INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

THURSDAY, July 22, 2021

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 2:00 p.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

PRESENT:

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

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

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

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

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

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

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

PRESENT: (continued)

AISHA DICKERSON, Ph.D., Johns Hopkins University

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

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

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

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

MORÉNIKE GIWA ONAIWU, M.A., Rice University

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

CRAIG JOHNSON, B.A. Champions Foundation

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

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

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

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

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

VALERIE PARADIZ, Ph.D., Autism Speaks

PRESENT (continued)

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

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

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

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

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

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

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

MATTHEW SIEGEL, M.D., Tufts University

IVANOVA SMITH, B.A., University of Washington

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

HARI SRINIVASAN, University of California, Berkley

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

PRESENT (continued)

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

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

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

PAUL WANG, M.D., Simons Foundation

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

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PROCEEDINGS

DR. SUSAN DANIELS: Good afternoon. Welcome to the second half of the meeting of the Interagency Autism Coordinating Committee. We are glad to welcome you today and hope that you enjoy the meeting. I have a couple of announcements to start us off. I wanted to point out again to everyone that there is a live feedback link on the NIH Videocast that you can use to provide short comments to the committee.

For the first half of the first session, we will be collecting those for the public comment session. You can make comments throughout the day, but only the ones that are in the first half hour of today we will make it into the public comment session because of the timing. But we will put all of them in the final document that is posted on the website and that live feedback comment document will be available on the website before the public comment period.

We also ask you or we also are mentioning to you that there is closed captioning. I was asked this yesterday and I forgot to announce it, but it is available on the NIH Videocast always. That is available to anybody who needs it.

I am going to ask the committee if you could please keep any comments brief as we go through these discussions. We are going to have a lot of compassionate discussion and we want to make sure everyone gets a chance to comment as much as possible. With such a large group, it won’t be possible for every person to comment, but we want to hear as many as possible. And Dr. Gordon and I will be doing our best to keep the sessions on time. Please bear with us if we have to bring a section to an end when people may have still wanted to comment. But we want to keep everything moving.

Thank you so much for being here. I will turn it over to Dr. Gordon.

DR. JOSHUA GORDON: Thank you very much, Dr. Daniels. It is my pleasure to welcome you back to Day 2 of our inaugural meeting of this version of the Interagency Autism Coordinating Committee. Really pleased with the level of discussion and engagement in yesterday’s group and that is going to be even more evident today. Today is really a day full of discussion.

First, we are going to have in the first hour, we are going to have a discussion on the impact of COVID-19 on the autism community and several of you mentioned – several committee members mentioned that their own groups are working on this issue. I am really looking forward to hearing from you about that. I will introduce that topic in just a moment.

The second and third will be a public comment session in which we will hear for the first half hour of that time period, we will hear from our public members. And then the committee will have an opportunity to discuss any issues brought up by the public that they would like to respond to.

And then finally, the third hour of today’s meeting will be a discussion around racial equity and health disparities in autism, an issue that is also deserving of this committee’s attention. These preliminary discussions will help inform whether and how the committee will address these issues through more formal presentations, symposia, invites, et cetera, in the future. I am really looking forward to hearing all of your perspectives.

With that in mind and given that this is a new committee, I want to implore all of you to be open and frank with your opinions and to make sure to give voice to your own thoughts and to those of the stakeholders whom you represent.

I also want to implore you to continue in the really wonderful tradition that this committee has had in the past of being respectful in expressing your opinions and especially respectful in expressing disagreement. I want to hear that disagreement. It is important that the federal partners at the table understand where the community speaks as one voice and where there are differences of opinion. It is especially important that we talk through those areas where there are differences in a respectful way so that we can figure out where there is consensus and how to respond.

So I am really looking forward to engaging with you all in spirited dialogue over the coming hours and indeed over the coming years, and also to using that spirited dialogue in a sense of friendship and cooperativity so that we can move everybody forward.

With that note, we will move right into the first item of our agenda, which is a committee discussion on COVID-19 response, issues and recovery. In a moment, I am going to open it up to comments, questions, presentations, whatever you would like from members of the committee. I already see a hand raised, which is great. We will get to you in just a moment, Ivanova.

But first, I want to just set the stage a little bit as putting on my hat, if you will, as the director of the National Institutes of

Mental Health. We knew even before the pandemic started that when faced with a national trauma like what we are enduring right now, that there are significant mental health consequences. We knew to anticipate in the early days of the pandemic that a large number of Americans would experience mental health symptoms of depression, stress, anxiety, increased substance use, and even suicidal thoughts. We further knew that most of these people would, given time, recover but that a small minority would experience chronic or severe symptoms, requiring professional help. And all of that has come to pass.

We see that 40 to 50 percent of Americans are experiencing one or more symptoms of mental distress. We know that there are increased demands for mental health services. We are seeing increased visits to emergency rooms for self-harm behaviors in adolescent girls, for example, and increased calls to suicide and disaster distress hotlines.

We are also seeing a remarkable response from the mental health community. We saw like other branches of medicine an immediate pivot from in-person to tele-health visits. And we imagine and think, and there is some data to suggest, that that transfer worked. For example, we are not seeing the kinds of increases in suicide rates overall in the United States that we might have expected. Indeed, suicide rates in 2020 went down overall despite the pandemic. That said, like many other things in our society, the mental health consequences of the pandemic were not felt equally by all subgroups.

For example, in the States of Maryland and Massachusetts, which are really two of the first states to release this kind of data, we saw evidence of increased suicide rates among black Americans as compared to white Americans where we saw decreases. We know that the black community among other minority communities has felt both the direct and indirect impacts of the pandemic most acutely.

It is with that spirit that I invite you now to participate in this discussion on the impacts of COVID-19 amongst individuals with autism. Some committee members have participated or ran surveys and other studies of that impact. I am really looking forward to hearing from you because to tell you the truth, there is a dearth of published data on these impacts. Some of the researchers in this room are studying them and we anticipate the results of your work coming out in the coming weeks, months, and years. But it is perhaps here that we and the Federal Government can first begin to hear both anecdotally and perhaps also in terms of quantitative evidence of these impacts and therefore begin to formulate additional responses that we might make to aid this particular disadvantaged community.

Thank you all for tolerating my brief introduction and especially to Ivanova, whose hand has been raised the entire time. I will let you begin with the question or comment that you have.

MS. IVANOVA SMITH: Thank you very much. I am Ivanova Smith, and I just wanted to address my concern around this issue. As an autistic individual, I am still experiencing discrimination based on COVID-19 and the struggles and there are many in my community in the self-advocacy community, autistics with intellectual disabilities, that lives have been restricted because of COVID-19. And even though many of us are vaccinated, our lives have been restricted and not being allowed to be with their friends or family, not being allowed to travel. I cannot get on a bus or a plane right now because they will not even accept a person with a face shield instead of a mask. I can’t have things on my face. There are many autistics like me that can’t have things on their face. They have been excluded from society because of COVID-19 and the protocol that makes it really hard for us to be able to be in our communities and be included and not be seen as a hazard or seen as a burden because we cannot do the same things other people can do.

I think that we need to figure out an exemption. We need to figure out a way to respect autistic people who cannot follow all of the protocols that they still should be allowed in their communities, especially if we have been vaccinated. We should still not be restricted from our communities in that way.

I think that I would really like to work with the committee on figuring out ways that we can figure out ways to honor exemptions and honor autistics that can't handle the sensory issues and still want to be in the community.

Many of us have gotten the shot, but we are still restricted because maybe our care providers will not get the shot and that causes struggles too for us, when we are still not allowed – many people are still not being allowed to leave their residential because the providers say that they can't allow them to leave. I feel that the community, the people that take it out of the community more because of COVID and that is something that is of great concern to me. Thank you.

DR. GORDON: Thank you so much for that comment. I just want to underscore that these are issues that we do need to think about. How can we accommodate individuals with autism who cannot handle wearing masks and how can we make sure that they have the ability to see their friends and loved ones despite potential residential restrictions? Thank you for bringing those up.

I see that Hari Srinivasan – Hari, you would like to speak. Go right ahead.

MR. HARI SRINIVASAN: I will be brief and based on my personal observations. So just want to point out one negative and one positive. A negative is the disruption of services for autistics especially things like special education related services. While regular education switched to Zoom, many autistics were stuck at home for nothing. Zoom does not really substitute hands-on services.

The positive is that Zoom has shown us the potential and high-rate employment solutions for adults. That means we can have more autistic and potentially engaged in employment if only we could get employers to also see it that way. Similarly, I am now able to do my cognitive behavior therapy sessions over Zoom instead of having to travel and wait there. But I do not want all providers across all areas to use this as a cop out and move everything to remote because it is more cost effective and convenient for them.

DR. GORDON: Thank you, Hari. I appreciate you pointing out that like most things for most people, the pandemic has both negative and positive aspects to its impacts.

Julie Taylor, I believe you are next.

DR. JULIE TAYLOR: I am happy to provide a little bit of a research perspective and actually I would love to hear if what we are finding is consistent with actually many of the self-advocates and others on this call. It is always a good check to see if what we are finding in our research actually feels like it is consistent with people’s lived experiences.

We ended up having I think like a lot of researchers - we were really interested in the context of our ongoing studies to try to add in a component to really understand the pandemic and how we can help support autistic individuals and their families.

We had two studies that we have some findings from. In one study, we were collecting data on mental health and mental health services actually and we collected that data the end of February, beginning of March in 2020 so like weeks really before things shut down and the pandemic. We had sort of baseline data on a pretty large group, over 300 autistic adults. And then we collected data again two months into the pandemic.

And what we found actually was really high rates of depression and anxiety not surprisingly two weeks in. But rates of depression and anxiety were really high before the pandemic in the groups that we talked with. On average, we did not actually see a worsening of mental health because a lot of adults were really struggling with mental health challenges before the pandemic even started and lots of studies have found this, that mental health is a real issue.

We did see just a tremendous amount of variability, not surprisingly, in people’s experiences. For example, if somebody lost their job in the first two months of the pandemic, they tended to have worsening depression in those cases. If somebody was experiencing challenges with depression prior to the pandemic, they seemed to be more negatively impacted by the pandemic. But there really was just tremendous variability with some people having mental health improvements. I think for some people having the opportunity for remote work, for example, where maybe they would not have had that opportunity in the past was something that was helpful to them.

I feel like in that study sort of incredible variability in terms of how people are impacted was sort of the name of the game.

We just wrapped up another wave of data collection a year into the pandemic. We will see what the longer-term effects of the pandemic are of mental health. You might expect the grind of all of this over time maybe where we see potentially some changes down the road. That is something that we are interested.

We had another study looking at service access. We collected some really detailed data on how services mostly for adults and young adults have been impacted by the pandemic and clearly challenges getting special education services like Hari noted was something that we really saw a lot in our study.

We actually interestingly saw that for many people, it was easier to apply for adult services. In Tennessee, oftentimes applications had to be done in person for different types of services and things like that. For different types of services, the applications worked in different ways. And more agencies had to move their application processes online. It actually seemed to make it slightly easier for individuals and families to apply. But it was much harder to get the service once you applied and mostly to find providers whether that is more in-home providers or direct support care providers or job coaches or things like that just due to social distancing restrictions and things like that.

Getting the service seemed to potentially be a little easier maybe or at least not harder, but then actually being able to make use of that service once you have gotten having a real challenge. We have not really seen that coming back online quite yet in terms of that kind of – it is never easy to be able to use the service and to get the service, but that has become even harder, I think.

DR. GORDON: Thanks, Julie. Real quick before I move on to the next person. Do you have preprints yet available or any sense of when we will have the data publicly available?

DR. TAYLOR: Yes. We are preparing and analyzing the data right now for service changes. That is hot of the presses in terms of what we are finding there. We had over 90 questions. We have added a couple of papers, two papers published on the changes to mental health. I am happy to circulate those. And then we have one under review that is looking at the impact of employment changes and potentially – specifically, losing a job or having significant reductions in your work and how that is impacting mental health for autistic adults. We should be very close to having that accepted for publication.

DR. GORDON: Wonderful. If you could circulate whatever you could, and we can help. Susan can help get that out.

Dena, I believe you are next.

MS. DENA GASSNER: Thank you. I just wanted to use a funnel approach to convey my opinion here. I am connected to a variety of people who have loved ones that have various different kinds of support needs. Many of them joined our family in the throes of transitional to employment kind of opportunities. It was an interesting thing that I would say eight to ten of my personal colleagues who have kids that are transitioning and have adult services coming on board. Interestingly enough, we were all asked to close our rehabilitation system cases, not because of hiatus, not to pause them, not to continue to provide training opportunities with videos and so on online. They just wanted us to close our cases.

