how many adults or what the prevalence is. I think there is a huge challenge there. I think it is very much a public health crisis because a lot of the things that we are seeing and a lot of the reports we get from families. It is interesting that with Social Security, you have to be identified before 22. But then there are adults. Is there anything that is standing in CDC's way from stepping forward to doing more research on adults?

DR. MAENNER: Well, I think – that is an interesting way of phrasing that question. There is incredible interest here in expanding. Historically, the programs have all been anchored in focusing on children in both in our surveillance work and in the research program at CDC, the study to explore early development. We are moving up the age range into adolescents and certainly for the SEED research project.

I think maybe some of that cohort, they are following – some of them might be starting to reach adulthood when they get through that. It is tough to wait for longitudinal data in real time.

Our activities are described through a congressional – there is a language about what we will do. I think we certainly would take any opportunity if we were able to expand into adults and have more programs in that.

MS. PRINCE: That is helpful information. Thank you very much.

DR. GORDON: Scott.

DR. ROBERTSON: Thank you, Dr. Maenner. I appreciate the presentation. I would like to concur with other folks who have brought up the adult focus. I think that we are very significantly behind the curve in comparison to say other countries, including United Kingdom, Australia, et cetera. UK has been doing adult tracking needs assessments, et cetera, since 2009. We are talking like the last 13 years. Australia also tracks a lot more on the adult focus/adolescent focus.

What I wondered is do we have the possibilities and I do not know if it would help foster things here, drive the ball forward here is maybe collaborating, maybe could you potentially be connecting more with your international counterparts, United Kingdom and Australia, to learn about what they have been doing for many years in terms of tracking, monitoring adults looking at needs assessments nationwide. I know there are smaller countries there. But I think maybe there are best and promising practices and approaches that they have been doing that could be adapted here and maybe could help facilitate the move toward having more focus on adults as far as again needs assessments, monitoring, looking at where the current status is as far as the lived experience in terms of the challenges that folks have and to help to have more concrete data rather than just estimates for autistic adults as in that paper although the estimate was helpful.

And then the second part of this is are there promising and best practices in the

ADDM Network right now and in SEED that could be also helpful that you think could definitely be applied for again having needs assessments across the United States for a plethora of different focuses for autistic adults and monitoring and tracking, where challenges lie, and what the current state in terms of the context for the population as folks age into and through adult life looks like. If so, can you share any of those specific promising best practices you have right now that could be applied to that adult focus?

DR. MAENNER: Thank you for your questions and comments. The idea of looking at what international groups are doing is excellent. I think as you were saying that what came to mind is cerebral palsy surveillance, which Australia, the UK, Scandinavian countries are like really the leaders in something like that. I feel like being more familiar with the population-level efforts in those countries and maybe connecting with them could be helpful and informative for our future work.

In terms of our work informing needs assessments, I think the goal of public health surveillance is to inform practice. It is done at a population level though. It might suggest clues in disparities or things that seem to be happening or are not happening that would warrant further investigation and conversation at least. But SEED is – I know that they pivoted in the last year and a half or so to do a COVID impact study to learn how families have been affected by the pandemic. I agree with you. I think there is a lot more we could do to think about how best to serve people and understand what their needs are currently.

MS. GASSNER: Just to clarify, I think Scott was referring to international studies looking at prevalence in regard to autistic adults. There is actually research out about that. Just to clarify. Thank you.

DR. ROBERTSON: Yes, very briefly, Dr. Gordon, I just wanted to clarify on that. Yes, I was referring to that the United Kingdom, for instance, has had a loss since 2009. It was around needs assessments for autistic adults. They did it across the entire country. They have expanded on that and enhanced that at the local level actually and then brought it all the way up to the national level. That has really driven a lot of what they have been doing for their service system to better meet the needs of autistic adults and some of the gaps that we often point out here in the states as far as employment, community living, transportation, health care access, et cetera, for autistic adults. They had more data to inform that with those needs assessments and monitoring and tracking. And there are similarities in some of the systems like in Australia. That is why I think it would be of even greater benefit than I think connecting with the folks as far as CP International, Cerebral Palsy International because those folks have actually focused specifically on autistic adults, which would be as I say a natural extension of what you have been already doing with ADDM and SEED, especially now that it is moving into that shift around adolescents, looking at older children as they age into adolescent life.

DR. GORDON: Thank you, Scott. I appreciate the point and thanks again, Dr. Maenner, for an excellent presentation and for entertaining these thoughts. We will I am sure have opportunity to revisit the issue around quantifying needs for adults at a later time.

We are now going to move on. We are about ten minutes late. We were due to take a 15-minute break. I think we desperately need this one. We are going to ten minutes now. We will start the next session five minutes late. It is 2:40. We will see you back at 2:50. Everyone shake a lag. Do what you need to reset yourself and we will come back and hear about The Lancet report.

(Whereupon, the Committee took a brief break starting at 2:42 p.m., and reconvened at 2:52 p.m.)

DR. GORDON: For the next segment today, we are going to hear from Dr. Cathy Lord, who is the George Tarjan Distinguished Professor of Child and Adolescent Psychiatry at UCLA David Geffen School of Medicine and the Semel

Institute of Neuroscience and Human Behavior. Dr. Lord was a member of the Lancet Commission that produced the report, which we have heard a little bit so far. And we are really pleased to be able to welcome her here today to update this committee and all the observers over the internet regarding the content of that report and its meaning for the future of health care and clinical research in autism. Dr. Lord, thanks for joining us today.

DR. CATHERINE LORD: I need permission to share my screen. Hello everybody. I have been sitting in since 7 this morning. I have been very impressed with the level of discussion and both the passion and restraint that people have exercised.

This list just shows you all the authors of the Lancet report. I titled it An International Perspective because --

DR. GORDON: Sorry. We are not seeing your slides.

DR. LORD: Let us see why not.

DR. GORDON: I only see your video. I do not see that you are sharing anything.

DR. LORD: Now they have blocked out the – maybe Anthony should just go ahead and share them because I can see them but I cannot even get to – here we go.

DR. DANIELS: And then the controls can be turned over to you.

DR. GORDON: They were there for a moment. Now, they are not anymore. Now, we can see the slides.

DR. LORD: I will go with those slides. Let me make this bigger.

DR. GORDON: We can see it just fine.

DR. LORD: Okay. Mine is very tiny but I think I will remember what I said. It is okay. I will just go with this.

I think what I wanted to do is just tell you a little bit about the process, so you have some idea of where these things come from. I think this is actually – I was asked to chair this commission by Lancet. And Tony Charman volunteered. We had just done - and he volunteered to co-chair with me, which was great.

And then Tony and I and Lancet tried to put together an international committee that reflected a range of different disciplines, countries, ethnicities, and perspectives. The group ended up having – coming from six continents and representing I think 13 different disciplines. We had three in-person meetings, including two conferences that followed meetings at UCLA and one in London.

And what we did was that the group, which overall had 32 members, divided into committees. The committee outlined sections, presented the outlines at the second meeting and possible recommendations. Everyone talked about them. People wrote things. It went back and forth in the full group and the next group and produced a formal first draft, which was then reviewed by three reviewers outside the committee.

We then did more revisions and reviews. We had two rounds of Lancet edits by people working for Lancet. And there was a final launch and publication in December of 2021. This was funded by basically from I raised money from autism advocacy organizations, from not-for-profit family foundations, and UCLA supplied some money. And none of us were paid for doing this at all.

Just two side notes. Hard copies will be available in the spring. I think they made – I cannot remember how many, but Lancet is going to produce some hard copies. If you are interested, let me know. I have also promised to write a plain language version, which will be done just as soon as I can get it done. And then we will have other people review it.

I think the first point is this is an international group and the first main thing people wanted to see and it is hard right now and so much is going on certainly in the United States and all over the world. But there is some urgency in addressing ways to improve the lives of all the people with autism in the world and their families.

I am preaching to the choir, talking to you all. But I think when we look at, for example, how much of the research money is spent, it is providing valuable information, but not having much direct effect on lives of people with autism and their families.

I think a second point is there is a fair amount of evidence and scientific data that we can use. But we need to have strategies for how do we use that data to better see what we can do to support systems and interventions, and for whom, when, and with what intensity, as well as how. And part of that is because autism is so heterogeneous. And group data only gets us so far. It is really backed a little bit to Matthew’s point, about median.

We acknowledge the autism is a neurobiological condition that basic and translational science efforts are very important. But I think the simple answers that 50 years ago we thought we might get if autism was produced by three genes and we could figure out what those genes are then everyone who had one of those genes could not eat broccoli has not happened.

We also want to call attention to the fact that the clinical challenges that autism raises for society and for autistic people and their families are unlikely to be solved by biomedical solutions for most people in the near future.

Our group decided that we were going to focus on recommendations for things that if put into effect could make a difference in the next five years. And for that, we wanted to focus on targeted research that can change lives now by improving mental and physical health of people with autism so not necessarily changing core features but trying to figure out what makes the difference in strengthening support systems. Again, it is not like, as you have talked about all morning, it is not like no one does this already, but to do this on a larger and more focused scale. That takes into account immediate and long-term effects on the quality of life for autistic people and their families. I think back to the comment that one of the members said is that we are focusing on autistic people. But with autistic people come families and a very high proportion of autistic people are still very involved in their families. We do not want to forget that.

We want to focus on research that has immediate improvements and how on earth do we get the government and funding agencies to actually do this because it is a very complicated system, as we well know, through federal funding, not just NIH, but in the UK, in Australia, in Europe, even in South America.

Again, this is based on the idea that autism manifests itself differently between individuals and that there are huge ranges, which you do not need me to talk about right now. You know. But also, that autism manifests differently within individuals across the lifespan. It is a developmental condition and people need different supports and can benefit from different interventions at different points in their lives. And the reality is we have separate studies that address, for example, adults and kids but we have not a lot of information about what might work with a 2-year-old, what might work with a 5 year old.

We proposed the term profound autism, which I will come back to. I think here we were not trying to create controversy. But we were concerned that sometimes the needs of autistic children and adults with severe intellectual and communication disabilities cannot speak for themselves and need extensive care throughout their lives are not addressed as often as we would like and as carefully.

We also want to recognize though that many autistic people have strengths that contribute to every step of society and that there is an importance to value autism in neurodiversity, which benefit everybody.

This is a very complicated slide. Basically, what it says is that lots of different issues interact across development to affect people with autism and actually this is probably true for everybody. But it is particularly important in autism because if you have, for example, unusual experiences and you have a biological risk of having particular difficulties, those experiences may result in greater difficulties than are really necessary.

The idea is that as you move from left to right and across time, you see different aspects of the environment and of experience causing different kinds of difficulties, which might include, for example, restricted access to jobs, which we have heard about this morning or limited access to doing something, vocational or leisure skills that you might enjoy where increased risk of other kinds of mental health difficulties.

Our point though was that change is possible. I think no one in this group would disagree with me, but often it is. We talk about autism as a lifelong disorder. But sometimes people think that means nothing can get better and that is just not true. We have a lot of evidence that there are ways of making things better in terms of both the environment and in terms of giving people skills and strategies that can help them adapt to the environment as well as changing the environment.

This is just a summary by a paper that many of you will have seen by Sandbank. But there are lots of data particularly about early interventions with young children. And some of these interventions have even been attempted in organized, randomized, controlled trials in lower and middle-class countries.

There is also pretty good agreement about helpful intervention strategies like Sam Odom’s list of all the different things that you can do. There is much less agreement on what works, which is really interesting. We do know something, and people every day are diagnosing psychopharmacological treatments particularly for co-occurring conditions in later childhood adolescents and then adults.

The point here in looking at this slide is that anything to the right of the line means that there was an improvement, a significant improvement over a control group.

But also, the point here is that if you – that most of the time the control groups are treatment as usual. They are not a different treatment.

On the whole, what we do not know is we do not know much about comparing treatments and particularly we do not know much about comparing treatments for different populations or the same population at a different time. If we knew this, we could use this information to be more efficient and save time in developing culturally appropriate adaptations across the globe, using the strengths and figuring out the needs of different communities. It is not that we wanted to have everything be the same everywhere. But it also is the case that if we start over – for example, there has been repeated push to try to come up with a single questionnaire that is going to diagnose autism of any age, any level, anywhere in the world, used by any person. There is absolutely no data that suggests that that is going to work even within the US, the UK, Scandinavia, wherever. We should be able to learn from that and say what does work.

I think it is also important to acknowledge and I think this came up earlier that many of the things we can learn from autism do have direct bearing on other populations, people with other kinds of intellectual disabilities, or people with mental health problems and that we could use information from that.

One of the things we felt was most important was the question of how do you personalize care in autism? We proposed what we called a stepped-care personalized health approach. And I think one of the important things is there have been stepped-care models for years. But most of the stepped-care models are very much created from the point of view of the provider from health systems. How can we cheaply provide services for people who might be depressed? Let us have them first watch a webinar. And then if they are still depressed then let us have them get a Zoom session. And then if they are depressed, maybe we will see them in person. This is done very much for the cost effectiveness of the provider, not for the individual.

But it is also important to remember that most of the time when people talk about precision medicine or personalized medicine, they are actually not even talking about whole people. They are talking about doing genetics on somebody’s tumor and then coming up with an appropriate medical treatment that addresses that form of cancer, not that person.

Autism is not a disease. It is a condition that can cause impairment in daily living. But, again, as I have said, it is with a huge range in degree and the individual profile of children, adolescents, and adults and their family resources, their community, and where they are from.

The idea here was to shift traditional stepped-care perspective to move to not just taking into account how cheaply can this be done from a hospital’s point of view, but also what are the preferences of the individuals looking for help, what is the burden on the individual in the family, and how can we personalize what we are doing around individual and family needs, strengths, and challenges.

I think the first thing that means is you need to know that information. It is not something that is going to come just with a diagnosis of autism. A diagnosis of autism really tells you very little about what kind of treatment or support somebody might need given the range of skills and difficulties that people with autism have. The idea is to be person centered, and updated also as children become adults. One of the things that became apparent even from European countries that have good initial assessment protocols is that often kids are seen once. They get a diagnosis and that is it. That is their assessment.

The idea of a stepped-care personal health model is to start with the left and consider what are the concerns of the family or the individual if we are talking about an adult or adolescent or older child. What is it that we want to make better? Then move to looking at individual factors like safety, age, preferences, severity of symptoms and then also basic information that we know does make a difference like cognitive and language skills and whether someone is having problems at school or work or home or everything and then strengths.

We also need to consider family factors for many people, not an adult who is completely independent if they do not want it, but for people that are very involved in their families. This includes particularly important across other countries, but we talked about here today too, is acceptance. Are people ashamed or embarrassed? Is there stigma and also what is going on with the rest of the family's lives?

And then we want to move to the idea of how we want to consider factors that affect families and also individuals. Something that is home based maybe easier for many families, but maybe very difficult for a family with a number of kids living in a tiny New York apartment.

Schedules may make a difference. We work with a lot of adults. And if adults are working, they may not want to take time off from work to come tell their problems to me. Trying to figure out how to schedule it. What could be done at school? I think a really significant question is how much caregiver effort do things take? In some cases, caregivers are dying to jump in and work with their kids, and in other cases, they can't or do not want to. Considering those factors right from the start in terms of determining care.

Just to give you a quick example is – different things for a family that has a minimally verbal child in a lower middle-class country so say a minimally verbal child in Argentina. We are going to start by trying to figure out safety issues, wandering, and concerns about the child eloping, maybe a very high priority. We are going to go on to try to figure out what are the severity of this child’s symptoms, what can the child understand in terms of language, how does this child communicate and where are the problems. If the child is doing great at home, but we are really struggling to find a school, that is a priority. And then we are going to determine what are the things that are most easily accessible, not just for the medical system or the school system, but for this family.

We would do something quite different with a 15-year-old with extreme social anxiety in a high-income country. Here, we would look at similar things. In this case, safety may not be an issue. Here, we really want to know if this family coming in and saying give us medicine. We want medicine. We are not doing something behavioral. What is the adolescent saying? What is he or she want? How much does the young adolescent want to participate? Is this person really dying to make friends or are they looking for support in other areas? How can we support this particular adolescent?

I think – to know in terms of research, if we are going to do this, we need to know more than that evidence-based treatments are mildly effective for some people. Group data really is just the beginning. We need to know what interventions are effective for home, when, at what intensity, and for how long. Ideally, we would find out why and I think that was the glorious mission of RDoC and biological mechanisms. But in the meantime while we are trying to figure that out, we really need to know practical things. Is an hour a week of speech therapy plenty or is it meaningless or does it need to be more? Are there really kids that need 30 or 40 hours a week of ABA or kids that would benefit much more from something else?

The 16 weeks of PEERS. Can we build on that to result in something that is generalizable? This requires personalized knowledge about a family and resources. I just was thinking of an example because CMS a couple of weeks ago announced that they were not going to let anybody do telehealth on a first visit. They rescinded that order. But of course, our hospital initially jumped on it and said that was true for everybody except Medicare and why elderly people get higher priority for me than people with disabilities. I do not get it. But that was the immediate response of a hospital. It would be so much easier if we just all stick to these results even though they are in direct contrast to the fact that in some cases, not all, we can do telehealth to organize somebody for an assessment for treatment that is much more effective than making people come in. And yet this was really completely ignored until we had the resurgence of COVID. We also do need to know more about what is financially feasible because there are kids and I think less so adults who get probably more treatment than they really need and they could use support in other areas. For example, the push for sports.

Another recommendation was we need more information about schools. I think there is a real contrast because in high-income countries, public schools cannot exclude kids with disabilities. Schools are often underfunded and there is a problem with workforce capacity. But kids do have to be served there. That is not true across the world. In some countries, there is nothing for kids or there are highly specialized schools that are not good and not appropriate for many of the people that end up there. We really need a way to figure out how autistic children across the globe can receive guaranteed high-quality education in schools and we need to know more about what does that mean.

We also are short of people providing these services. And much of that I think is financial. It is that we do not generate revenue. In the medical system if you have someone who is seeing autistic kids, they are probably costing more than they are resulting in money and that means that hospitals are not going to hire a lot of developmental behavioral pediatricians or clinicial psychologists doing autism.

There is a challenge also that the reality is that much of the work in autism is not going to be done by experts. We need to figure out how do we help people provide adequate care with sufficient training who are not just autism people. And we need to consider how do we push reimbursement and funding models for service delivery.

One of the ways and this is not in any way unique to the Lancet, but our commission has the idea of task sharing and figuring out who can do this work and then how do we ensure that there is adequate training and support to help this be done more efficiently.

I think it is really important to remember that 95 percent of children under the age of 5 with developmental disabilities do not live in high-income countries. They live in lower and middle-class countries. There are really service deserts where kids can get almost nothing.

I think even in the United States, COVID has certainly shown us the inequities in medical provisions across our country. One of the issues, I think, which I think somebody has already raised is that for families and for autistic individuals who are independent, they may be service users their whole life and they need to know how to do this and know how to do this easily so that they can get the services to which they are entitled.