DR. GORDON: Dena, who are they?

MS. GASSNER: My friends. Just personal friends, contacts, colleagues.

DR. GORDON: Your friends wanted to close their children’s cases.

MS. GASSNER: I am sorry. No. Vocational rehabilitation asked us all to close our cases.

DR. GORDON: Which is a state organization?

MS. GASSNER: In different states across the nation. Yes. To get to the next tier of this, in our personal scenario, the barriers that we saw were people not really being effective at meeting online. In our case, our person was good at finding YouTube videos for training and so on. Also, the museum my son aspires to work at has training videos about the content of the museum that they worked through and he memorized all of that as part of his rehab training. But now, he is beyond what they consider observation and he needs to actually engage in employment to continue his case. Yet the museum is not hiring right now. This is what he wants to do and there is only one museum in town. It creates difficulties. We have had one in-person meeting since COVID with our support person. I am concerned about that.

And then today on top of this, Time Magazine released an article today talking about the implications of COVID and long-haul individuals who deserve what they need as well. I am not saying that they are not a priority but that they are kind of inundating Social Security in terms of new applications. They are struggling with some of the same things that people with less externally represented support needs like autistic people are experiencing in that they do not have a massive history of disability. And Social Security has had a huge budget cut. They closed over 60 offices. Like us, sometimes they have symptoms that defy measurement.

I am just very concerned that systems that have struggled to keep up with demand both vocational rehabilitation and Social Security with the demand for services particularly in the light of people whose disability issues are not easily measurable or documented that are more internalizing as is the case with the COVID people and with our autistic population and then some who are in both schools that we are not ready. And the budget increase that President

Biden is suggesting of 10 percent is not going to come close to addressing the first cut, which was 22 percent that previously happened. We are not even meeting the previous cuts halfway.

I just have global concerns about the loss of services, the loss of employment opportunities, continued delays with Social Security benefits being approved quickly enough. People have lost their homes already that have been experiencing COVID long haul symptoms.

It is a variety of things. Basically, the systems that are designed to help disabled people are going to be flooded. I predicted this well over a year ago. Unfortunately, we are just now having this conversation. I look forward to continuing the dialogue and hearing from other people that may be experiencing similar cutbacks. Thank you.

DR. GORDON: Thanks. I see a number of hands up. Let us go ahead and go with Valerie Paradiz. Actually, Valerie, before you, if one of the other two people who have raised their hands or maybe you, Valerie, want to respond directly to Dena’s comments about disability resources, including vocational health, it would be great and we can then go to Valerie, unless, Valerie, you want to respond directly to that.

DR. VALERIE PARADIZ: Sure. I can add to Dena’s comment specifically from our family experience. My son, who is 31, is an SSI recipient. He lost his job two weeks after the shutdown began. He was working part-time bussing tables at a small café. As things have reopened in the little tourist town where he lives, he has returned to work but did experience pretty significant challenges communicating with the SSI office near him about returning to work. He is extremely vigilant about reporting his income to SSI and experiences a tremendous amount of anxiety when he does not know what will be happening next. There were very significant delays for him in getting any kind of correspondence or information. And that led to some pretty serious panic attacks just last week to where he had to be hospitalized and have a number of other tests done for heart arrythmia that may or may not have been associated with the panic attack. I guess I wanted to just dovetail on Dena’s real lived experience.

And then just very quickly add and this will be very high level, for Autism Speaks where I work, our public health and community inclusion team issued a special report on COVID-19 and autism in March of 2021. I will just note some high-level takeaway points that I would like to have on record for today’s call. One very significant finding was that households with people with autism are experiencing significant food insecurity especially minority households compared to households with no disability. For anyone who is interested, this information and report is available on our website. But this is an area that we are very concerned about at Autism Speaks.

Food insecurity is measured in this report as worry about food running out before having money to buy more. We know that this worsens significantly for many households especially minority households during the pandemic.

Other high-level findings were a greater percentage of people with autism either alone or with intellectual or developmental disability died from COVID-19 than people with no chronic conditions.

And then finally, the other finding I have to share is that people with autism alone or with intellectual or developmental disability were substantially more likely than those with other chronic conditions to be hospitalized with COVID-19. I just wanted to share that data as well. Thank you.

DR. GORDON: Thank you, Valerie, for updating us. I was aware of that report. It is one of the really most important reports that have been so far published out there. We really appreciate Autism Speaks' effort.

Let me turn it over to Alison Marvin, who is our SSA rep, who may be able to help let us know what SSA is trying to do for individuals with autism and other disabled individuals through the pandemic.

DR. ALISON MARVIN: Thank you so much, Joshua. First off, I would like to direct people to the www.ssa.gov/coronavirus website. SSA has been extremely active right from the get-go when the virus started. We launched our COVID waiver where no adverse events nor adverse actions could be taken against anybody during this period.

Also, we have been doing a massive amount of outreach. I actually am from the Division of Center of Excellence and mine is actually doing analyses to try and find out who is not signing up. We have actually been focusing, especially trying to find people. We are also looking at geography and we spend a lot of efforts actually doing outreach efforts, publicity, radio, television, desperately trying to get people to sign up. True. A lot of the offices are not open, but you can make appointments. You can actually make an appointment and meet someone actually at the office and things are being done online. I just wanted to make everybody aware that right from the get-go, we were very active in doing this and making sure we were protecting people and getting people signed up. I do encourage people. Please do sign up for benefits if you think you apply.

DR. GORDON: Thank you so much for that and thank you for being here and listening to this and hopefully be able to bring back some of these firsthand experiences with you to try to do what we can to improve things.

Next up for me, I have Alycia Halladay. You can go ahead next.

DR. ALYCIA HALLADAY: Hello everyone. I am glad my camera is showing today. I apologize. Yesterday it was not. Thank you to Valerie and also to IACC who put on the website some research reports that have been done not just by Autism Speaks, but also the Simons Foundation around some research data on how people are affected and how they were continuing to function during COVID.

I wanted to point out. There are two additional reports. One by Simons Searchlight, which looks specifically at those with autism and rare genetic diseases, and another led by UCLA that kind of dovetailed on that one and looked at the people with rare genetic diseases that are not represented in Searchlight. We have worked together. That was put together by agenda.

In any event, both of those surveys ask specific questions about telehealth. I think telehealth was one of those things that before the pandemic, everybody was a little bit afraid of and now that we have used it, it is probably going to be here to stay and that is good news for some people and that is sobering news for other people.

But there are specific things in which telehealth has been very helpful for and that includes medical visit appointments where you just sit and talk to your doctor in a doctor’s office. It is helping people not have to get on the bus or take time off of work to get that appointment and also believe it or not, adolescents are finding it helpful for mental health treatment.

Where it is not being so helpful is for little kids and for behavioral interventions across the lifespan. I think one thing that the IACC can do is really think about how we can, what I like to say, use telehealth for good and take advantage of the things that telehealth does that alleviated some problems for families, including not being able to take time off of work. People who lived in rural communities. ASF is funding a study right now looking at telehealth utilization in rural communities, which has always been an underserved population. But then also maybe kind of embrace what we like about it, but then kind of manage what doesn’t work about it. It is not all bad, but it does need to be polished a little bit.

I think that that is one thing that – it does not solve the Social Security issue. I apologize. I know we were talking about Social Security. It could, in fact, help with some employment issues. But I think support of telemedicine, telehealth, and access to these services could be something that we look at.

DR. GORDON: Thank you, Alycia.

Next on my list is Mercedes Avila.

DR. MERCEDES AVILA: Thank you. I have to apologize. I cannot see the raise hands or raise my hand, but thank you for that.

I have three specific topics. One of them is as a parent. So many schools move remotely very fast even though we are talking about how effective telehealth and telemedicine and Zoom can be for improving access to community. We also have to keep in mind that many families do not have access to Wi-Fi in 2021. There are so many areas in the US that do not have access to Wi-Fi. Many families that we work with do not have access to computers or devices where they can connect. And many families have language access limitations that they cannot – they might not be able to understand health literacy or information provided to them in specific forms. There were consent forms sent to use Zoom that were four pages long that families were supposed to read ahead of time. Those are all barriers that prevented many families from accessing services equitably.

And then the other two areas that we saw at least very salient in our state in Vermont was a registration for testing sites for COVID-19 testing sites. Many of the registration forms that were available online were not in plain language and they were not providing accommodations to many of our community members. It was very hard to register for testing unless you had someone helping you register or there was a lot of advocacy that had to happen at the state level with advocacy groups and different organizations to ensure that this happened.

That also connected to many communities not being able to access information in a timely manner when the pandemic started. A community that had language access limitations or they were limited English proficient. They did not have access to information for weeks and in some cases for months. Some areas here in Vermont. It was not until June that some communities did not get the right information that led to outbreaks in several of these communities. I think COVID has taught us and is still teaching us because we are still living with the impact right now of mental health and homelessness and other issues that we have many infrastructure improvements that we need to make for public health, specifically, looking at language access continues to be an issue across the United States in not providing interpretation, translation, ASL, even for press conferences. Sometimes you see press conferences and they do not have interpretation that is required by law.

Finally, in Vermont, I was involved with several advocacy groups in vaccination efforts for racially diverse communities and also for vulnerable communities. Again, what we found is that we needed to do community education around vaccine hesitancy about safety of vaccines. That has to happen ahead of time because there is distrust with the medical system, with the health care system in many communities that have had a negative experience with the systems. We have had to be proactive providing education before we go into vaccination.

Finally, every state looked at different priority groups for vaccination. In Vermont, specifically, when we went for underlying conditions, the original request was to have medical proof and a doctor’s name to be able to register for a vaccine. And several of us opposed and advocated against any type of accommodation to be able to access a vaccine because our goal is to reach as many people as possible with vaccines and not put barriers that can cause more distrust. These are some of the problems that we saw. And we are going to continue to see connected to some of the distrust and issues that have happened historically in the US. But we need to be continuing to look at them. Thank you.

DR. GORDON: Thank you for those comments.

I just wanted to add on to this equity piece of what someone said earlier, that individuals with autism they found to be at higher risk of hospitalization. Individuals with mental illness in general are at higher risk of contracting COVID and of higher risk of hospitalization and death if they do contract COVID. It is important to think of individuals with autism and individuals with mental illness more generally as a risk population in COVID. It is probably true of other infectious disease epidemics as well. I am glad you brought up the issue of equity and of course it applies directly to the populations that we serve here in this committee.

Sam Crane, you are next.

MS. SAM CRANE: Hello everyone. I am Sam Crane from the Autistic Self Advocacy Network. I cannot see myself. Is my video working? Great.

I wanted to jump back a few speakers back to some of the points that Ivanova made and connect it to Julie's research because I think that there are very different experiences between people who may, for example, be living independently or at home versus people like in the situations that Ivanova was discussing such as group homes or institutional settings that severely restrict visitors and severely restrict the ability to leave the campus.

We are really concerned about increasing isolation of people in institutional settings during COVID. At the same time, we implemented a COVID case and death tracker, which is I believe the only attempt to track cases and deaths in institutional settings across the full variety of those settings and in a way that disaggregates residents versus staff.

And what we found was that residents in institutional settings were still far more likely to contract COVID and far more likely to die as a result of COVID despite attempts to use restrictions to prevent outbreaks especially at this point when people are vaccinated, continued restrictions that prevent people from seeing friends and family really need to be viewed as posing their own significant health risks.

In addition, we have seen attempts to address COVID in ways that have other significant impacts on people with disabilities. In particular, people who are in need of health care who visit the hospital or doctor’s office have often been unable to bring a supporter with them and in the case of people with intellectual disabilities, people with anxiety disorders, people with communication needs that was particularly troubling. We have been part of complaints and attempts to draft model policies that balance the need for safety against the need to make sure that people with disabilities can have equal access to health care including when that requires the presence of a support. Those were the main points I wanted to make.

DR. GORDON: Thanks Sam. Those are excellent points and echo what others have said in the past but expand them. Thank you. Alison.

DR. MARVIN: I just wanted to add from the Social Security Administration in response to a previous comment that the Social Security Administration actually maintains a site in Spanish and that is SSA.gov/espanol. I apologize for the pronunciation. Also, if you go to the regular SSA.gov website, at the top, you click languages. You can actually see all the languages, all the brochures in different languages. And also, we have free interpreter services. And on that same page, it mentions if you have had difficulty receiving services due to a language barrier issue, please contact the regional communications director for your state.