Some of the recommendations were just the need for service systems to be more responsive. We heard a discussion of that with SSA this morning. Also, service systems need to integrate evidence-based interventions into their care models. This is not routinely done in many service systems. We look at early intervention. There are some things that are there and some things that are not.

We need more high-quality research conducted in lower- and middle-class countries to address the science and we need to ensure equitable access to services for underserved and minoritized groups in all countries and that includes girls and women. It includes people that are minimally verbal. It includes LGBTQ. And it includes racial and ethnic minorities.

One of the recommendations from people particularly in other countries is that we really need formal documentation through government, mental health care, education, and social systems, which I think in the US we have.

We need government and health care systems to recognize the need for integrating across systems, which you have heard about all morning. Although I think as a practitioner how you do that is really tough because the medical system is certainly not geared toward doing case coordination.

And then we need focused research strategies that prioritize clinical practice that increase the understanding of what interventions work for whom, when, how, with what outcomes, and at what cost. That is something I have not heard about in the discussions so far. It happens on the small basis, a grant here or there. There is a PCORI 1 grant. There is another NIH grant, but in order to do this, we have to have large samples. If you are going to look at differences in when something works, you have to have a big enough sample to do it. And just having a smart design, for example, where you move from one treatment to another treatment has not resulted in information about who it works for. It has resulted in information about a treatment compared to another treatment compared to nothing. But we are ready for moving on and saying who does this work for and when. Again, as we have already discussed, equity in access and use of services and research.

Here is the profound optimism page. I think that the intention of the group was not at all to be negative toward people speaking about autism. I think the intention was to make sure that people who have very severe needs for support get acknowledged and that someone always pays attention to them. Although, for example, in ICD-11, there are lists of subtypes of autism. The reality is that if you have a list of 15 subtypes on the whole, people are not going to use it and they are not going to attend to whereas having a word does help.

In order to define this, we agreed that what we were talking about were people that need 24-hour access to an adult who can care for them if concerns arise. Somebody living somewhere who has somebody in the house there if they need help or if they decide they want to wander and somebody who cannot necessarily take care of their basic adaptive daily needs.

We ended up coming up with using IQ or very limited language because there are data for those that are available in large samples. That is where those came from. And if we could come up with a better metric, I think all of us would agree.

We are aware that in this population of people who have IQs below 50 or have very limited spoken language and receptive language though that is a difference between somebody who understands but cannot talk well. There are often complex co-occurring difficulties. But these difficulties do occur as people have said in other populations. They are not unique to this group. But they are more frequent.

It turns out that we were able to look at three data sets. We are able to identify if we use the IQ below 50 or very limited language so basically single words or very repetitive phrases. We were able to identify kids and placing someone in this group from mid-childhood or later so somewhere around 8 to 12 was stable into at least early adulthood.

We are suggesting this as a voluntary term. We are not suggesting that everyone has to get this term. I think we are concerned about restricting people’s experience. We are very clear that this could be something that you could not use if you do not want it or certainly if you do not need it.

But what we did find is that in three different samples, we got a huge range of how many people fell in this category. And 48 percent I can say is from our early diagnosis study, which is kids who are diagnosed with autism at age 2 over 30 years ago. It does not reflect who is getting diagnosed at age 2 now or even 4 or the latest CDC data.

I think one important thing that came out though in doing this is MoBA is an epidemiological study in Norway where they followed 100,000 births or actually 100,000 pregnancies of women from their ultrasound at

16 weeks all the way up to some of the kids are actually 20 now.

And one of the interesting things there was that frequently in Scandinavia, registries are used to identify who has autism. But registries are primarily populated by physicians putting in the diagnosis. And what we found in the MoBA data was that if we look at registries, there are hardly anybody who falls in profound autism. But we actually have data from early childhood where kids were seen for diagnosis and that raised the level of population and when we followed up those kids to about 18 percent.

The point there is those kids are not getting in registries. And who they are were kids with autism and severe intellectual disability, but who probably get services through various what they call habilitation in Scandinavia and never even make it into psychiatry.

One of the important things is they are kids that are lost to research. We need to be conscious of wait a minute, where did they go?

Our goal in having this term is not at all to exclude other people, but just to at least begin to identify this as a group who are often not included in research because they cannot sit through imaging, for example. There are many things they cannot do. It is harder to work with them until they cost more money and they take more time. But they deserve being able to improve the quality of their lives just as much as anybody else. I do not think any of you would argue with me.

But just to summarize, we recommend personalized, developmentally targeted interventions over the life course. We need to include implementation science and see what is actually being used outside of academia and how effective are things in the community, particularly contrasting what make the most sense to difference subgroups or at least different people in different strata.

We need cost-effectiveness research to support this decision making. We need to include stakeholders in figuring this out and also developing new and better intervention. We need to offer the possibility of culturally adaptive and tailored intervention approaches because things are going to be different in different countries in different places. And we need large samples and use of more advanced research designs to help answer complex questions.

I just wanted to end with this slide. This slide is just the idea that people can reach certain levels of independence. That is going to be different for people who have different levels of cognitive ability. But how much support they get in their society is going to make a difference there. If we move to a society that does not even find kids to a society that identifies populations, if it does not provide as good as services and all the way up, we can do better for everybody for people who have very limited cognitive skills, for people who have very high cognitive skills and everyone in the middle.

Again, I think we want to have a message of hope that if we work together, we can do a better job of using what knowledge we have and we can also apply it to other developmental disorders and mental health conditions. But we do need to work together. This is a perfect group to present this to and I am happy to answer questions. Thank you.

DR. GORDON: Thank you so much, Dr. Lord. That was really clear and powerfully articulated. We will now open this up for comments and questions from members of the IACC. Please.

MS. GASSNER: Hi, Cathy. It is good to see you again. Thank you for such an incredible amount of work that your team did here. I am very impressed with it. I just have to make a – I am trying to figure out how to do this. One of my colleagues has breached a question that I am curious about as well. In looking at the 32 participants that engaged in this, it seems like there were no autistic researchers that publicly identify, definitely nobody from the autistic researchers committee from INSAR and just a disproportionate underrepresentation of autistic voices. I know there were a few people as stakeholders there. And then my colleague, Morenike, has also asked a question about people of color that were chosen for this. Again, I just want to champion you for these last two articles actually. The first one on autism in Nature was brilliant, as well. But I am just wondering how you might address that for our constituents because they are asking.

DR. LORD: It is a fair question. I think there were three people who identified as autism who are involved in advocacy on the committee. We were trying to recruit people from different perspectives: Alex Plank, who you probably know, Marina Gotelli, who is from Argentina who is a researcher, but not a large-scale, and James Cusack from Autistica. Maybe we should have had more. You can imagine. There were also two African American people. There were two people of Latinx people. All sorts of – actually, people representing all sorts of other ethnicities who were not white.

You are right. I think that it is quite difficult to put together a committee that pleases everybody. As I know more, I definitely might have changed things slightly. But we were trying to make everybody happy, including Lancet. It is a valid point.

I think we really benefitted – we benefitted from Marina, who is a mother of autistic kids and has autism herself, who is not a professional advocate. She has a PhD and very bright woman from Argentina. Alex, who has his own perspective and knows a lot of people and is very interested in communication and then James Cusack, who also does not do research anymore, but is a PhD. I think they were very important parts to this group. There were three of them.

The group also is probably – the group that we started with was somewhat smaller and then we added on people as we needed help. About the last five people or so are people that were running around and writing sections, making tables, et cetera. It is a fair comment.

MS. GASSNER: Thank you, Cathy.

DR. GORDON: Helen, please.

DR. TAGER-FLUSBERG: I would like to focus on the content of the report and particularly, Cathy, your presentation, which I thought was just a tour de force. I think a couple of the key points that you made really are something that our committee needs to grapple with. It is bubbling below the surface. But we have a very effective way of treating kids with autism, using behavioral interventions. It would be low-hanging fruit to address that critical issue that you brought up. It does not work for everybody. But it does work for the vast majority of kids, we think. But who exactly and how and when and where? Those are critical questions. It is just shocking to me, for example, that in the last RFA for the Autism Centers of Excellence, treatment was simply not even mentioned once.

I think your call from your committee for large-scale studies to really address this broad issue of behavioral interventions from a personalized approach is critical because it seems to me the way you presented, we are sacrificing the current generations of individuals across the lifespan right now because we are investing so much in the personalized intervention that targets genetic therapies that as you say are not going to be realized for quite a long time.

I think that is something that we all – I think could bring us together on this committee. We are divided on a lot of factors. But I think focusing on what is it that we can do research wise that would bring the behavioral interventions to the next level that we need in the way that you described.

Thanks for all your work, Cathy. I know how much this has taken from you. The work of the committee is really to be commended.

DR. GORDON: Sam.

MS. CRANE: I also wanted to add on to what Dena said that I think it is really important in future work, not only to include autistic self-advocates, but also specifically to include people who do have high support needs, who do need to use AAC, who have intellectual disabilities because in my experience, when I have come to the conclusion that a single spectrum of mild to profound is not the correct way to refer to autistic people. I am not really speaking from my own experience. I am speaking from listening to the experiences of AAC users and people with intellectual disabilities and people who need significant assistance for independent living who have expressed concern about that kind of language. I think that it is just really important to include that.

We have members of IACC right now like Ivanova and Hari, who are – Hari is an AAC user. Ivanova is a person with intellectual disability. They have expressed quite well their concern that if those needs are sort of lumped together into something called profound autism, then it often obscures what people actually do need.

DR. LORD: We did have parents of people with severe intellectual disabilities and autism and sometimes of other things. But we did not have any individuals.

MS. CRANE: And that can provide a very different perspective.

DR. GORDON: Thanks, Sam. Jennifer.

DR. JOHNSON: Hi. Jennifer Johnson with the Administration for Community Living and HHS. Thank you for the overview. It was very thorough and detailed. I appreciate the information.

The recommendations in your discussion seemed focused on the individual and the individual’s immediate environment and how services and supports can impact that individual and their immediate environment, which makes perfect sense based on the way you described it and the various ways in which autism is experienced by different individuals.

But I was wondering about the extent to which the discussions address system issues and the interaction between the individual and the system and the system that ultimately designs the services that the individual is receiving. And the reason I ask about it is because I am curious about – we hear about issues of intersectionality and how individuals who come from different diverse backgrounds experience the service system and the system that designs those services differently from the white majority. There does not seem to be many recommendations aimed at researching the system and researching it through that intersectional lens and if we did, better understand the system and again systems and services through that intersectional lens. If we better understood that, could we create greater equities and better outcomes for individuals who come from diverse backgrounds? I am just wondering if you could speak a little bit to the extent to which the committee looked at these issues. It seems like it might be in there a little bit, but just was not as obvious as some of the recommendations that seemed more individual or individual services and supports.

DR. LORD: You are absolutely right. I think we did talk about services. We have a number of members who were supposed to represent services who really pretty much bailed on us. I think that what you see represents the knowledge of this committee. It is not at all that services and systems are not important. You are absolutely right. I think we just ended up sticking to what we felt like we knew enough to say something sensible about. You are completely right that we need more about systems and both implementation and all sorts of aspects of systems that I actually know very little about except as a participant. You are right.

DR. GORDON: Alice.

DR. ALICE CARTER: First, I want to really thank you, Cathy, for just a beautiful and passionate talk. It is really nice to see you. I actually was going to raise something very similar in that in addition to highlighting which intervention at which point in time for which person really trying to figure out who can do the pieces of these evidence-based interventions is critical. I really just appreciate you highlighting that we are not going to be able to rely on developmental pediatricians and psychologists. And we really need to start looking at existing services systems to figure out how can we just do a better job of more quickly disseminating evidence-based interventions because as Helen was saying, we have quite a few of them that have a fair evidence base. But we are still not so great at getting them into communities and getting access. We do not need to go into low and middle-resourced countries like here in the United States. In most part of the country, people cannot access appropriate evidence-based services. I also just thank you for everything you are doing. My two cents was also improving the service sector.

DR. LORD: Again, I completely agree. We talked a little bit about task sharing, which I think is aimed at the idea of who can do this. I think there has been a lot of focus in recent years about early identification and who can identify kids early, but much less focus in terms of research on who can actually provide intervention and support. We need to do that. We absolutely need to do.

Even then, we need to know what do they need and who is going to benefit from this and who is not and who needs more and who does not even need it.

DR. GORDON: Alycia.

DR. HALLADAY: Hi. Hi, Dr. Lord. From the personalized care, the stepped approach model, there are so many different great things that not just this committee, but individual researchers need to do. Would you be able to identify maybe three to five of them that we should be putting into the Strategic Plan to make sure it gets priority research if that makes sense that we kind of like start out strong in a particular way in our Strategic Plan?

DR. LORD: I think part of the problem is we need multi-site studies with relatively large samples. I think that we could be focused about what interventions are provided. But I think that we do need sufficient documentation of the kids and adults that are in these interventions where you cannot say who they are going to work for. I think that is one of the problems of doing, for example, totally effectiveness or research without considering who is there. But I think we could be focused about that.

There have been some studies that have compared treatments. I am across the hall from Connie Kasari and she has done two of them and they are still not published because they are so hard to do and so complicated to report. I think we need to figure out how to prioritize that and support the information that gets out.

I think we need to decide what are possible factors. As people out in the community have repeatedly said, there are hundreds of things that could make a difference. But I think we could narrow it down to four or five things at different age levels that are likely to make a difference in somebody’s need for a certain kind of treatment and response to that treatment. And then we would need to expect though that a sample that somehow people get big enough samples that are diverse enough that we can study that. I think part of it is our whole system is predominantly investigator-based studies on people who develop a treatment. It seems pretty good. And then they repeatedly show that it works compared to whatever most limited comparison group they can find in whatever group is most likely to respond to it. We need to step back and do something in a different way. I think that is one recommendation. But I think that takes – I am not – luckily for you all, I am not leading NIH or any agency. But I think we need help from Dr. Gordon and Dr. Daniels and Alycia, about how do we make this happen. But I think we could do it.

And I do not think it would cost when compared to the amounts of money that have gone into, for example, genetics, which I am glad it has gone. But I think we could find out things that would answer simple questions.

DR. GORDON: Thanks. Alycia, did you want to say something else because --

DR. HALLADAY: No, I want others to have a chance to speak.

DR. GORDON: Other comments or questions from members of the committee? This has been a really illuminating discussion. Okay. Thank you very much, Cathy, really for joining us today for presenting the Lancet report. Susan, am I correct that the Lancet report is available on the IACC website?

DR. DANIELS: We have a link on our website.

DR. GORDON: Great. And I see Larry giving me the thumbs up as well. I assume that is either because he knows it is available or because he wants to tell you what a great job you did. I am sure that we all share that sentiment.

I do encourage the members of the committee to read the report. I think there probably is some specificity that we can take with us into the Strategic Plan. I particularly like this formulation, Cathy, that you mentioned in particular around ensuring that the – there has been a call already and in fact, this call has been around now for several years for an increased focus on research that will affect those suffering from the consequences of autism in the here and now. I think the notion that we would want to ensure that it has impact by aggregating groups and creating larger studies that will compare treatments is a wonderful suggestion that I think we can take to heart at NIMH.

There are mechanisms that we can put in place to facilitate that. To a certain extent, the ACEs are meant to do that. To the extent that they are not, I think we have to look hard at that.

Paul, you want to make a comment.

DR. WANG: I am sorry. Very briefly. Going to the issue that Jennifer Johnson raised earlier and as Cathy responded, the commission article does not adequately address those issues of intersectionality. For those who may want to use the article as a springboard or a platform to discuss that, there is at least some mention of it specifically in the key messages box on page

1. It talks about the need for coordination between health care, education, finance, and social sectors across the lifespan, et cetera. There is at least something there that you can spring off of, I think.

DR. GORDON: Thanks, Paul. Again, we thank you for your contribution. We are running a few minutes ahead. Susan, I would suggest since we had some abbreviated breaks, that we take another break and come at 4 o’clock as scheduled to do the rest of our committee business for the day. Does that sound good to you? Okay. We are going to take another break and it is now 3:50. We resume at 4:00 and try to complete the rest of the business we have for the day. Thank you very much, everyone, and thank you, again, Dr. Lord.

(Whereupon, the Committee took a brief break starting at 3:50 p.m., and reconvened at 4:00 p.m.)

DR. GORDON: We are now going to go to the final segment of today's meeting, which is a return to the IACC committee business. I will turn it back over to Susan. I think there are two more aspects that we need to discuss today.

DR. DANIELS: Okay. We are going to be talking about the IACC Summary of Advances. We talked about this last meeting. We did not complete the discussion, so we were going to come back to it today. As a reminder for 2020, we started a little bit late on putting together the Summary of Advances because the committee only started work again in July. We are trying to catch up on that.

You have submitted a number of nominations and today we want to do the final pass at refining that list. And after we have made decisions on a few items that were question marks, we will go ahead and send the committee ballots and you will be able to vote on the top 20. Everything that is on the list will be listed in the back of the document. They will be acknowledged somehow. But only the top 20 will have written up summaries of them in this document. Today, we are going to talk about those nominations. That is what we are planning to do. We will move into that now.

I will let Josh lead this discussion of some of the remaining articles that we need to discuss.

DR. GORDON: Just to remind you so we are all aware of the procedures. As Susan said, we are aiming to choose 20 of them to select. The IACC staff went through the nominations. There are some that they wanted to bring up for discussion. But I also want to enable although we do have limited time those of you who have interest in discussing any of the nominations that you put forward to try to bring them forth or any nominations you have concerns about to please go ahead and do so. You can even start raising your hands now. But we are going to go through the nominations question by question. And the first question is on Question 1 screening and diagnosis. These questions, of course, are taken from the old Strategic Plan. We will revise this process next year when we have the new version of it.

There are a number of nominations in the screen for diagnosis. One, two, three, four, five, six, seven, eight. There is something like 12 or so of them. Two of them were identified by our staff as some concern because they may not be ASD specific enough.

One is Trends in Pediatricians' Developmental Screening and the second is Validation of the NIH Toolbox Cognitive Battery in Intellectual Disability. These are just concerns that were brought up by the OARC staff for your consideration as you consider how to vote.

But I wanted to open it up to any questions or comments or promotions for any of the other nominations or these two for Question 1: Screening and Diagnosis and see if there are any comments from any members of the IACC on any of those nominations.

DR. DANIELS: I will mention at the top there, that was not the best wording. These articles are not questionable. These are questions that we had about the articles. That was inadvertent.

We do have polls to use to get at what people feel about these articles, but you can feel free to talk too. Feel free to discuss. You do not have to do the polls.

DR. GORDON: Let us not do the polls. I think the polls are a little too binary for this point because everybody is going to be able to vote. I would rather have people discuss if they have any particular articles they would like to bring up. I am not hearing any.