It says that in English. But I think it also mention that in some of the other forms in the different languages. I just wanted to make sure people were aware that we do have multi-lingual capabilities at SSA.

DR. GORDON: Thank you. Hari.

DR. DANIELS: Hari asked me to give a comment for him in the chat. He said, unhappy about current post-pandemic trend at large organizations where work from home is seen as top executive’s privilege or perk and not for other employees, which means autistics will get left out of potential hybrid solutions.

DR. GORDON: Thanks for that comment, Hari. I think a lot of organizations are reevaluating their work scenarios. Some are moving to increased flexibility and others are not. I think it is important to recognize that in rethinking work situations, organizations should not lose site of the individual needs of their employees. I think you are bringing up an excellent point that hybrid work, as you mentioned before, represents an opportunity perhaps for increased participation by individuals with autism. It is true. If we limit the flexibility for that, that would be a huge misstep.

I note next on my list is Diana Bianchi.

DR. DIANA BIANCHI: Thank you, Josh. Just to remind everyone. I am the director of the National Institute of Child Health and Human Development. I am reacting to Mercedes’ comment. We are all very deeply troubled about the short-term and the long-term effects on our children being out of in-person schooling and particularly the effects on children with special needs.

For this reason, we convinced the Office of the Director through the RADx Underserved Populations program to focus on safe return to school. This is a $50 million program, 5-0, that started in the spring. But the first group of teams will have data by early August that we hope will provide evidence for getting children back to school. Importantly, several of the investigators are running initiatives based on populations of students who have difficulty following typical mitigation strategies.

So someone mentioned not being able to wear masks. We know that. How do you keep students safe when they are unable to wear masks or children who have difficulty following directions or for whatever reason cannot maintain hand hygiene or social distancing? I just wanted you to know that these are really outstanding investigators that are covering a wide variety of populations of children, not only ethnically, racially, intellectual disabilities, geographic parts of the country, including tribal nations. Stay tuned on that. These are going to be very, very important studies. Thank you, Josh.

DR. GORDON: Thank you, Diana. While we are on the subject of NIH and their research platforms, a lot of the – it is incredibly helpful to hear the individual stories and the data that you are all collecting. It is really, really helpful.

There are sponsored studies at NIH to look at the impacts of school closures, in particular, that Diana’s institute and ours and few others collaborate on. And definitely there are foci there, particularly on children like those with autism who might be affected most.

I see Dena again.

MS. GASSNER: Just quickly, to add another tier to Mercedes’ comments, we also have to remember the high frequency of neurodiversity in the parents of disabled people. Whether they have a learning disability or attention deficient or they themselves are on the autism spectrum, when you are looking at a bilingual scenario, compounded by the communication barriers or the organizational challenges of being a neurodiverse parent, the burden becomes even heavier.

One of the challenges is although we report in these agencies to provide accessibility support, I have asked for a separate waiting area in several different Social Security offices that they have absolutely no idea how that might operate in real time. And also, not having access to a navigator, someone that understands what the question is actually asking when based on neurodiversity or lived experience or cultural differences, you may easily misinterpret that request. There is a historical layer to this. I am dissertating on this.

But I think that we can also moving forward in light of COVID, it is an opportunity for us to grow some new solutions that can have broader implications. Thanks.

DR. GORDON: Thank you, Dena. It is a great point and I like the focus on solutions.

Ivanova.

MS. SMITH: Thank you. I just wanted to comment real quickly. There are alternatives to masks like face shields, but the thing is not everyone is recognizing face shields as an alternative and that has been a big issue. If we could get a policy or something that says, hey, face shields should be a reasonable accommodation for people with IDD, I think that would be fair. I do wear a face shield. But a lot of places do not recognize face shields. I even have had issues trying to even get medical care and people trying to deny me medical care because I could not wear a mask. I had a wear a face shield. Nobody should be denied medical care because they can’t wear a mask. I just do not think that is ethical to deny people medical care.

Another point I wanted to make real quickly is technology. A lot of people, now that everything is virtual, a lot of specialized programs are virtual, but not everyone is being given access to technology. There are people that are not allowed to have Wi-Fi in their residential or that they cannot afford the Wi-Fi so they have not been able to connect with the virtual community. They are isolated because of lack of technology access and broadband access. That is another big issue that has forced isolation of people from the virtual community that were created due to COVID-19. Thank you.

DR. GORDON: Wow, Ivanova, I had no idea. So there are residential settings that either do not allow or that don’t supply Wi-Fi, so people pay for it themselves.

MS. SMITH: Yes.

DR. GORDON: In this day and age, that is disturbing to hear.

Joseph Piven, I have you as next.

DR. JOSEPH PIVEN: Thanks. My comment is not so much to do with issues or problems to kind of report, but under the heading of what the IACC might think about doing to – inaudible comments – great success. I wondered about the extent to which we wanted to modify the annual strategic plan to address this current COVID situation a little bit more directly, either adding particular items where we review research or summarizing existing surveys, considering our own survey, possibly forming a special workgroup about this. But it seemed like something that we ought to consider this time around.

DR. GORDON: Thanks for that comment. And I think we can probably accommodate that on some activity related specifically to these impacts and looking at the equities that are out there in terms of discovering these impacts and finding a way that we can contribute to them. That would be helpful.

I see four hands raised and we have four minutes left. I am going to try, but I cannot guarantee that we will get to all four of them. Actually, I take it back. It looks like one person removed their hand. We have three. Please keep your remarks very brief because I do want to be able to get to our break and to also the people who are waiting to make public comments.

MS. JALYNN PRINCE: It is not working really well here today for me, thank you, or yesterday. We will get on top of it.

We have experienced a lot of things. We work directly with people on some acreage that we have and we also monitor a lot of conversations and input from families across the country. Something that we have seen is that there has been something a little bit than the population we usually represent, that is, single parents with multiple children. There were a lot of parents who were isolated away from their families and did not really have any additional caregiving people coming in to help them because that was not part of the school situation necessarily. And the schoolteachers and the other supports were gone.

I think there has been a lot of damage done to the parents themselves with the confidence that they have had in their parenting. Then the children themselves – and we are very much aware of this because we have opened things up and we have had people returning to our area for therapeutic riding and different types of equine therapies. The speech delays on all ages have been greatly hampered and very noticeable after not seeing people for a period of time and noticing where they were and where they ended up after the pandemic.

I am still very concerned about physicians being trained to understand patients in emergency care, especially if there would be no other supports around that individual. We heard several situations.

There was good technical, medical care, but there was very little conversation with the individual or understanding where they were in allaying their fears, especially when they were so anxiety ridden and that there has been a lot of challenges when people have returned home with nightmares, different types of things that parents have been reporting because of difficult situations in hospitals.

DR. GORDON: Thank you for that comment.

Paul Wang.

DR. PAUL WANG: Briefly picking up on and underscoring points have other made. First, broadband access. We heard about that from Ivanova. We heard about it from one or two other speakers before then. We need to have broadband access for the autism community. It is a challenge in rural, in Native Reservations. It is a challenge because of cost even when you are in areas that you would think are well served by broadband. In terms of solution perspective, we need broadband.

Hand in hand with that, we need to better understand how to optimize tele-services and also parent-mediated interventions. There is more and more research on that. But I think that the pandemic has really shown us that we need to jumpstart that and really understand when it is most appropriate and how to make it as good as it can be.

DR. GORDON: Thank you. I am going to take a moment to read one of the comments in the chat from one of our members who has communication issues. It is from Morénike.

With regard to what Ivanova shared, this is a greater issue than people realize. It impacts autistic people in congregate care settings as well as families with an autistic individual in the household who might reside in certain types of housing arrangements.

These individuals technically have Wi-Fi (in theory), but the Wi-Fi is so slow, unreliable, et cetera, that it might as well be nonexistent. How is someone supposed to actively participate in virtual therapy, which is often not equitable to begin with, or complete educational requirements, or engage in social programming when this is the case? Thank you, Morénike, for contributing that.

And last for this session, Hari has another comment to make.

MR. SRINIVASAN: It takes many years to learn skills and manage face-to-face social interaction, which is stressful at the best of times. The pandemic was a huge setback in terms of loss of skills and the transition back is going to be so difficult for many like almost relearning skills. I know most typical students are so thrilled about hopping back to a full social life. But I feel so stressed about how I will again assimilate back in less than a month.

Another thing, my college will be requiring weekly COVID tests once you are past six months of your vaccination. Getting the shot itself was super traumatizing and sincerely a struggle, involving multiple people, multiple attempts and all manner of special arrangements. Having a swab up your nose each week is going to be a sensory nightmare.

DR. GORDON: Thank you for that, Hari. One piece of information that might be helpful to some who suffer similar issues. Some places do offer saliva-based testing. It is not quite as accurate as nasal based, but it is fairly accurate, and it is worth looking into and inquiring if that could be an accommodation that might be useful.

We are going to take a five-minute break, which puts us two minutes late. But I think we need to take a breather. At 3:02, we will return for public comments. Susan, you are going to run that session. Susan will start us back up at 3:02. Until then, we are looking forward to seeing you all.

(Whereupon, the Committee took a brief break starting at 2:57 p.m. and reconvened at 3:02 p.m.)

DR. DANIELS: Welcome back, everyone. I think we are ready to start the public comment session. Today, we are going to be hearing some public comment. We have three different types of public comment that we are going to hear about today. We have five speakers who are going to be giving virtual oral comments. And then that will be followed by some written comments that are being summarized by one of the staff from our office, Luis Valdez-Lopez. And then I will give a brief summary of the live feedback comments that came in during the meeting.

After that, we will have the discussion period for the committee. We just ask similarly to the last time that the committee to try to keep your comments brief so that we can give many people a chance to comment. With the oral commenters, you each have three minutes. If you start going way over, we will try to move you along because we want to make sure that there is time for discussion at the end of the session.

With that, I would love to welcome Chris Banks on behalf of the Autism Society of America to give his comments.

Chris Banks? I am not seeing Chris right now.

We will move to the next one. We will come back to Chris if he is on in a little bit. Next, we have Jill Escher on behalf of the National Council on Severe Autism.

MS. JILL ESCHER: Thank you, Dr. Daniels. My name is Jill Escher. I am president of NCSA. I am also a research philanthropist and autism housing provider and a mother of two children with nonverbal autism.

I want to talk about the big picture for a minute. The IACC has been around for two decades. I think it is fair to ask, are we better off today than we were 20 years ago. I think the answer is unfortunately no. We are most definitely not better off.

While some minor battles have been won along the way, we are losing the war and we are losing it big. With modest exceptions, we are still nowhere close to identify causes of autism nor any meaningful roots for preventing this often devastating disorder of brain development.

Autism rates continue to climb. Over 20 years, autism – California’s DDS has seen a ten-fold in moderate to severe autism. In New Jersey, autism affects 5 percent of 8-year-old boys. Meanwhile some advocates still promote the absurd idea that the increase is not real, while others continue to flog the dangerous and debunked theory that vaccines cause autism. And much of mainstream science, let’s face it, as much as I love mainstream science, is stuck in a rut of repetitive and irrelevant research that will not help a single autistic person alive today. We have made almost no progress also with respect to treatment. The meager toolbox we have today is largely the same as 20 years ago.

Then, of course, the massive elephant in the room, which is the growing adult autism crisis. We have fewer housing options, not more. More and more adults are living with aging parents unable to access brick and mortar or the supports necessary for their complex needs.

We have fewer employment opportunities, noncompetitive employment, which is the only viable option for a vast expanse of the spectrum, is being stripped away and replaced with nothing.

As for Medicaid home and community funding, that system serves only a slice of our disabled adults. Even if you have the good fortune to escape one of the year’s long waitlist, good luck finding a provider. They pick and choose, and they do not choose our severe adults.

If you are a family in crisis living with an aggressive, destructive, or self-injurious loved one, you are pretty much on your own and nearly non-existent crisis care system means your child will likely land in an emergency room ill equipped where your child is drugged and restrained with nowhere to go.

Finally, what will happen to this burgeoning population of severely disabled adults after their parents die? This is a major public policy question no one can answer because we still have no plan. We almost have no discussion toward a plan. The disparities in autism are growing and punishing those affected by severe autism.

Please ignore the crusade to trivialize autism. Focus instead on what Congress directed you to do. Further federal efforts to find causes, prevention, treatment, and lifespan services. Thank you very much.

DR. DANIELS: Thank you, Jill. And a reminder also to our public audience that you can access the comments that were submitted online on the IACC website.

And next, I will try to go back to Chris Banks. Chris, are you here?