I wanted to highlight two that I found particularly of interest. I do not want to dominate the discussion though so please if anybody else has things that they want to discuss. One of the nominations is indeed one that was done I think, by the Department of Education, the Mozolic-Staunton article. I feel like I should share my screen. I do not know if I have the capacity to do that, on early detection outcomes. This article uses a new Social Attention to Communication

Surveillance tool. I have the document that was shared with you all with all the nominations. It is the Adobe Acrobat document. I just put in a couple of notes on my own.

This article here particularly is attracted to me not because it is a definitive new way of screening, but because it was a potentially new tool that was piloted in a very large group of children and in particular, it suggested this tool may have a higher positive predictive value than the current state-of-the-art tool, the PEDS tool, for addressing ASD. It is still a little bit early to say that this is what we ought to be using, but I thought it was a particularly interesting article to bring to your attention.

The other one that I thought deserves a second mention is an article by Harris et al., who was nominated by our OARC staff. Validation of a different tool, a developmental check-in tool for low-literacy autism screening. Although this one wasn’t – it was also sort of early in the process of defining the tool and the study was not quite as large. What I liked about this is it was conducted in real-world settings and in children from low income and racial and ethnic minority families where English was not the primary language, which fits with the growing interest in studies that are relevant to disparity populations.

Those are just two that I happen to find interesting and any others that people would like to mention, please feel free to do so.

Alycia, did you want to make a comment or a question?

DR. HALLADAY: I just had a question about the Harris article. It is listed in

2020 because that is when it was online and then it was published. The December article is really --

DR. GORDON: That is correct. I think staff nominated anything that came out in 2020, whether it came out in print or in E-PUB form.

DR. HALLADAY: Okay. So E-PUB --

DR. GORDON: Paul.

DR. WANG: I just had another question also please. In light of the comments, Dr. Gordon, that you just made about a couple of articles, could you please remind us, or tell us again, your vision of what merits being designated in advance. How significant, how definitive, things like that.

DR. GORDON: Ideally, we would be talking about things that we really want the public to know about because they are either very promising or definitive enough that we want the public to be following up on this. When we say the public, we also mean of course Congress to whom the report is being made.

That has to be tempered by the fact that we really want to highlight advances in each of the seven areas. Some of those areas have advances that are ready for primetime. I think we might talk about one or two of them and most of them do not. I think we have to temper that.

What we do want to try to avoid is, number one - we have spoken in the past about that we really want it to be novel, not just reviewing something that has happened in the past. Number two, we want to avoid giving for lack of a better term, false hope by citing studies that are really too small to give us the answers. These two things that I am citing are early, meaning they are tools that are being tested for the first or second time have not been really proven over and over again. But the studies themselves are large enough. This one, for example, 600 underserved children. The studies are large enough that we can be confident in those study results. We just do not know how generally applicable they are. That is what I have to say about that and others may add to it as well.

Alice.

DR. CARTER: I guess I just wanted to say, given all the sensitivity around screening, I guess I think maybe we should wait for more definitive findings just because – I do not know. It is an issue I really care about. It is just like I am just seeing measures be pushed out too soon and then they do not actually – with controlled whatever. They do not work quite as well. I do not know. I just think given the importance in terms of wanting to see screening recognized, maybe the more definitive studies.

DR. GORDON: Fair enough. Alice, are there any in this category that you saw that speak to you then because there are others – the others that I noticed were more about what is happening in the world right now in screening. This next one, the Lipkin article where they are looking at trends in pediatricians' developmental screening. This is describing the state of affairs. But it is not really an advance in terms of helping us know what to do.

DR. CARTER: Right. Although for me like the studies that speak to what is happening and disparities seem really – especially the article speaking to disparities seems particularly important.

DR. GORDON: Right. That is this one here, the Constantino article is the one you are referring to. Thanks, Alice. That is a good nomination to consider. Let me change the color of that highlight there, which is my own shorthand for things that I personally was interested in. I appreciate that input.

Others? You all should be listening to this input and thinking about which ones you might want to vote for.

One more comment on the first group and then we should move on to the next.

Dena.

MS. GASSNER: I just have a clarification. I have a 2000 and a 2021 document with very similar names.

DR. DANIELS: -- looking at 2020.

DR. GORDON: The document we are working on now is 2020. The 2021 document. We were going to solicit additional nominations for it over time and we will come to consider that. When are we going to try to work on finalizing that one, Susan?

DR. DANIELS: We are going to work on that in April. We are just catching up.

MS. GASSNER: No problem. I am clear now. Thank you. I was just confused.

DR. GORDON: Okay. With that, we will move on to the next tranche of studies.

DR. DANIELS: Josh, are you going to come back to the ones that had questions because we need to decide on those?

DR. GORDON: Let me stop sharing and go back up to those. I do not think we need to decide on them is the issue, Susan. I think people are going to vote. No?

DR. DANIELS: The problem is that we do not know whether we should include them on the ballot. Should we include regardless so we are including anything on the ballot?

DR. GORDON: I think these two may not be ASD specific, but it is not in my mind – they are not harmful to include in the ballot.

DR. DANIELS: It was just in the past we had had most of the articles focused on ASD. But we are fine if the committee wants to include things that are generally about development or other things. Just where is the line for what gets included as a consideration for an autism advance. If the committee wants to include them, they are fine.

DR. GORDON: Right. Susan, let us then actually take a vote on these two with that in mind. It is not a criterion that I discussed earlier. But it could have been one that I gave in response to Paul. We really tried to focus on articles that are focused on autism. Now, these two actually are slightly different in that regard. One is –

remember, I mentioned that the other article on trends on when pediatricians are screening for and this article is really about developmental disabilities writ large and not just autism. That is the first one.

The second one, which is Validation of the NIH Toolbox Cognitive Battery in Intellectual Disability, is a little bit different in the sense that it is validation of a toolbox and they are validating it in fragile X is my recollection and a couple of other neurodevelopmental disorders, which include autism. It is a little bit of a gray area in terms of whether it is sufficiently dealing with autism.

If we are restricting articles to things that focus on autism for the purposes of it then I think, Susan, what you are saying is maybe we should be eliminating these articles even from the larger issue. We will have the

20 that we voted on and then all the other nominations. The question is whether we should include these at all. Is that correct?

DR. DANIELS: We will have a ballot and you will be able to choose the top 20. It is a question of whether these should be on the ballot for things that are considered autism advances.

DR. GORDON: Why don’t we go to the poll on that then? Let us do put up that poll. Again, the question for each of these articles separately is whether it is specific enough to ASD that we would want to include it in the ballots to be voted on. Everyone should go ahead and vote. I should say everyone on the committee. You can say yes or no individually to the two, as I said, because they are different issues presented.

(Poll)

DR. GORDON: Do we have the results yet? While we are waiting for the results, let us move on to Question 2 because we want to try to make progress here. In Question 2, there were a number of articles submitted on the biology of autism.

The results are mixed for the second article and more of a significant no to the first. I would suggest, Susan, based on that, the vote is close enough for number two. We should probably include it to be on the safe to be inclusive. But I think the first one we can eliminate.

Question 2: Biology. There are a number of advances here. Many of them are what we might term basic sciences advances, that is, advances in the biology that help us understand the basic science processes underlying, but not yet primed for treatment development. Can we get to Question 2 on the slides here?

DR. DANIELS: There were not any. We did not have any for Question 2. The next one we have questions for is Question 4.

DR. GORDON: Would anyone like to make any comments about any of the articles nominated in Question 2 either for – if you will, to lobby for them or to lobby against them?

MS. GASSNER: Do we have a new slide that has the specific questions? I am sorry.

DR. GORDON: We do not have specific questions on any of the articles in 2. We are now just asking for comments from any of the nominators or anyone who has any concerns about any of the articles nominated in Question 2. The question themselves – it is just the themes from the Strategic Plan. The second question is about biology. We have nominations of articles, which speak to the biology of autism.

DR. DANIELS: And if you want the whole listing, it is in a document that is labeled 2020.

DR. GORDON: Let me share my screen again and I will pull them all up. Now, you – the nominations under Question 2: Biology. There is a number of articles that have to do with genes that have been associated with autism and their biological consequences, including this one that I happen to like on Shank3 mutations and their motor function. What I liked about this one is that they also tested a drug, which suggest the possibility of a treatment target. I am not sure and maybe some of you on the committee can talk to me about how important motor symptoms are in individuals with autism, but that is what the focus of that study was.

There is another study here, which I also think is an actionable item. That has to do with the trajectories of symptoms in autism and cognitive ability. And one of the interesting things from this study, which was also nominated by our folks from the Office of Autism Research Coordination at NIMH, showed that participants in mainstream schools showed significantly fewer ASD symptoms at 23 years versus those in specialist settings. That is an interesting observation. I do not know though how confident we are in it.

Sam.

MS. CRANE: I have three comments on three different studies. I agree, Josh, that motor is critical. It is very important and particularly to people who are non-speaking. Many people who are non-speaking report having significant motor planning concerns and we really need to know more about the role of motor in autism. I think that that is very interesting.

I thought the sleep onset study was also very interesting. It is a really important concern for a lot of people in our community and getting an understanding of the physical and physiological underpinnings of sleep onset issues could really help maybe lead to better understanding of interventions.

I was a little confused about the Simonoff study, not that I think it is a bad study. It looks like a really great study. But I do not know why it is in Question 2. I thought we could talk about that.

DR. GORDON: That is a good question. I am not sure why it got categorized in there either. Maybe because there is a focus on the cognition ability, but it is a good point.

MS. CRANE: I think it was a very important study and I would love for it to be in the Summary of Advances. I just thought it was a little weird to put --

DR. DANIELS: It does fit in the criteria for Question 2 – the Strategic Plan organized.

MS. CRANE: I like it.

DR. GORDON: Thanks, Sam. And I appreciate the input on the motor issues. That is really helpful.

Paul.

DR. WANG: A general comment on this category. First, I will jump on the bandwagon for the importance of motor issues. Earlier at this meeting, I already commented on how important, I think, sensory issues are. Of course, sensory issues are in the diagnostic criteria.

I will also say that I think sleep is important even though it is not a diagnostic criterion. I like all those topics.

More generally, I typically do not get very excited about the broad significance of any research paper that focuses on a single gene, especially when those genes account for only a very small fraction of cases of autism. There are some genes even though there are single genes where I do get somewhat more excited. I think FMR1 fragile X is an example because its product interacts with so many other genes, which are also implicated in the underlying biology of autism. But otherwise, in general, single gene – I am skeptical about.

DR. GORDON: I share your skepticism about the general relevance of single genes. I cannot argue with regard to say the WNT or the eIF4G microexon one. I think Shank3 would be in another category like FMR1 for very different reasons, not because it interacts with many genes like FMR1 does, but because it clearly in and of itself creates a syndrome, which includes autism. Understanding how that gene exerts its many effects on the brain can as it perhaps does in this study, too early to tell for sure, can suggest treatment targets that at the very least would help people with Shank3 mutations and have the potential to help others as well. But in general, I think you are right. A study that focuses in on one gene is often - has challenges in terms of generalizability.

Any other comments about any of the papers here? I have heard that people like the focus of Lutz on treatment and motor control, the MacDuffie on sleep. I will keep in - there is a question about whether it really belongs in this category, but the longitudinal epidemiological cohort, which is a really fascinating study. Any other comments on any of these other ones?

I will note that there is one on sex differences that studies individuals with autism.

DR. DANIELS: I would just like to make a really brief comment about the fact that there are some nominations in there from our office. We were trying to help jumpstart this process because we came into the year halfway through the year. We helped fill in places where there were gaps. But ordinarily, we just take nominations from the committee. For 2021, we have also tried to help fill in the gaps where there might not have been enough nominations. But happy to step back at any point. We are just trying to help out.

DR. GORDON: Let us move on to Question 3. I am going to stop – actually, let us just take comments. Let us keep on this for a moment and just ask if there are any comments on any of the nominations in Question 3. Here, we are talking about risk factors. I happen to highlight two of them that I think are interesting because they involve environmental risk factors, which we have really been trying to push. I want to thank especially our colleagues at NIH and the National Institutes of Environmental Health Sciences who has really put a focus on identifying environmental risk factors of a number of conditions, but especially autism and neurodevelopmental disorders. The Bilinovich article talks about gene by environment interactions.

There is another one here. I think the Satterstrom – that is a genetic one. There was another one that I was looking at. I particularly liked that one.

Are there any other comments? Dena?

MS. GASSNER: I like the very first one that looks at the potential implications for parental lineage primarily because I see it as an opportunity to provide more intensive parental support especially in the early intervention years.

I do know that speaking as an autism parent, trying to coordinate services and supports in those early years with multiple therapy sessions a week and dealing with school systems was so incredibly difficult. I hear that from so many parents. Autistic parents quite often due to the nature of their disability struggle with that multi-tasking. I do not know. I have some concerns. But I largely think examining this as a proactive measure to support families more dramatically and more significantly could be very helpful.

DR. GORDON: You know, Dena, this is why I value the input we get from the IACC so tremendously. I was looking at this as ho-hum, another genetic study. But you are pointing out that this is beyond genetics. It has the potential to really influence the need for care delivery in particular situations. I think that is a really helpful insight. Thank you.

Other comments or questions? I am going to stop sharing. I think there are some questions for Question 3. Questions on articles from Question 3. Is that right, Susan?

DR. DANIELS: We actually do not have any questions on Question 3. Next is Question 4 for us.

DR. GORDON: Let us go to those then since we have this up. There are two articles in Question 4, I think, that we wanted to bring to your attention. Question 4 regards treatments and interventions. Again, we will have the opportunity just to ask for any comments about articles that you all wanted to highlight. But there were two, and these pertained to the issue that we actually did discuss at the last meeting. There are two. One is a literature review. One is a meta-analysis that we have typically either not included in terms of literature reviews or only occasionally included in meta-analyses regarding interventions to draft health outcomes and the Project AIM autism intervention. Again, the reasons why we have not generally included these is because it is typically not very novel in the sense that there is a review of old literature.

Now, in the case of meta-analyses, when the meta-analysis reveals a new result or solidifies our understanding of the impact of a result then we have tended to include it. Any comments about either of these two articles, particularly if whoever nominated them might want to discuss why they nominated them. That might be helpful. I am not seeing anyone.

Alycia.

DR. HALLADAY: I probably – I do not know if I was the only one but I did nominate this Project AIM. I understand it was a meta-analysis and almost even a systematic review. But this particular article really highlighted – took the data and the vast amounts of data that do exist and really dissected it in ways that highlights what sorts of both proximal and distal factors need more attention when it comes to autism behavioral interventions. They really focus on things like publication bias. They really identified a lot of issues that I think are – that should, in fact, influence and actually did in my comments influence some of the Strategic Plan recommendations.

This project was considered outstanding by the Autism Society for Autism Research. It won an award. I think it has been cited many times and people refer to it a lot when they think about what is needed and what questions are still relevant. Obviously, I nominated it. I am advocating to keep it. I am happy to discuss.

DR. GORDON: Thank you. Anyone else want to discuss either of these two articles? Julie, go ahead.

DR. TAYLOR: I will just add really quickly. I personally agree with the tack that we have taken in the past I think were really reviews unless there is something just absolutely exceptional about it that brings something brand new to light with how they looked at the data. But I would say that is not going to be the case 99 percent of the time. And then for meta analyses too. It sounds like what Alycia is describing. I read this article and I agree with her. I do think it brings new information out from these studies that we did not know before.

I am most familiar with the adult literature. There is just an exceptional amount of reviews that come out that are rehashing research that has already been done. I worry about elevating that to the level of the new research – selling short maybe what needs to get done in some domain. It is a long-winded way of saying I agree.

DR. GORDON: Julie, I think what you are saying though is you agree that Benevides –

you are personally arguing that maybe Benevides is not appropriate, but you have no problem with Sandbank being on the ballot. Is that correct?

DR. TAYLOR: That is what I am saying.

DR. GORDON: Okay. Great.

Elaine and then I think we should go to – Susan, while Elaine makes her comment, why don’t you put up the poll for these two?

DR. ELAINE HUBAL: I do not know that I am adding anything significant. If it is really a systematic review, I have not read this. But I guess in line with whether there is a real – if systematic reviews are done to ask studies in and of themselves and follow the methodology and glean new insights, I think we do not want to just – just because it says it is a systematic review in the title, we do not want to assume that it is. But I do think we do want to make space for using state-of-the-art methodology to synthesize information from across studies. As long as we are thoughtful about it, I do not want to put lines in the sand.

DR. GORDON: Okay. Julie, you still have your hand up, but you went off camera. I assume that you are done.

Dena, a very quick comment.

MS. GASSNER: Just quick. I nominated this and I think the reason that I nominated it was, A, I did not understand your criteria. But, B, because of the rule outs they had in examining the literature, this was focused primarily on interventions as experienced by autistic adults. The narrowness of that examination was part of our criteria. That being said, I am going to beg off anymore comment because I was an author on this article.

When you describe systematic reviews and their role in this determination and the novelness, I kind of see where you are coming from. Thanks for hearing me out.

DR. GORDON: Okay, thanks. If everyone will go ahead and answer the poll. And meanwhile, we can cut out of this. I do want to go over – if you could end the presentation and put up the poll, I am going to go ahead and share my screen again. I think the poll has already been shared. I cannot see because I already answered it. Whenever we get enough answers, we can put that up.

(Poll)

DR. GORDON: Meanwhile, I will just share the screen for Question 4 just in case this suggests to anyone any others that they would like to see. Here are the ones. There are elopement patterns, the review we just mentioned, randomized controlled trial functional communication training. I was not sure about that because it is not apparent to me how large or generalizable. It is only 38 children although it was interesting.

Here is one that – it is a mouse. It is treatment development. But it is a little bit early, I think.

I actually thought this Rogers' one was interesting. It was a negative result in the sense of looking at increasing treatment intensity did not improve treatment performance, but I think that might be an important negative result, especially vis-a-vie what we were talking about earlier today.

Any other comments from anybody on any of these articles?

MS. CRANE: I agree that the negative result on treatment intensity is important.

DR. GORDON: Thank you. We have a no on the Benevides and a yes on the Sandbank. We will eliminate the Benevides, and we will keep the Sandbank in. Okay.

Let us move on to then to Question 5, which is around services. We heard earlier that we want more on services.

Julie, your hand is up again. Sorry, did you want to say something?

DR. TAYLOR: I just wanted to ask if we are – this is back to the last article in Question 4, which is sort of a consensus statement on I think weight management, expert recommendations. Obviously, all agree that weight management is super important. But I was not sure if that was sort of fitting the criteria of what we would want to put in here.

DR. GORDON: That is a good point. Unless there are really new findings or it is a new observation, we generally have not I do not think.

DR. DANIELS: I believe that that was maybe the next slide in the slide set. I think we had a couple more. Sorry. I cannot remember what is on the slides until I click on it. I think there might have been a couple of questions for more articles in the section. Sorry about that.

DR. GORDON: That is my fault.

Dena.