I will move on then to Bin Feng.

MR. BIN FENG: Thank you for allowing me to speak here. My name is Bin Feng. I am from Queens New York. I am the Autism Speaks volunteer advocacy ambassador. And most of all, I am the father of a 21-year-old son, Vincent, who is on the autism spectrum.

During the last four years, we help him learn and keep a job. Now, he is working independently as a janitor in New York City. Before the pandemic, he was able to travel by himself each way two and a half hours to work and then come back. He never was late. Even during the pandemic, he still learned how to wear the mask and go back to work even when New York City was still locked down and it was the worst time during the pandemic. It was June 1, 2020, he is back to work. Literally, he is a frontline worker, still working during the pandemic. We are very proud of him.

For working as a janitor for him, it is not only just numbers on his paycheck, but he learned lots of things. He learned how to manage his daily schedule. He learned how to travel by himself. He learned how to manage his communication. And most of all, he learned from the mistakes he made and bounced back. For us, we see a big future for his independence coming from the employment.

For the next one, because of that, the next one we are probably looking more supported housing options because he already shows some ability can be gained independence. But we know that even for us, for Vincent, to get a job, it is very hard. It is really not easy. We see the system still have lots of things not to encourage people on the autism spectrum to work, but put a lot of block on it.

We hear a couple of members before talking about Social Security. Now, he is a young man, getting a very low wages and working only half time. But his income already gets a risk to losing his SSI. Of course, he wants to work more hours, but we are very hesitant to do that.

We know that pre-vocational training is very critical for the young people on the spectrum to getting work. But many of the pre-vocational training, they only start at age of 18. In New York State, they try to plan close some of the workshops and for lots of the young people on the spectrum, this is probably the only place they can work comfortably there. If they close, they have nowhere to go. We know that it is lots of things we need to do. I know it is not an easy one, but it is worth it.

The employment can give young people a big different life. I encourage everybody think of this one as a priority and I thank everybody for the good work that you do and I thank you.

DR. DANIELS: Thank you so much, Mr. Feng.

Next, I will go back to Chris Banks. He was having some technical issues. But I believe he is with us now.

MR. CHRIS BANKS: I am now, Susan. Thank you very much. I appreciate that and thank you to the members of IACC for your tolerance with my technical challenges there. Thank you.

The Autism Society of America appreciates this opportunity and the efforts of IACC and its committee. Our organization, with its 74 affiliates throughout 33 states, has traditionally had representation on IACC. Since 1965, the Autism Society has worked tirelessly to support the autism community through advocacy, education, information and referrals, support and community building.

The Autism Society and our affiliate networks serve over 668,000 individuals and families affected by autism in 2020. We have made it our mission to improve the lives of all affected by autism alongside our affiliates nationwide.

Through the decades, the Autism Society has proudly served the autism community and established itself as the nation’s oldest and largest grassroots autism organization. Together, we are creating a more inclusive and accepting society full of opportunities for autistic individuals and their families.

At the onset of COVID-19, we were the first national organization to produce and share a COVID-19 toolkit. In 2020 alone, more than 390,000 people availed themselves of our digital and virtual supports. Our toolkit has been accessed by 135,000 users. Nearly 200,000 people have viewed our original coronavirus Facebook live series. This is nearly three-quarters of a million people who have turned to the Autism Society of America for supports and solutions.

This past April, the Autism Society proudly promoted through our affiliates, autism acceptance month. Words matter, which is why the Autism Society officially our campaign to encourage media and government officials and government agencies to remove using autism awareness month to autism acceptance month. Autism advocates have been using this terminology across the country for years because acceptance can help ignite change and inclusion for the autism community.

As we work to create a more accepting society, we must accept autistic individuals and their families for who they are. Acceptance is one of the biggest barriers to being valued and finding and developing a strong system support. As one of your panel members, Hari tells me in many of our conversations, acceptance leads to inclusion, and I add inclusion leads to belonging. We look alongside self-advocates, national disability organizations, and the greater autism community to federally advocate for all things related to autism.

As you all know, the Interagency Autism Coordinating Committee, IACC, coordinates federal efforts and provides advice to the Secretary for Health and Human Services on issues related to autism.

Since the IACC mission is to provide advice to the Secretary, facilitate the exchange of information, and this third one, increase public understanding of member agencies' activities, I would like to share with you three very important things that are going on at the Autism Society. While it is unfortunate that we do not have official representation on the committee and we are hopeful that future committees will include representatives from the largest and oldest autism organization in the nation, we do appreciate the opportunity to express these concerns.

In addition to our legislative agenda of the Consortium for Citizens with Disabilities, which the Autism Society fully supports and working diligently to see it fulfilled, we are working on three areas around our strategic plan, which you all have been talking about for the last day and a half. Dr. Daniels has been talking about solutions. Here are some solutions I would like IACC to be a part of and help us.

First responder training. We know there is a bill in front of Congress for the Safe

Interactions Act. This will provide training that we are developing for training local law enforcement, fire, and EMT through our affiliate network. The teams will include representatives from law enforcement, clinicians, like social workers, self-advocates, parents, and researchers. In addition, there will be subject matter experts included in the training and certification process for police departments, first responders, and criminal justice professionals, district attorneys, and law enforcement agencies. We have seen too many horrendous crimes committed by these individuals against the autism community and we need to bring an end to it.

Efforts in this area will result in a reduction of injuries, a reduction of fatalities, and a reduction of arrests within the autism community.

Our second strategic initiative is water and wandering safety programs. We have been talking about that. This is one of our strategic initiatives that recognizes that drowning is among the leading cause of death in the autism community. A study by CDC found that children with autism are significantly 60 percent more likely to wander than children in other groups. Furthermore, children with ASD are substantially at risk for injury and mortality from drowning.

Again, we will build a curriculum for water and wandering safety based on research and best practices where we will use the train the trainer model where we will arrange for our affiliates across the nation, again, we are the only country that has this network. Ideally, these affiliates will set up and complete comprehensive training on water and wandering safety.

And the third and last issue, please bear with me, Susan, if I am over time, is employment. We know the recent data about unemployment and underemployment being as high as 90 percent. We recognize the need for systemic change that provides opportunities for professional and non-professional employment, as well as a need to increase opportunities for competitive integrative employment and other services and supports in the community. Working with collaborators nationwide and members of the autism community, we are gathering government officials, organized labor, educational institutions, employers, and individuals from the autism community to address this issue in a comprehensive way, in a way that we do not believe currently exists.

Lastly and in closing, I would say that we believe there are many other issues surrounding the autism community. We are also concerned about vaccine hesitancy, and we are prepared to help the CDC do that. I am delighted for the reference that was made about Autism Speaks report on food scarcity. It is one that we are so interested in hearing more about. Housing, which I know that JaLynn and folks at First Place are discussing. Transitional services, diversity, and inclusion.

The Autism Society of America would welcome the assistance of IACC in coordinating interagency cooperation on our strategic initiative and our legislative priorities that are singularly focused on improving the lives of those impacted by autism. Thank you for the opportunity to share today.

DR. DANIELS: Thank you so much, Chris.

And next, we have Kelly Israel on behalf of the Autistic Self Advocacy Network. Welcome, Kelly.

MS. KELLY ISRAEL: Hello. Thank you for providing me with the opportunity to offer a summary of the Autistic Self Advocacy Network’s comments. ASAN is pleased that after the 2020 coronavirus pandemic led to a temporary halt to meetings, that the IACC will resume its efforts to properly allocate funding for autism research. We think these new meetings represent an opportunity for the IACC to reform its autism’s research priorities or influence the priorities of others, in order to truly reflect its stated goal in the 2018-2019 Strategic Plan, namely, to accelerate and inspire research, and enhance service provision and access, that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan.

We support research projects and workshops included in the IACC Strategic Plan that address important and previously underexamined research priorities in our communities such as mental health and autistic people and co-occurring conditions of which we have many. We are also pleased that some researchers have been taking proactive steps to include the perspectives of autistic adults in this research. We encourage the IACC. In fact, to recommend the use of community-based participatory research that includes autistic people and autistic adults ourselves.

Nonetheless, autism research funding remains excessively directed towards topics that are of little benefit to autistic people who are alive today such as the biology and causation of autism. Over 61 percent of autism research funding towards these subjects. But only 3 percent of funding went towards lifespan research. And only 3 percent went towards research on services and supports that was not in the practitioner training sub-category.

We urge the committee to recommend that the direction of autism research be changed to research that primarily benefits the autistic children and adults who are alive right now and who desperately need research on which services, supports, and lifespan supports benefit them rather than researching research, investigating how to prevent autism.

We additionally recommend that the IACC direct stakeholders to collaborate with and utilize research on other intellectual and developmental disabilities besides autism. Autistic people are not all that different from others with intellectual and developmental disabilities. We tend to experience many of the same academic and social difficulties and many of the same lifelong support needs and co-occurring conditions.

Autistic people are not served by research that reinvents the wheel or that views us as a separate category entirely rather than part of a common group of people with disabilities.

Furthermore, ASAN recommends that the IACC prioritizes significant additional research into how non-speaking autistic people may best establish other forms of effective communication. ASAN reviewed the autism research database at IACC, and we were troubled by an excessive focus on prioritizing verbal speech above all other possible forms of communication that disabled people use. Communication research and autism should focus on all of the possible forms of communication used by autistic people particularly under-researched communication types such as augmentative and alternative communication or AAC.

ASAN again thanks the IACC for the opportunity to comment. We hope the IACC recommends new and bountiful directions for autism research that help all autistic people rather than retreading upon the old and over overtreaded ground. Thank you again.

DR. DANIELS: Thank you so much, Kelly.

Next, Dr. Noemi Spinazzi on behalf of the Down syndrome Autism Working Group of the Down Syndrome Medical Interest Group.

DR. NOEMI SPINAZZI: Thank you, Dr. Daniels. My name is Noemi Spinazzi and I am an assistant professor at UCSF and the medical director of the Down Syndrome Clinic.

Down syndrome is the most common chromosomal condition diagnosed in the United States. And each year, about 6000 babies are born in the United States with Down syndrome. In the past, it was believed that autism rarely co-occurred with Down syndrome. But now, we know that autism spectrum disorders occur more frequently in individuals with Down syndrome, akin to other genetic disorders. The prevalence of autism spectrum disorders and individuals with Down syndrome has been estimated to be 16 to 18 percent based on recent meta-analysis though estimates in the literature vary due to differences in diagnostic approach and methodology. This means that about 1000 of the 6000 children born each year in the United States with Down syndrome will eventually be diagnosed with autism.

When autism co-occurs in a patient with Down syndrome, it leads to a complex neurodevelopmental profile in which characteristics of autism, communication impairments, social impairments, restrictive patterns of behavior and interests are super imposed on common challenges in Down syndrome such as intellectual disability, speech impairment, short attention spans, and memory impairments.

Furthermore, children with Down syndrome on the autism spectrum are more likely to be diagnosed with other mental health conditions such as anxiety, attention deficit hyperactive disorder, aggression and self-injury and elopement. Unfortunately, many frontline providers and educators lack awareness of the dual diagnosis and its presentation.

Due to diagnostic overshadowing and the lack of evidence-based guidelines for assessments, the diagnosis of autism is often significantly delayed in persons with Down syndrome, therefore, delaying the start of targeted therapies that can improve the functioning and quality of life of a child with a dual diagnosis.

There is also inadequate research on which educational and behavioral interventions are most successful in supporting children with a dual diagnosis. Given the high prevalence of autism and Down syndrome, the significant impact that this additional diagnosis has on the life of a child with Down syndrome and their families and the paucity of evidence on best practices for evaluation, diagnosis, and intervention, more attention needs to be directed to this underserved patient population.

The Down Syndrome Medical Interest Group is a group of health professionals committed to promoting the optimal health care and wellness of individuals with Down syndrome across the lifespan.

We have partnered with Autism Speaks and the Alliance for Genetic Etiologies of Neurodevelopmental Disorders and Autism, AGENDA, to promote collaboration, raise awareness, and accelerate research efforts. Our group thanks the National Institute of Mental Health, Interagency Autism Coordinating Committee for your attention and seeks its support and collaboration. Thank you.

DR. DANIELS: Thank you very much, Dr. Spinazzi.

That concludes the first session here.

And next, I am going to welcome Luis Valdez-Lopez from the Office of Autism Research

Coordination to give us a summary of the written comments, a brief summary. And you have the full text of the comments online that you can look at as well.