MS. GASSNER: The article that I put – I am sorry. The poll keeps getting in the way while we are trying to read the screen. In this Benevides article, I do not think we have captured in the description here the implications of this research. What we are finding is that people who are of different ethnic backgrounds whether it is racial and ethnic disparities and eligibility, and spending are not moving into recognition of their eligibility for Medicare and Medicaid enrollment and this study is really examining that disparity. It is a huge gap in services and spending. I just wanted to speak to that because I do not think that we were able to fully capture that in this description. Given what we are looking at in terms of health care disparities, I just thought it was really timely at this point.

DR. GORDON: Thanks, Dena. I appreciate that.

We are going to go ahead and move on to Question 5: Services.

DR. DANIELS: Should we get back to the slides and make sure --

DR. GORDON: I thought we would go back and forth. Let us run through it first and then we can look at the ones – any comments on any of these? Sorry. We actually have one on disparities here.

MS. GASSNER: I kind of liked the Wehman study that is looking at Project SEARCH and autism supports for employment outcomes. My only caveat would be that I am concerned about some bias and the fact that Project SEARCH tends to choose individuals who are most likely to succeed. They are not often working with people who really struggle with employment as much. But I think looking at whether Project SEARCH aided in collaboration such that the person could obtain employment is something very interesting to look at in terms of transition.

DR. GORDON: This is a randomized, controlled trial of Project SEARCH plus ASD supports compared to what – employment outcomes. It is not clear to me what the comparison group got. Does anyone know?

Any other comments about anything in --

MS. GASSNER: I am sorry. It says at the very end that this is an improvement over traditional community-based employment training programs. I do not know if that was the control, but that is what they were comparing to.

DR. GORDON: Yes. We might be able to figure that out. But in the meantime, why don’t we – I will stop sharing and we can go back to the questions now if we can go back to the ones that we had questions about.

DR. DANIELS: We need the --

DR. GORDON: -- the next slide. Let us move on to the next one.

DR. DANIELS: The second one or the second slide is the weight management study.

DR. GORDON: Let us move on to the next one because I think we pretty much decided that one.

DR. DANIELS: That is decided? Okay.

DR. GORDON: Yes. Question 5: Services. There is one here, which is a small size of N equals 6 on Undocumented Mexican Mothers of children with Autism: Navigating the Health Care System. I have spoken in the past in previous iteration committee about the importance of not including articles with very small sample sizes. This one certainly seems to meet that. Any other comments or questions about this particular article?

MS. GASSNER: I guess, Josh, I would just reiterate my concern about not examining qualitative research as a foundation to build more larger sample size research upon. That is all.

DR. GORDON: Right. I think we all recognize the importance actually of the qualitative research as an initial step, but just marking it in summary advances can be problematic.

DR. JOHNSON: This is Jennifer Johnson. I think another factor is that you are likely going to have a small sample size with that type of population. I am not familiar with the research so I cannot speak to the contributions of the research itself. But I do think we have to factor in the fact that it is going to be a small sample because I do not know how many mothers that fit that criterion would come forward to participate in research.

DR. GORDON: It is a very good point.

Let us now discuss – sorry, we should go back one so we are still in 5 Services. Is there a poll associated with that one? Go back one. No. That is weird. What happened? Is there a poll associated with that, Susan?

DR. DANIELS: Yes.

DR. GORDON: Let us do it.

DR. DANIELS: I will need the team to put the poll up.

DR. GORDON: Given the comments you just heard, do you think this should be included in the list of nominations? Again, it does not mean you are voting for it. It is just that you want it to be on the ballot.

(Poll)

DR. GORDON: While we are doing it - treatment condition, control condition. In the study we were just talking about where we are studying the effects of the Project SEARCH plus ASD supports, the control was indeed treatment as usual – attended their assigned high school and received the services, accommodations, and modifications stipulated in their IEP. And then some received some community-based employment training, but not everyone. The control is not what I would say is an ideal control. I am not arguing we should take it off the list. I am just giving that information.

Do we have the results from the poll on Question 5 on this article? The majority is no. I would be inclined to take it off.

Let us move on to Question 6 now. Question 6 is lifespan issues. Again, we will have the opportunity to consider all of them if people have comments to make on lifespan issue article nominations. But there were at least two. We had these questions about this article by Benevides on Listening to the Autistic Voice and another one on Changes in Access to Education. And the first one was an information-gathering activity akin to I guess a qualitative study. But it is really just defining priorities to guiding research. It typically not included those things in the past.

And then the second one is one educational health care services for individuals with intellectual and developmental disabilities writ large and not ASD specific although it is about COVID-19. Any questions or comments about those two articles and whether we should include them or not? Why don’t we put up the poll for those? While the poll is going up if you could stop sharing and I will share the Acrobat again. People can answer the poll question if they feel like they want to.

(Poll)

DR. GORDON: While we are waiting for the results of the poll, I am going to go through. I was already in Question 6. There are a number of nominations on Question 6. Trends in supplemental security and payments to adults with autism, the aforementioned Benevides article, and listening to the autism voice, an article on health disparities among sexual and gender minorities. I thought that was interesting because it is certainly defining a need that we need to know more about. The COVID impact one although it was interesting to me although, again, it does not focus on autism. Defining positive outcomes in more or less cognitively able autistic adults. The adult focus was interesting and also to me, it suggested a potential to point to treatment targets for functional treatments. Qualitative study. Here we are. Development of psychometric testing of adult autism provider self-efficacy scale. Any comments. JaLynn, you wanted to comment on some of these.

MS. PRINCE: I am a bit confused, and this is resting on me because you kind of have two different areas in the literature that came out about some articles and some advancements and so forth to make everybody aware - and then there is this listing here. I think perhaps I did not see how this maybe related to something that I think is important when you are talking about advancements. It is something that Madison House has been working on with First Place Arizona, Watts College, the Morrison Institute of Public Health in Arizona about housing because services - in a way, it is services but not - this is an adult area where there are few services when you are starting to talk about things of that nature. This was a study that was put together to follow up on the Opening Doors study that was done about a decade --

DR. GORDON: Sorry, JaLynn. Are you talking about one of these nominations when you say --

MS. PRINCE: Yes and no. But I have a question because this was not nominated. But I am having a question about how things like this can be put into something of this nature. I think this was my fault on this that it has not necessarily been clear to me. There is a lot of research in this, and it is moving something forward by leaps and bounds with what happens to be in this publication.

DR. GORDON: JaLynn, you should feel free to nominate a publication for the year that it was published. I am not 100 percent sure exactly whether the publication you are talking about would - whether we, as a group, would accept that it is an advance. But I do not think we have any preconceived notions about what constitutes - if it published, I do not know that we have any preconceived notions about it.

You have heard us debating the relevance of – debating the inclusion, not the importance, but the inclusion of different kinds of reviews that build off of prior research and that I think the consensus that we have sort of arrived at and forgive me because I am doing injustice to a larger discussion was that if it brings up new and important ideas and comes to novel conclusions that we might consider it. But I do not think we can consider it in the context of this discussion unless it was already nominated.

MS. PRINCE: All right. But I am hoping that it will open up the conversation for other nominations as we go into next year as well.

DR. GORDON: Absolutely. If you have any questions about that and if you have any questions about that, you can talk to Susan and her staff. She can help you with that.

Dena, I see your hand raised as well.

MS. GASSNER: I just wanted to champion the Pohl, Blakemore, Baron-Cohen on the Comparative Study of Autistic Women. It had a sample size of 355 autistic women. The original sample size is well over 1000 participants and whittled down to that. And then 50 percent of that number approximately were non-disabled parents. Again, going back to my previous comment about service delivery. This could give us a great bit of insight as to where autistic mothers may need extra support or where they may actually have a neurodiverse advantage in parenting. I just wanted to put a you-who in for that one.

And also the Social Security work. It is so critical right now.

DR. GORDON: That was one of the first ones. Right?

MS. GASSNER: There were actually two from Paul Shattuck’s lab. The first one in regard to Social Security payments. If you get the maximum amount of money under SSA, you are still almost $2,500 a year below the federal poverty line. I think anything we can do to look at that system is an asset for our population.

DR. GORDON: Thanks, Dena.

Julie, did you want to make a comment about any of the Question 6 issues?

DR. TAYLOR: Yes. I see two here that are like really methods focused, and maybe we want to keep in mind and let people vote. But the last one here, the McGhee Hassrick is really – I am super excited to see what comes of this method down the road. But this is really just kind of like can we use a social network type situation in modeling for young adults and - 17 young adults in their networks, I think. I think the conclusions were this may work with some modifications.

DR. GORDON: Yes. You will point out. This is really a study to test the feasibility of a method. I also agree with you. I would not classify that as an advance.

DR. TAYLOR: Hopefully, it leads to some really cool advances but I do not know that this in and of itself.

And the other one that sort of fits into that same idea although maybe we want to leave it and let people vote is the testing of the measure development and testing of the measure for health care providers.

DR. GORDON: Oh, yes. That is up here somewhere, I think.

DR. TAYLOR: -- about that maybe for the Nicolaidis one. Again, I think this is going to be a super helpful tool. I am excited about this work. The results of this particular study where the health care professionals do not really know how to treat adults with autism. Hopefully, this tool will be really helpful down the road, but that conclusion, I feel like we have a pretty good handle on. Those were the two from Question 6, which are the studies that I am the most familiar with. I was less convinced by.

DR. GORDON: Thank you, Julie. I appreciate the comments.

Just note that the poll pretty convincingly argues against Benevides inclusion. There was a slightly more mix with Jeste. I do not know what to do. I would say let us throw out Benevides. I am torn about throwing out Jeste or not, given that 40 percent think it should be on the ballot. I would rather be inclusive than not. We will keep it in for now.