DR. LUIS VALDEZ-LOPEZ: Thank you, Susan. Good afternoon, everyone. Since the July 2019 Full Committee Meeting, the IACC has received written public comments from 47 commenters. For the purposes of this presentation, we have organized these comments into seven broad topics. The committee has been provided with the comments in full and they are posted on the IACC website for public access. I will provide a brief summary here.

Topic one. Programs, supports, and housing options for severely disabled autistic individuals. Fifteen comments were received on this topic, including Ms. Martha Gabler, Ms. Connie Louderback, Ms. Lisa Elliott, Ms. Jane Kleiman, Ms. Karin Lunsford, Ms. Rita Whitney. Dr. Mary Barbera, Mr. Stephen Wallace, Ms. Debra Wallace, Ms. Adrienne Benjamin, Ms. Francine

Hogan, Ms. Heather Gordon, Ms. Rachel Johnson, and Ms. Joy McDaniel, all wrote individual comments expressing a need for viable long-term programs, supports, and housing options for adults on the autism spectrum with high support needs.

The concerns were particularly pressing for those living with parents who are aging, who are otherwise anticipate being unable to meet their substantial needs on an ongoing basis in the future.

Ms. Brita Darany von Regensburg stated that transparency and improve staff training are of major importance for a better life for adults with profound autism living in congregate settings.

Topic number two. Concerns about medical practices and potential causes of autism. Ten comments were received on this topic, including. Mr. Oren Evans expressed that fluorescent lighting and other environmental lights with strobe effects may be contributing to an increased prevalence in autism.

Ms. Ramey Chisum suggested the need to focus on undetected hyperthyroidism as a cause of autism.

Ms. Elissa Leonard submitted various comments about how excessive folic acid and low vitamin B12 may be contributing to increases in autism.

Dr. Harold Frost III attached a treatise on the topic of predicting adverse bio-effects of medical diagnostic ultrasound. He states the needs for analytic physics assessments of the effects of radiation on gene expression.

Dr. La Donna Ford urged the committee recommend federal funding to investigate the genetic and epigenetic impacts of halogenated anesthetic gases on the germ cells of the parent generation and on the neurodevelopment of subsequent offspring.

Additionally, Ms. Alicia Mesa wrote separately in support of this comment by Dr. Ford.

Dr. Eileen Nicole Simon submitted a comment, urging research to focus on the inferior colliculus in the midbrain auditory pathway as a site of injury that leads to difficulties with language development in childhood autism.

Ms. Kim Oakley called for more attention to be placed on self-injurious behavior as it may be rooted in underlying, undetected, and untreated medical and dental issues.

Topic number three. The role of the IACC and the Federal Government. Nine comments were received on this topic, including Ms. Resa Warner recommended that HHS prioritize independent replication of subject research as a priority in the autism research agenda and budget.

Mr. Marc Lefebvre stated that as a parent of a teenage child with both developmental disabilities and mental health issues, he appreciates IACC’s committee on addressing housing/independent living. He suggested that tracking people’s medical histories to identify those who are treatment resistant and providing them with targeted assistance should be national priorities.

Mr. Happy Bird requested IACC’s materials in full Japanese translations as well as new resources such as a video series, pamphlets, and a multilingual AAC app.

Ms. Jean Public states concerns about the committee promoting vaccination when she feels vaccines can cause lifelong injury.

Mr. Kevin Tallman stated that the Department of Labor has not mandated self-funded health plans to require speech, occupational, and physical therapies for those with developmental delays. He asked for resources and advocates for the DOL to not allow these exclusions based on developmental delay.

Mr. Alexander MacInnis requested that the IACC make it a high priority to establish robust autism birth prevalence estimates that cover a wide range of birth years and be fully supported by data and appropriate analysis.

Topic number four. Service needs, resources, and policy implications. Seven comments were received on this topic, including Ms. Blesse Fields describe that her personal experience – that she had been unaware that school resource officers had no access to behavior support plans unless parents gave consent. She recommends mandatory training for school resource officers and law enforcement.

Ms. TD Wallin attended the NIH Videocast titled “Addressing the Mental Health Needs of People on the Autism Spectrum” and expressed the need to provide information on non-invasive therapies that can be easily afforded by families.

Mr. David Kassel submitted a comment on behalf of the Massachusetts Coalition of Families and Advocates, linking to their recent blog post on a mother’s battle to ensure adequate care for her son with ASD who has an intellectual disability, is nonverbal, and needs 24-hour care.

Ms. Deborah Blair Porter described how the needs of individuals diagnosed with autism have been under addressed by California’s education system and now these students are beginning to progress into adulthood unprepared and unsupported by California’s judicial system and related agencies.

Ms. Jennifer Degner is concerned about the lack of autism screenings and resources for young children that she has noticed as an early childhood special education teacher in Kansas.

Ms. Arzu Forough submitted a comment on behalf of the Washington Autism Alliance, stating that there are very few licensed behavior analysts nationally that have training or desire to work with teens and adults with ASD around severe disruptive behaviors and activities of daily living.

Ms. Dawn Sikora wrote that she feels that there is an increase in intolerance within the autism community towards people diagnosed with Asperger’s syndrome. She would like to see a stronger stance against discrimination and harassment against older persons on the autism spectrum and their families.

Topic number five. The COVID pandemic. Three comments were received on this topic, including Ms. Nayeema Bashar, who developed a proposal for some initiatives at the school of her 18-year-old autistic son. She indicates that her son has been adversely affected by the pandemic.

Ms. Paula Notarino is disappointed in the State of Connecticut in delaying access to the COVID-19 vaccines for her 36-year-old son with ASD and intellectual disability.

Ms. Ann Lindsey-Frost states the need for additional support, advocacy, and assistance for individuals on the autism spectrum, particularly regarding housing referrals in the Ohio region during this pandemic season. She states that calls were going unanswered, and funds were not being allocated to those on the spectrum.

Topic number six. Employment. Three comments were received on this topic, including, Mr. Trenton Ashizawa would like research around combating the negative stigma associated with autism and employment based on his own experiences.

Ms. Lin Zhang hopes that there is expanded assistance for self-employment for autistic adults.

And topic number seven. Graduated electronic decelerators. After the public comment deadline, the IACC received over 120 comments related to the overturn of an FDA ban on the use of graduated electronic decelerators. About half of these comments were from three email campaign form letters. The letter writers expressed concern over a court decision and are asking the IACC to encourage the FDA to completely ban the device and to engage in other related advocacy activities.

Examples of the three form letters are provided in the public comment packet and individual comments will be shared at the October meeting.

This concludes the summary. Thank you once again to everyone who submitted written comments.

DR. DANIELS: Thank you, Luis.

I am going to just be very brief about the live feedback summary, given that we are a little bit over time. We received comments from Jinny Davis, Chris, Sher DeGenova, Jane McCready, Lynette Scotese-Wojtila, Matthew Belmonte, Nicole LeBlanc, and Riah.

And the topics that were covered were transition supports and high support needs for people on the autism spectrum, the need for IACC to increase its public presence and do more for families, concern about a large proportion of funding that is dedicated toward research, investigating the causes of autism while there is more need for other concerns, including employment, housing, and quality of life.

Someone that hopes that the IACC will focus on the needs of individuals who are severely affected.

Someone who just expressed her gratitude to be able to watch the meeting.

The need to expand Social Security disability insurance for adults with autism without intellectual disability.

Someone applauding the diversity of backgrounds and viewpoints on the new IACC.

And someone who is curious about expanding funding for community-driven research, aid, and action.

That is the brief summary. This document is also available on the website. I do not want to take up any more time because I want to give you all a chance for discussion. We are opening up for discussion. If you can use the raise hand function, I will try to call on you.

First, Sam Crane.

MS. CRANE: I actually might have more to say later, but I do want to really second the comment about the importance of community-driven research and action. We have seen really great studies that followed participatory community-based research models. And in particular, it is our experience that participatory and community-based research tends to be more responsive to questions that are important to community members and it tends to have better analysis of – they are better designed and the data is better analyzed because it has feedback from people with lived experience that can notice trends that maybe researchers who do not have lived experience would not. We would absolutely support that.

DR. DANIELS: Thank you.

Dena.

MS. GASSNER: Thank you. I spent a considerable amount of time looking through these. I just want to address a couple of the people who wrote in. Let’s start up here with Mr.

Tallman. I want to thank you for letting us know about the limitations of both unionized and non-unionized self-funded plans in terms of being able to provide insurance support for individuals with autism. I think that is a very important point you make, and I am grateful for that.

In terms of the SROs, I think that – we have found that the cards, which is what Ms. Fields suggested with some kind of ID card, creates a risk factor because if they try to reach for that wallet in their back pocket out of a panic, the outcome could be very tragic. I would suggest you invite your SRO to your IEP meeting.

In terms of Kelly's comments earlier from ASAN, I would expand on and ask for a variety of communication tools to include an expansion of all kinds of intervention tools.

To those of you who wrote with your hearts about the challenges that you have experienced, supporting someone who has more externalizing, high support needs, I just wanted to tell all of our listeners that the American Dental Association has mandated IDD training for all dental students going forward. That means at least one new system will be accessible to us in a different way. It will be a while until they finish their training, but it is going to get better.

But I do not profess to speak for everyone or even everybody in this room, but I would like to say that speaking for myself, I give all of you my word that I am very committed to doing what I do at the ARC, which is representing the entirety of our community and I will always elevate the needs of those who have high support needs whether visible or not visible by subjective observation. I just wanted to know that I bring that commitment in and I wanted to share that with all of you.

I am fearful that sometimes when we do not respond to some of these comments with that kind of a commitment, people think they are not being heard. I just wanted to make sure everyone knew that I for one very much hear those needs. I live with that experience with autism and I am here for everyone. Thank you.

DR. DANIELS: Thank you, Dena.

Next, I have Alison Marvin.

DR. MARVIN: Hi. I am from the Social Security Administration, and I just wanted to respond to the comment about expanding SSI to those with ASD without intellectual disability. Just to make sure people are aware that SSI is available to those with ASD with or without intellectual disability. And, in fact, there is a recent paper, which I can send around where we actually looked at the increase of the number of individuals where ASD was the primary diagnosis for those qualifying for SSI. I just wanted to make people aware of that and they should apply if they think they qualify.

I just wanted to recognize a comment I forgot to mention earlier, that for those who do not have broadband, they can apply to Social Security, using the 800 number, 800-772-1213.

That is 800-772-1213. And there are interpreters in almost every language. They are available for people. Thank you so much.

DR. DANIELS: Thank you, Alison.

Next, I have Scott Robertson.

MR. SCOTT ROBERTSON: Hi, Susan. I am filling in for Jennifer this afternoon. I just want to say that the employment-related concerns especially resonated with us and we are listening to all those concerns whether written or in oral formats and taking consideration with future activities. I know that a lot of folks especially have had additional stress during the COVID-19 period as far as gainful employment, careers, et cetera, switching to telework, switching from telework back to in-person work, et cetera, return to work, staying at work, et cetera. These are all something that we are heeding.

I want to also emphasize related to that on the COVID-19 that we have resources, for instance, our job accommodation at work, on the job seekers, and in the workplace, and folks can access that at askjan.org, including on COVID-19 and other things related to accommodations for the workplace and seeking employment. They can connect also with specialists for free, who provide free expert confidential assistance. Then we have other resources from other technical assistance centers like EARN, askearn.org, for employers, for instance.

I also want to emphasize on the broader quality of life and communication access, et cetera that especially resonated with me as an autistic person that I hope that is something that we look into more as a body, as a committee, because I take that to strong heart that there is some additional marginalization that folks on the autism spectrum who use augmented alternative communication and have diversity ways of communicating and interacting may not always be fully included in research and support needs. I hope that long-term health research longitudinal studies, et cetera, that there are additional priorities for that with AAC folks because I think some folks have not been as expressly integrated into research priorities and maybe that can come up hopefully with the strategic plan on the long-term.

And then the additional focuses around quality of life, et cetera, that also resonates. Again, we are taking heed. We are very glad to be collaborating with our seat on the committee as a department right now for DOL.

DR. DANIELS: Thank you, Scott.

Next, Teresa Souza.

DR. TERESA SOUZA: Hi. I am Teresa Souza. I work in the US Department of Housing and Urban Development where HUD is a new member to the IACC. We are very glad to be part of this conversation and to be learning from all of you.

I heard a lot about the concerns on housing assistance and housing being an area of need with lifespan concerns. I just wanted to mention that I am hearing this. I wanted to share some information. We know that housing assistance is not an entitlement. It is a program that serves about one-fourth of people who are eligible for housing assistance.