Last question. We do not have any specific applications to call out from our perspective. But the last question is on infrastructure and surveillance. There are a couple of CDC articles I will point out, including the one that characterized the data that we already heard about today. I highlighted them because they are the latest data on surveillance.

There are a couple of other studies about a statewide registry, for example. Maybe that is a little bit more methods-y, but it does point to high comorbid medical and psychiatric conditions, which is something we know. I do not know how much of an advance it is. But it is well quantified.

Any comments about any of these surveillance ones?

MS. GASSNER: I just want to champion the Dietz et al. national estimates of adults with autism spectrum disorder. It is a really good study. It is critical to my dissertation right now. I like the way that they work the math to try to come up with some kind of a number we could use. If you have not read it and you are looking for advocacy tools to communicate the needs of autistic people that are over 18, it is well done. I still think we are massively missing a lot of people but it is something to work with.

DR. GORDON: Thank you, Dena.

Okay. I think that is it then. You have heard all the items that people have cared to discuss. I believe, Susan, you can clarify. I believe you will be sending out emails for people to vote on the ballot, which will have some of the articles eliminated, the ones that we have discussed today, but all the rest of them in there.

I ask that you strongly work to try to spread your votes around. Try to vote for one to three in each category if you can. If you feel like no, there are not any in any category that you really want to vote for, by all means, I am not going to make you but we are going to try to make sure that we highlight some of the advances in each area with at least one or two of the articles in each of the areas. We encourage you to spread your votes around.

Sam, did you have an overarching question or comment on this process? Sorry, Alycia.

DR. HALLADAY: Sorry. I was waiting for Sam to answer.

I looked at the list. I saw a couple from Dena and two from me. I know I submitted

18. I do not know if they were all excluded or what happened.

DR. GORDON: My guess is that the others for 2021.

DR. HALLADAY: Right. I thought we were talking about 2021 right now.

DR. GORDON: This is just 2020. We are a year behind.

DR. DANIELS: We are catching up on 2020.

DR. HALLADAY: The slide says 2021.

DR. DANIELS: This slide does. This is just talking about the next version. But with the 2020, we are going to be sending out a ballot. You will get to vote. And then our team will be working on a draft of the final document, and we will share an update with you in April about that.

For the 2021, we have already solicited the nominations. We will talk about them at the April meeting basically and then probably do the ballot after the April meeting for the 2021 to try to catch up.

DR. HALLADAY: Just to be clear, what is on the website as the 2021 summary advances nominations is not complete from what people have submitted?

DR. DANIELS: It is complete. I believe it is complete. We will be talking about it next time. We did not want to confuse people and also do not have enough time to talk about that.

DR. HALLADAY: I would doublecheck because I submitted 18 articles and I see two on here and there is only three pages.

DR. DANIELS: We will check.

DR. GORDON: On the 2021 document is what you are saying.

DR. HALLADAY: Yes.

DR. GORDON: You are not talking about the document we just reviewed. You are talking about the next one.

DR. HALLADAY: No. I am talking about 2021, which is the --

DR. DANIELS: And we are also collecting for 2022. It is getting confusing. We hope to get these other documents done so we can just work at one year at a time.

DR. GORDON: Alycia, why don’t you doublecheck with OARC staff about your nominations for 2021? Let us make sure we are not losing any.

Sorry, JaLynn, did you have another comment to make?

MS. PRINCE: Yes, because the publication I have been talking about is 2020 and I was getting confused between the years as well and trying to figure it out. It qualifies in with this.

DR. GORDON: Yes, JaLynn. But unfortunately, it is too late to take the nomination. I do not think we can do that at this point.

MS. PRINCE: I wish there had been a little bit more clarity.

DR. DANIELS: I believe, JaLynn, the document you are talking about is a report that was prepared. We usually do not include reports from agencies and organizations as advances, but that is something that can be brought up if the committee wants to include reports that are being put out by various organizations in addition to peer-reviewed research. That would be another whole question to ask.

DR. GORDON: Oh, yes. I would feel strongly. It has to be peer reviewed. That does not mean that if your organization submits it for peer review to publish in a journal or a book series or something like that that would be acceptable, but it would have to be peer reviewed.

DR. DANIELS: But there are other places to highlight things. We have the whole Strategic Plan, which is a place to highlight a lot of different things that may not necessarily fit in this category.

MS. PRINCE: Okay. Perfect.

DR. GORDON: I encourage you to bring it forward to Susan and her staff. It may merit some other considerations in some other way by the committee.

MS. PRINCE: There is some important information that can advance and very relevant things. Thank you very much.

MS. GASSNER: Just a gentle request. When we are, as a body, taking on a new task and we have so many new members to the IACC, if we could schedule some kind of a brief orientation. There was confusion among some of the members. I fielded a couple of questions where people are not really 100 percent sure what they were charged to do. I think when it is presented in an email with a lot of language, it is very confusing. I think if we could maybe schedule an optional time for people to be oriented that might be helpful.

DR. DANIELS: Sure. We can always do that.

DR. GORDON: Thanks, Dena. And maybe what we should do is try to do that before the April meeting for the 2021 Summary of Advances discussion so that people know what to expect.

MS. GASSNER: I think people will participate more and they will really understand what their task is so thank you.

DR. GORDON: Thanks for that.

Okay, next up in the final order of business, we try to allow people opportunity to bring any updates to the committee and to the community that they have. We really only have two minutes before we are supposed to adjourn, but I will ask trepidatiously, whether anyone has any brief updates to give. I see, Alison, your hand is raised.

DR. MARVIN: Very quickly just directing people to the round robin document, which is on the website. But I did want to mention that the application for the ARDRAW Small Grant Program has opened. And the applications are due by February 25. This is for graduate students, $10,000 stipend for the graduate program.

Just one other thing. We have a State of the Science Meeting where we looked at lessons from SSA demonstrations. That book is available for free download, a book of all the things that went on, all the papers, discussions by 30 leading disability and social policy researchers. If you go to that round robin document, you can download that book for free. Thank you.

DR. GORDON: Susan, there is a question in the chat, and I think it is a good question, and maybe we are providing it and they just do not know. But the question is from Lindsey. Is there a way we can receive access to the full text of the nominated studies when we are considering for the Summary of Advances? I think if we are not already doing that, let us make sure we provide that.

DR. DANIELS: We do. In the past, we have been able to provide zip files to people of documents. We can’t provide them on the website because a lot of this is journals charge you to see their --

DR. GORDON: I think Lindsey is pointing out that many of those on the call do not have access to pass the pay wall to get to these. I think that is important. Let us make sure that happens for the 2021 Summary of Advances before that discussion. Thank you, Lindsey, for bringing that up.

Alycia, I think you get the luxury of the last round robin.

DR. HALLADAY: Thank you. I just wanted to mention that the Autism Science Foundation Day of Learning will be hybrid this year. Last year it was all virtual. We will be on March 30 so before our next IACC meeting, which is why I wanted to mention it.

Actually, on the docket will be a ten-minute summary of the talk that Matt Maenner gave today, as well as some other talks by individuals with autism as well as researchers.

We are also in the process of reviewing. We are back on track after COVID. We are reviewing our new post undergraduate grant mechanisms, pre-docs and post-docs. And also, we have released the RFA for our undergraduate research program, which is restricted to individuals from underrepresented groups, undergraduates, that is, and then also those who are studying racial and ethnic disparities in autism. I just wanted to mention those three things.

MS. GASSNER: Also, I wanted to add that the INSAR community collaborators’ requests are help wanted ad pages and set to launch Thursday the 20th so if autistic – people are looking to find participants in research or collaborators that they can find them on that one page. It might take us a lot to populate, but it is going to be happening this week. Thank you.

DR. GORDON: Great. Thank you. And I will just point everyone who is listening to the IACC website where there is a long document with lots of announcements like this called the IACC Round Robin Updates. You can find it on the IACC website under this meeting’s link. I encourage everyone to go there. There is a lot of interesting stuff, grants, deadlines, information, workshops, lots of stuff on there.

Next up, Susan, I think we do want to take some time to thank the OARC staff. Of course, Dr. Daniels. But lots of other folks. Dr. Oni Celestin and Dr. Katrina Ferrara, Steve Isaacson, Dr. Tianlu Ma, Rebecca Martin, Angelice Mitrakas, Luis Valdez-Lopez, and Jeffrey Wiegand. This is a great group at OARC. They have done a lot to get this meeting up and running and to make it happen as well as our contractors who have been helping us out with the technology. I want to thank all of them.

They are not only responsible for putting the meeting on, but they are also responsible for taking all the wonderful input that you have given us and putting it to action. Look for some improvements along the way.

The next meeting is April 13 to 14. We tried to split today up until we really could not. But we are going to do this in two segments next time because it is just so much easier and less exhausting. I do not know about you, but I am pretty tired at the end of this day.

And just one final note. I appreciate as others have already said the passion and the back and forth that we have had today on a number of issues. It will not be the last word on those issues and more. But I appreciate the respect that we all gave each other and the opportunity to hear all these different viewpoints. We will get to know each other more over time and learn even more how to listen to each other and how to make sure that different viewpoints are represented. Thank you, all, for your contributions.

And to those of you who have been following us through the videocast on the web, thank you for joining us as well and thank you all for the work that you do on behalf of communities and individuals affected by autism. Thank you, all. Bye now.

DR. DANIELS: Thank you, everyone. Bye, we will be in touch.

(Whereupon, at 5:05 p.m., the meeting was adjourned.)