But in an analysis of people who receive housing assistance, we found that people with disabilities have higher rates of assistance than people without disabilities. HUD serves people with disabilities in all of its programs.

I wanted to mention a few programs that you might want to be aware of. The mainstream voucher program received new awards in the past year. And that is a voucher that is going to serve people with disabilities and people who are at risk of homelessness. That is a great resource to look at.

HUD also has a new program, the Emergency Housing Voucher program that is going to award 70,000 vouchers to 626 public housing agencies that administer the housing voucher program. That is another area to look at.

And HUD is also giving assistance – eviction protection grant assistance. It is a program that was launched in July and is receiving applications. Those are some of the things that you could try to find at HUD’s website. We can try to find ways to connect you to those resources. Thank you.

DR. DANIELS: Thank you for sharing.

Next, Alycia Halladay.

DR. HALLADAY: Hi everyone. I have a quick question. I also have been reading the comments or have read the comments. I think a lot of them deserve further research. Some of the assertions that have been made have not necessarily been supported by the research. Clearly, we need more understanding of these issues. I am wondering to what extent some of the public comments or some of the discussions that we have had may make their way into the Strategic Plan because I think a lot of these deserve further – actual research studies. Some of them I do not think the research supports them, but some of them I think we definitely need more research and that is how we are going to get to the solutions as to understand it in a scientific way.

DR. DANIELS: Our team is collecting information from all of this and we will feed various parts of it into the Strategic Plan process. You will have a chance to do that. We also will be soliciting specific public comments for the Strategic Plan. Thank you for sharing. All the public comments are really important to us.

Dr. Gordon, do you have something?

DR. GORDON: Let me lend a little specificity for it. Absolutely part of what we hope and expect from you as members is that you will pick up off the public comments things that you think we need to address through further examination or things that we need to include in our Strategic Plan or other recommendation. By all means, please identify those items in there that you would like to see incorporated. Let Susan know about it and also bring it up as you are reviewing documents or if you think that more discussion and perhaps presentations from experts in the field as well as voices of lived experience at future IACC meetings. If there are ideas in there that you want to expand upon, there is absolutely an opportunity there.

DR. DANIELS: Thank you for those additional clarifications. I agree with all of that.

I am going to jump and just say that Tiffany Farchione wanted to raise her hand but was having trouble. Tiffany, would you like to speak?

DR. TIFFANY FARCHIONE: Sure. I just wanted to make a comment related to one of the written public comments that had a specific ask of the FDA and it mentioned about the ban on the graduated electronic decelerator. I just wanted to let the folks who submitted that comment know that I have taken that information and passed it along to the team that worked on that original rule, the one that was recently overturned in court. They are now aware of your concerns.

DR. DANIELS: Thank you. We appreciate that. Getting right to the FDA as soon as possible for further consideration.

MS. GASSNER: Can I just clarify? Are we going to take time today to talk about that?

DR. DANIELS: This is the time. It is not an agenda item. It is a public comment. You have that time right now. But we have more people with their hands raised. If you want to discuss it, go ahead and raise your hand.

Hari.

MR. SRINIVASAN: I want to add something about moderate severe autism. I have seen dozens of autistics like me in the moderate to severe category that have grown up with - gradually disappear into group homes and other places, which means many of our issues get hidden too. Out of sight is out of mind of society, which affects access to spaces, funding, and resources. Providers who want the easy cases are quite routine for programs meant for autistics to politely tell them, you are not a good fit, which is PC for you are too much work and there are enough easy cases to make us look successful. Even day programs don’t want the severe cases. I have adult friends stuck at home because no one wants to take them. I can just see a huge crisis in the future with huge numbers of very unhealthy aging autistics due to side effects of the psych drugs, which do not really work on our physiology.

I once heard Dr. Antonio Hardan of Stanford say psychiatric drugs do not work the same way on autistics. I have to wonder why they are still given to us anyway as the only option for behaviors. We are already marred with the challenges of medical comorbidities, which are getting ignored on dental, Medicaid, or even parental insurance does not cover anesthesia for dental work. No way anyone is poking the inside of my mouth unless I am totally knocked out, which means many will not get dental care. My friend’s family has an anesthesia bill for $6000 because he needs sedation for a simple cavity procedure – should not be penalized for having a more significant form of autism. I am very saddened by the huge number of issues we have to sort out just for a basic quality of life.

DR. GORDON: Let me interject for a moment. Thank you. It is precisely for this reason that we wanted to make sure that individuals like yourself with more moderate to severe autism had a seat at the table of this particular IACC. I am pleased to hear those comments. I think that is definitely a topic area that we want to visit. I do not know that we have given it true justice in the past. It would be something that we think for future IACC meetings to have more in-depth discussions about. Thank you.

DR. DANIELS: Thank you.

Next, I will call on Aisha Dickerson.

DR. AISHA DICKERSON: Thank you, Dr. Daniels. I just wanted to highlight the comment from – last name Fields. I do not want to mispronounce the first name – about issues with interactions with police officers or school resource officers. I was hoping that we would get the chance to discuss that during our 4 o’clock discussion on racial equity and health disparities. I wanted to let the person who wrote that comment know that that is something that I intended to discuss within today’s discussion. I hear you and I am here to advocate for those changes as well.

DR. DANIELS: Thank you. JaLynn Prince.

MS. PRINCE: Thank you. I agree wholeheartedly on the research. Heading a 501c3, one of the major things that we find is we are trying to compete for monies because we do not have a regular governmental stream coming into us, but we need to have information and data that we can give to people who are asking us questions. We are able to generalize to some degree. Drexel has been very helpful in some of the departments of health in different states, but it is not a consistent message. And if we can figure out a way to get more information and research that isn't necessarily the test tube type, but to find out what lived experience is and what needs are and we do need to work on the lifespan issues. I am hearing that again and again and again.

By the time somebody is 21 throughout the rest of lifetime, and I hear very little about that totality. And if we do not address it now, we are going to have an even greater crisis. We are finding so many more adults being diagnosed as being on the spectrum and they are going to be aging and there will be some issues that they may have not anticipated or their families. We need to look at those things. Thank you.

DR. DANIELS: Thank you. I will take two more questions and then we will have to conclude. So it will be Valerie and then Dena.

DR. PARADIZ: I lowered my hand again. I no longer need to --

DR. DANIELS: Okay, I see that Morénike also wrote in so we will do Dena and then Morénike.

MS. GASSNER: I am sorry. I misunderstood that we were not really going to create a space to discuss JRC. But in light of all the comments that came in, I feel like we need to at least acknowledge those. I personally would love the opportunity as discomforting as it may seem, to actually see if we can't get an invitation to observe there. And if not, if we could get some of the people who are no longer or are currently housed there to come and provide testimony to us here at the IACC. I think we would benefit from hearing from those folks so that we, as an organizational body, can discuss that. I do not need a response. Just making a statement of concern and interest for future study.

DR. DANIELS: Thank you. Of course, we welcome public comment from anyone who would like to give public comment. So we will keep that in mind.

And then I am going to read something from Morénike. As an autistic individual for whom text-based communication is a more accessible option than speaking, I have made a number of remarks this afternoon in the IACC live feed feature related to several of the public comments, particularly with regard to several remarks made related to those with higher support needs (I prefer not to use stigmatizing terms such as "severe" autism). Hopefully that feedback is, or in time will be, available to the meeting attendees and the public at large. Thank you.

I have read the ones that I have. I am not sure if there is something that has been missed. But we make the attempt to read those things live in the meeting.

DR. GORDON: I think Morénike was probably responding and correct me if I am wrong in the text, Morénike, if you can, to the fact that – responding during the public comment period itself perhaps as you read them. I am not sure. Correct me if I am wrong, Susan. But anyone who enters in the live public comment stuff – we will put a final version of that out with all the comments on the IACC website. Is that correct?

DR. DANIEL: Yes. We will update the packet just based on how we run the meeting. Because public comment is in the middle of today, we had to end – what ended up in that live feedback summary I gave you in time for me to read it to you. But we are continuing to receive them and we will put the rest in the document and put them up on the website for viewing. They will be available to the committee so that they all will enter the record.

With that, thank you everyone for sharing. We really appreciate the public comments, every person who took the time to be with us whether it was virtually in an oral session or if you took the time to write a public comment in or share with us on the live feedback. It is deeply appreciated by the committee, and it will be taken into consideration as they move forward with their work.

At this time, I believe that we are ready to take our break and then come back. We are a little bit late. Do you want to start us at 4:03, Josh?

DR. GORDON: Let’s start at 4:03 or perhaps 4:04. I will get us started since I am handling the next part of the agenda. Good. See you all in five minutes.

(Whereupon the Committee took a brief break at 3:57 p.m. to reconvene at 4:04 p.m.)

DR. GORDON: This third and final segment of today’s meeting of the IACC is on issues of equity in autism. Now, again, I feel obliged to give a brief introduction although there are others here on the committee who might be able to give a more significant introduction than I.

There are known facts of inequalities in autism particularly with regard to the nature of diagnoses and treatment access. One known fact is that individuals from minority groups tend to have diagnoses delivered later than individuals who belong to majority groups. And there are also disparities in age at diagnosis by socioeconomic status as well as race and ethnicity.

We know that that gap is narrowing somewhat over time as we have increased knowledge of the importance of things like universal screening. But of course, there is more work to be done.

There are also documented issues with regard to access to care, access to quality care, et cetera, that are impacted by where one lives and who one is instead of need. I wanted to open this up for conversation. Any members of the IACC who would like to comment about it.

The goal for this conversation is to begin to identify some issues that we might want to address with further exploration in the coming months. With that, I will ask any members of the committee who would like to open up with comments or thoughts or data that they are aware of to please go ahead and do so. Thank you, again, Ivanova, for kicking us off. Go right ahead.

MS. SMITH: Hello. I just wanted to address that a lot of people that are immigrants - they have a harder time applying for services because the services are very strict and what type of medical documents you need to get services. I think that will be an issue that affects a lot of people that are marginalized.

Also, there are a lot of disproportionate people of marginalized identities being institutionalized and not getting supports in the community. We talked about just a tiny bit with the Judge Rotenberg Center. But the vast majority of the students there are people of color, indigenous, and that is a really lost disparity. There are statistics that show that too. If you look at autistic archive of JRC, you get a lot of resources that will show that there is a lot of disparity of people being institutionalized and not getting the supports in the community where it is better to get support in a community.

And language barriers of families is another big issue. You cannot get services or you want to get community services. But because you are having struggles with the languages with the service providers that has caused issues too and the families do not get the right services because they are not being given the support because of the language barriers, immigration status, and a lot of those kinds of things. Those are some of the things. I know some advocate community for autistics with intellectual disabilities are being institutionalized and last to get vaccinated because they do not get out to them in time or they do not know if they can go to the clinic safely or people are afraid because of immigration status and all that stuff. Thank you.

DR. GORDON: Thank you.

Jenny is next.

DR. JENNY MAI PHAN: Hi, everyone. This is Jenny. My comment will be brief. I just would like to reiterate what others have said before about community-based participatory research being a pathway to include racial minority groups within research and to make sure that their voices are represented when it comes to caregiving, housing, services, mental health, all the important issues we have already discussed.

I can probably speak specifically for the Asian American community in terms of -- there is a recent paper that came out. I can share that with the committee where they found that the Asian American community are more likely to receive an autism diagnosis through school rather than clinical diagnosis partly because there is still a huge stigma of autism spectrum disorder within the Asian American communities. This is why I think a bridge there could be through community-based participatory research and education among communities that might view autism spectrum disorder within the stigma white.

That is the comment I would like to add and maybe bring to everyone’s attention. Thank you.

DR. GORDON: Thank you. Jenny, let me just underscore an aspect of what you are saying that might inform our approach if we were to take additional steps in this area. You said that Asian Americans more often get the diagnosis in schools than in medical settings. You hypothesized a mechanism and provided some evidence behind that mechanism. I think from an NIMH perspective, a mechanism-focused approach is really important and it is not incompatible with community-based research. It is not incompatible with trying to understand the role of social determinants of health like stigma and other aspects that prevent equal access to care.

And the reason why we emphasize a mechanism based approach is because as you identified, if you can recognize a mechanism then there are solutions that you can propose to reduce those disparities and equities based upon those mechanisms. I really appreciate that comment.

Dena, you are next.

MS. GASSNER: I just wanted to say, I have never disclosed this yet in a meeting, but I am a social worker by training. In my private practice, I help people to access Social Security disability. I can tell you that many people of color are not even attempting it. They are still mired in the public school setting where many disabled folks of color are turning into this interweaving with the school-to-prison pipeline. The behaviors are seen as disciplinary issues rather than a form of communication. Many people of color are not provided any access to information about autism. My son was 3 years old before anybody suggested I should look at it. I have privilege and I have opportunity and I was not working at the time. For people who do not have the privileges that I have experienced, accessing that kind of information is considerably more difficult.

In terms of an anecdotal story, I had a woman who was a grad student talk with me. She was a woman of color, diagnosed in her late 20s and she said that in her community, autism is considered a white person's condition. And that people of color believed in her neighborhood and it could be an ethnic difference that you actually die of autism. It made me wonder if that is actually not the experience of many autistic families whose young people have a behavioral experience have run into negative outcomes with law enforcement.

I think anything we can do to better inform the community and help people to navigate systems. I cannot emphasize that gap in our services any more than that. We just really need to take advantage of the skill set that social workers bring and helping people to get through doors that are otherwise very difficult to maneuver or navigate or closed all together. Thanks.

DR. GORDON: Thank you, Dena.

I have Aisha next.

DR. DICKERSON: Thank you. What I have seen not only in my research, but within the black community is that a lot of the disparities in age of diagnosis is primarily due to lack of screening with general practitioners. When we think about just a regular well-child visit, the doctor might check the temp, check the heart rate and the blood pressure. But rarely do doctors just use a basic screening tool to check for autism spectrum disorder. What happens in the end is that children who are from marginalized populations typically do not get a diagnosis, but an autism designation until they are in school, at which point we know that it might be a little too late. Because the earlier that child is identified, the earlier they can get interventions and they are more likely to have better outcomes later in life.

DR. GORDON: Aisha, can I just interrupt for just one second right on that point? And then I want to hear what you have next to say. You underscored a really important point. As you probably know, but others may not. The US Preventive Services Task Force has declined so far to endorse autism screening in early childhood although many professional organizations, including the American Academy of Pediatrics, does endorse it. But one obstacle to getting it more widely adopted is to get that imprint from USPSTF. We are working hard. We have funded research that answers some of the remaining questions. One of the most important remaining questions that they have asked us to answer is specifically whether screening can help change that age to diagnosis and change outcomes in minority communities. We have funded research that is specifically trying to answer that question so that we can expand screening.

Sorry to interrupt because I definitely want to hear what you had say next. But I felt like people should know that we are working hard on that issue.

DR. DICKERSON: That was a great point. Thank you for adding that.

But what I also want to say is that on top of screening, even if we did start to implement screening, we need to make sure that that screening was culturally competent. As was mentioned earlier by Dena, autism is often seen as a white person’s disorder. People are not familiar with what to look for, not just the parents of black children, but also health care providers of black children. If something is culturally competent in one household or socially acceptable in one household, it might be socially acceptable in another household. That is my second point.

And then the third point is that as somebody who is neurotypical and highly educated, I myself often receive unfair treatment within the health care community. It is important to point out that in order to have effective screening, we also have to make sure that these people from marginalized populations are getting fair treatment within the health care, not just based on race, but based on income because anybody with great insurance is expected to get better health care treatment. But again, as someone who also has great insurance, I do not always get the best treatment. Those are just the primary points that I wanted to make.

And then I will come back later on to interactions with police if that is okay.

DR. GORDON: Sure. Just put yourself back up on the list. When you are ready, I will call on you.

Next, I have Alice Carter.

DR. ALICE CARTER: Thank you. I actually wanted to follow in. I have just completed one of the studies that was looking at addressing health disparities in age of autism diagnosis and access to autism diagnosis that was funded by the National Institutes of Mental Health. What is a little unusual about our project is we actually implemented screening in the Part C early intervention system.

What we have observed is that many times even when pediatricians are screening, child flags positive for autism, that child may get referred to early intervention, but not get referred for a diagnostic evaluation. It is sort of like let’s see how the child responds to treatment. But in addition, there are major issues of cultural competence. The findings of our study were very positive especially for Latinx children. We were doing screenings in Spanish and English. We were able to address the gap in disparities in age of diagnosis for Spanish-speaking Latinx kids relative to white families and English-speaking families. Overall, we saw dramatic increases in identification for kids in early intervention getting access to autism diagnosis. That is across all groups.

But that said, we did a lot of training for doing screenings and also worked to try to do trainings in a culturally responsive manner. I think that we have some qualitative data suggesting that families do not see their providers as – these are their early intervention providers – as culturally competent as the providers see themselves. They also maybe are not expecting them to be so culturally competent. But I do think this is an area where HRSA could invest some funding because I do think we really need to work on increasing culturally responsive capacity, helping systems understand just the systemic racism that is baked into how they do business and trying to really work on developing an anti-racist stance, which is not easy for anybody.

But I do think that early on screening can serve to help kids get access to diagnosis. There still in our data are challenges and we are still working this out. I can present on this more later. But even with a diagnosis, there still are challenges in getting equal access to care. I think when we are talking about equity, there is still a lot of work that needs to be done.

DR. GORDON: Thank you so much for that up-to-date update and for pointing out that you have not just – it is not just a screening issue.

Next, I am going to ask for a comment from Mercedes Avila.

DR. AVILA: Thank you so much. Just to briefly share. I do racial equity workshops across the nation. This is one of the areas of the work I do, looking at racial equity at the intersection of health equity. What my research has found similarly to what Alice was sharing and Dena earlier. My research shows that most providers and these are health providers, do not know that the history of systemic racism in the United States. They do not know how this country was founded, the history of redlining and other intersecting issues related to systemic racism, and it directly impacts health disparities and inequities for many of racially diverse communities. That is one piece.

The other piece is I am going to second, third, fourth, fifth – I think it has been mentioned many times, but participatory action research. I think as a committee, we do have the responsibility to make recommendations about looking at participatory action research as one of the most effective ways to work with communities.

We have our responsibility to work with underserved communities and not in and on communities like we have done historically in academia and through research. Research has to benefit the communities. In this case, we have to be looking at improving accommodations, services, access to programs. I could not agree more about participatory action research.

I am also a social worker and one of the degrees I have. When people have mentioned in the public comments and in this section as well that SROs, school resource officers need training, I am going to expand that. I agree that SROs need training. I am going to also add that everybody needs anti-racism training. Assuming anti-ableism training, structural competency, cultural humility. Sometimes we make an assumption that because someone has been trained as a special educator, they understand ableism, racism and that is not necessarily the case or because somebody is trained as a doctor or as a social worker because the training also has failed. We live in a society where training for health professionals focuses more on intellectual training than critical thinking and emotional intelligence, which we need to be focusing on.

I think just expanding this mentality that, yes, law enforcement now is on the news all the time. They are the most visible force right now so everybody is looking at law enforcement. But I want to also expand that mental health providers also need extensive training. Health care providers, allied health care providers, special educators, speech language, all health and allied health providers need extensive training. We need to focus on equity, health equity, and anti-racism when it comes to racial equity. Thank you.

DR. GORDON: Thank you.

Next, I have – let’s go with Hari Srinivasan.

MR. SRINIVASAN: I am a BIPOC autistic and actually got to do a short paper on race and autism diagnosis for my stigma and discrimination class last semester. As part of the literature review for that paper, this is what I found. (Indiscernible) 2002 points to societal judgments made about the black community that they are somehow less deserving.

Goth, et al 2014 highlights racial bias and that black children are thought to be less innocent than their white counterparts. What this racial bias translates to is substantial delays in the diagnosis of autism for black children after the parents initially expressed concerns about the child’s development despite the parents having health insurance.

(Indiscernible) 2020. Delays in the referral process and lack of time getting the autism diagnosis often meant missing the crucial early years of services that could potentially lead to better outcomes.

(Indiscernible) 2018. Non-white parents were often told that it was not autism or given other diagnoses.

Martinez, et al 2018. The 2020 (indiscernible) study further demonstrated implicit racial bias in autism identification and stigma. In the study, white participants were more likely to diagnose black children with conduct disorder. And white children with autism while the reverse was true for black participants.

In addition, black parents themselves were delaying in reporting autism symptoms, mistaking it for disruptive behaviors compared to white parents even if the symptoms were more severe.

Donohue et al. 2017. While my assignment was specific to the black community, I imagined you could draw variations of this for the other BIPOC communities. Newly immigrant parents and low SES parents, for instance, have no idea of how to even begin to navigate and access the system in this country. There are fundamental, systemic inequities in getting diagnosis and in receiving services. Then the whole idea of stigma against disability within many cultural communities, which adds to all the issues going on. It is double isolation. Where families and individuals are not only excluded from the mainstream community and services due to all the stigma and low expectations around disability, but also excluded from the supports of your own culture or community as well like growing up. I never got to interact or get included with any of the Asian or South Indian kids on my street though I would observe them hanging around together. Thank you.

DR. GORDON: Thank you, Hari.

Next on my list is Alice.

DR. CARTER: I just want to add one more thing, which is we have heard a lot about community participatory action research. But the other thing that we could on the board recommend is in my recent grant, we are required to have a DSMD. I made sure that some of the members of our DSMD are both scientists and parents. But we have recently decided in our group to also add an advocacy consultation group. I do think we could work within -- studies of autism could be required to include diverse advocates and I think that is not a thing currently.

DR. GORDON: Thank you.

Diana, I don’t know if you are aware of this or if there is someone else who is aware. I believe that that is a component of the Autism Centers of Excellence, but I am not 100 percent sure. Can anyone on this call verify that?

DR. BIANCHI: Alice Kau would know. She is still on the call.

DR. GORDON: Alice, are you on? I do not see her. We will get that back to you. I do see her. Alice, are you able to unmute yourself?

DR. ALICE KAU: What was the question specifically?

DR. GORDON: The question is whether the Autism Centers of Excellence program requires or generally involves individuals' lived experience on their oversight boards or advisory boards.

DR. KAU: I don't think we have that detail requirement. But the engagement of the community and playing a leadership role is generally a requirement for many years. But we can look into it and see how we can incorporate that.

DR. GORDON: Let's try and get that for the next meeting so we can report out on it.

MS. GASSNER: Josh, if I could just share that the Autistic Researchers Committee is currently working on a database for researchers to be able to tap to find collaborators who represent a variety of expressions of autism and socioeconomic status and race and color because part of it is the connection, making that connection between researchers who are looking to do community participatory research and adding those people to those teams and connecting the people to the teams. It will be a while but we are working on that. I hope that helps.

DR. GORDON: Thank you, Dena. That is very helpful.

Next, I have Scott.

DR. ROBERTSON: Thanks, Josh. I wanted to call attention. I agree with the other comments in terms of on other facets of racial equity that have been brought up, including participatory action research need and community-based participatory research to expand a focus in terms of especially making sure that autistic people from diverse backgrounds are involved in the research process.

I wanted to call attention also spotlight the executive orders that relate to this topic, focus of racial equity for us in the Federal Government in terms of what we are implementing here at DOL and the other federal departments and agencies. There is an executive order on advancing racial equity in support for underserved communities throughout the Federal

Government, EO 13985, as well as an executive order in diversity, equity, inclusion, and accessibility in the federal workforce itself, EO 14035. Those are really shaping a lot of our activities and priorities for us at DOL. I am sure that is probably equally true for a lot of the other departments and agencies that are represented here on the committee and our other sister agencies. I hope folks understand that that is a large part in terms of our work, our outreach right now.

For instance, on our end, the cross connection to historically black colleges and universities as far as the pipeline for accessing gainful employment and career pathways and other minority-serving institutions and other organizations that support folks from underrepresented backgrounds and that overlap or intersection with the lived experience of disability.

This has also come up. I just wanted to mention it briefly. There are local autism at work groups throughout the country and there is one here for the DC, Maryland, Virginia, West Virginia area. Several months ago, at the meeting, one of the topic focuses that we discussed was actually racial equity and that outreach to folks who are black or identify as black or African American or Latinx, Hispanic, and folks from other, for instance, indigenous populations in terms of making sure that they have full access to employment and career pathways and considering linguistic and cultural competence in these focuses.

I do not know if the other agencies would like to share, but in terms of how they are implementing those executive orders right now. But I know it has major importance for this discussion right now. And what we may want to consider as a committee for what goes into the strategic plan. And I would emphasize that focuses on racial equity and intersectionality and gender identity, sexual orientation, socioeconomic status, et cetera. I would say that

that would be a good idea for that to be considered to be weaving throughout the Strategic Plan in terms of the intersection with the lived experience of autism and other disabilities and other facets in terms of where folks face additional marginalization in terms of their lived experience, in terms of access to service supports, opportunities in life, quality of life and diagnosis in childhood, adolescence, and adult life. Thanks.

DR. GORDON: Thank you, Scott. I am happy to do so on behalf of my colleagues. But given the challenge you just mentioned, I think it would be worthwhile for us to briefly recount the focus that NIH has on enhancing our research in disparities and equity. I do not know if any of the other IC directors would like to jump in at this point. I can go ahead briefly. I hear the silence so I will go ahead and do so briefly.

NIH and all the individual institutes at NIH have renewed our focus on diversity, actually preceding that executive order, but including responses to that executive order. There are a number of new programs, some NIH wide, some institute wide that seek to understand, for example, the mechanistic basis of disparities, develop interventions to reduce those disparities, and increase our investments in understanding the social determinants of health both broadly and those that apply to disparities. Some of those have already been announced. Some of them will be announced shortly. I think we can look forward to investments in the area of autism research just like any other aspect of the NIH research portfolio.

I should add, given the tenor of the conversation today that there is explicit call to the need for increased community-based and community-participatory research.

Going back to my list because there are still some folks who would like to make comments, I have JaLynn next.

MS. PRINCE: I’m getting better at getting on. Thank you. There is something that you had mentioned a while ago that I think is very important and it is a term that is fairly new out there. The social determinants of health. I heard a very interesting podcast a few weeks ago. It surprised me as I was driving. I have been doing some investigations since. The CDC had made a statement about the social determinants of health within the black population. As they read down those particular comments, I thought wow. That is parallel to the lived experience of adults on the autism spectrum. Why isn’t there a designation and an acknowledgment about a population with a disability like autism? The lived experience would be a bit different but the issues are the same.

I think there is one other thing with autism that adults with autism in large part, not exclusively, but in large part are invisible in our communities. They may be at home. They may be in group homes. They may be doing any one of a number of things, but they are still somewhat isolated and not seen and not recognized. Perhaps if CDC or a larger government agency was to recognize some of these things, it may give more credence to community leaders and thought leaders throughout the country to take a more serious look at their constituencies and the people that they are serving and working with within their communities.

DR. GORDON: Thanks, JaLynn. Actually, the former executive director of the National Alliance on Mental Illness identified mental illness as one of the greatest health disparities and one of the most unrecognized one. I think that recognition should be applied equally to autism at least equally to autism as it applies to other serious mental illnesses. Individuals on the spectrum should be considered as a group that needs to achieve equity and I think some of the comments earlier about access to care issues generalize beyond the intersection between autism and other marginalized identities.

Next, I have Skye. I have a few other folks on. I know that some of you have been waiting a little while. You will get your chance. Go ahead, Skye.

MS. SKYE BASS: Hi everyone. My name is Skye and I am from the Indian Health Service. We are the federal agency that provides direct care to American Indians and Alaskan Natives. I was just so appreciative of the comment made by Aisha earlier about the need for cultural competency.

On June 1, our agency released training on cultural competency, and it was improving cultural competency when serving American Indians and Alaskan Natives. This is available free on demand with continuing education credit for anyone to take, any health care providers to take so they can improve.

We also released 13 trainings on trauma-informed care to help health care providers across the country be more mindful of the historical trauma faced by America Indians and Alaskan Natives and to improve our ability to freely diagnose and to help our health care providers improve at that. We have actually also been releasing quite a bit of trainings on screening diagnosis so we can early detect autism. Thanks.

DR. GORDON: Thank you, Skye. I am glad you commented. The issues of equity are especially applicable to our Native American communities.

Craig.

MR. CRAIG JOHNSON: Thank you, Dr. Gordon. I have a comment, but also a question if I could. One of the things with what Dr. Avila was saying about training I think is so important especially for all the organizations that are out there, all social workers, community advocates and everything.

One of the things that we lack many times is resources and tools on training like this, which would be so valuable and obviously, the various things we are going to be talking about.

When I look at Dr. Avila or I look at some of the others on this board, just so passionate about certain areas. One question I had was does the IACC – could they become a resource or a tool of training where trainings can be done in collaboration with some of the different experts and different areas where organizations and communities and states can use that in different times. Because there are things I am learning from many of the contributors today that I did not know, and I have been involved in it for a long time, I think it could just be so valuable. I do not know if we do that.

It is something I think could be so valuable and down the road that there could be maybe working with Skye or working with different ones that maybe already have that training or we put that training together on different key areas for these different organizations to connect with people to get training out there, to get resources out there. Obviously, we are still dealing with awareness around autism. I think the more we can and the more maybe – it may be in all these different organizations, but maybe in this overall, it could be a great resource. That is one of my questions that I had for you. Is that something the IACC could be a part of or look to do in the future?

DR. GORDON: Susan, feel free to jump in if I say something incorrectly. The IACC is not a service-providing organization. We are not equipped nor are we empowered to provide training or develop training ourselves.

It is very much within our purview to recommend to the Secretary that there be an organization – one of the many organizations the Secretary has at his disposal within HHS that training be developed. I think a number of different kinds of training have been discussed today.

I think we may want to take a somewhat – we may want to take a varied approach to it in terms of really thinking about the different aspects of training that we would like to see developed and implemented. Some people mentioned training for health care providers, which often is the purview of the organizations, medical schools, and professional organizations. Folks have mentioned training for law enforcement, which is the purview of the Department of Justice as well as other things. We have many of the agencies here. But the one we can influence most directly as a committee is HHS, but we can certainly make recommendations to the other members of this committee. I assure you that they are listening right now and thinking about how they can affect some of those recommendations as well.

MS. GASSNER: This is Dena. The Arc is having their convention in November. And our self-advocate orientation and raining session is going to be teaching people with IDD how they can engage with first responders more effectively. We do a lot of training on first responder training. But we have kind of dropped the ball somewhat on teaching people with disabilities what they need to know. We decided to prioritize that this year for our group. People can jump in there if they would like to.

DR. GORDON: Thank you, Dena.

I meant to say this in concert with my earlier remark. One thing that we very much can do is make sure that people are aware through our various channels to publicize things of resources that do exist out there. We have really a tremendous web page, web presence. We have a social media presence and we have of course these meetings as well. I am glad for everyone to take advantage of these opportunities.

I am going to read aloud two comments by a member, Morénike. I believe, Morénike, you want me to read both comments that you just wrote at 4:40 and 4:44.

I do not have the capacity to express the complexity of my thoughts and feelings regarding this topic given the limitations I am facing right now. But as a multi-ethnic black autistic person with black disabled children, including children on the spectrum, I want to share that this has been a major concern for many in my community and we have been “screaming into the void” about it for years and largely ignored.

Also, it is an enormous disservice not to mention a slap in the face when white people make careless and insensitive comparisons that trivialize the lived experience of those of us living at the intersection of race, disability, and other marginalizations. I cannot emphasize how hurtful, demoralizing, and inappropriate such comparisons are. And like these two comments read aloud please.

Thank you very much for those comments, Morénike.

Next is Georgina and then Aisha.

DR. GEORGINA PEACOCK: Thank you. I just wanted to let everybody know that Dr. Walensky, who is our new CDC director, has challenged us at CDC to look through the health equity lens in all of our programs. And one of those populations that she has called out that we need to be focusing is on people with disabilities and looking at health inequities among people with disabilities. I wanted to share that as a follow up to one of the comments earlier.

And then also let you know specifically within our division, we are looking and working with other HHS sister agencies to look at disability as a demographic indicator on national health surveys. I think one of the things that is really important is that if we are going to describe the gaps and needs of disability populations. We have to be able to see that measured in national surveys. We have a lot of staff working really hard across different agencies in the COVID context to look at this.

DR. GORDON: Thank you, Georgina.

Now, Aisha.

DR. DICKERSON: I want to say that I appreciate the comments from both Morénike and from Mercedes. Thank you for sharing your thoughts on how autism has impacted marginalized communities.

I concur that, yes, everybody needs some cultural competence training. But what I have heard from the black community and specifically parents of black adults with autism are that their primary concern at the moment is their interactions with police. Because a child that is being considered disruptive within the community is easily handled in most cases. But a large adult who is considered disruptive can often be misconstrued as having other issues whether it be someone might assume that they are on drugs. And when someone calls the police on someone black, it is already a little bit of an issue. But to have a police encounter with someone who not only has language comprehension issues, but also potentially issues with language communication. That provides a whole other definitely exponentially dangerous situation.

I am hoping that the committee as a whole can come up with some options for how to better train law enforcement officers to handle not only people or adults with autism, but particularly adults with autism from marginalized communities because video cameras are fine and well, but sometimes those video cameras are just a way to record somebody’s death and that is what we do not want it to become. I am hoping that we can come up with some better solutions for how to work with law enforcement to help them, one, recognize that someone might not be neurotypical, and two, how to deescalate a situation.

DR. GORDON: Thank you. Aisha.

Maria.

MS. MARIA FRYER: Thank you so much for your comments. I would just like to say that I am from the Department of Justice, Bureau of Justice Assistance. My day-to-day world is to enhance responses to people with mental illness and as well as disability.

What we are engaged in through our office is involving national experts, organizations, and The Arc. The Arc is a major partner in this work to design – currently, right now, we are undertaking the expansion of the national curriculum to train law enforcement.

We are also exploring – this fall, we have an event called taking the call. This is where we are exploring alternatives to law enforcement response specifically to people with disabilities. We are collecting and gathering these responses from around the country, community-led responses to sort of determine if this is a direction that might be appropriate in many communities and kind of figure out best practice. It is going to be a two-day discussion. We have invited a lot of experts. Approximately 42 jurisdictions around the country are looking at alternatives to law enforcement responses, sort of the continuum of response to people in need.

I just wanted to just add that we are definitely increasing tools and products and training and assistance for law enforcement and the criminal justice profession as a whole. Thank you.

DR. GORDON: Thank you, Maria.

JaLynn.

MS. PRINCE: I appreciate very much, Maria’s comments. I had an opportunity to talk with some people that have been in the legal arena. And there is a slightly other component to this. Yes, I think we do need things with the officers that are right on the street right there with people.

But there are two other areas that seems like there is a need for training and that is attorneys that are defending some of these individuals that have gone into court and also the judges because this former federal court judge was saying that when he would have a case in front of him, he would have to go do research and try to find out what autism was all about and what these things meant and how to fairly adjudicate a situation. It seems like it is kind of a three-step thing. Maybe there is continuing legal education that could be encouraged in various states. It would be an interesting conversation with the Department of Justice to see where you all stand on that.

DR. GORDON: Maria, did you want to respond?

MS. FRYER: Certainly. I am really glad that you raised that. This is an area that we are definitely exploring. I have to say the order of things - when we began so many years ago developing a lot of tools, we actually began our work with the Arc and Pathways to Justice in 2013. It sort of began with the jails. That was the first place where we noticed people were flooding because of the lack of treatment options and service options in the community. And then from there, the advocacy community and clinicians and mental health communities really started building our portfolio of work. And then on came law enforcement. Then we started working more and more with law enforcement and believe it or not concurrently with courts.

Recently, we really just started ramping up that part of the portfolio for prosecutors and recently convened a group through the National District Attorneys Association. We formed a focus group. It is called the Prosecutors Call to Action. I just wanted to mention that so you would be encouraged to know that this is an area that we are definitely ramping up. We have a number of videos and products that I would love to share. I will get them to the IACC so that Susan can make them available to everyone. I really appreciate your comment and it just makes me feel validated in the work that we are continuing. Thank you.

DR. GORDON: Thank you, Maria.

I have two more people who wish to make comments or raise issues. We have one minute left. I am going to ask Valerie and Dena in that order to please make your comments as brief as possible. Of course, this is not the end of this conversation.

DR. PARADIZ: I just wanted to -- for those who may not know and those listening in, there will be an INSAR policy brief on the criminal justice system in autism forthcoming. I do not know the timeline for that as of yet because it was delayed due to COVID. But I participated along with many other people on the development of that brief. It is extremely comprehensive in scope and approach. I do look forward to when that is published and issued and hope that we can engage Dr. Lindsey Shea at Drexel, who is the lead on this project and others in informing our committee and our community in the future.

DR. GORDON: Thank you, Valerie,

Dena.

MS. GASSNER: Just quickly, without judgement, I would encourage our members to be very vigilant about how they phrase what they say and realize that when we are talking about people of this particular marginalized population, we need to realize that their voices get to have the priority. We are here to make space for them. Some things were said that were hurtful and I do not think it was intentional. But we need to maintain a safe space. Thank you.

DR. GORDON: Thank you, Dena. I agree with that completely.

Thank you all for a really robust discussion on issues of equity as it pertains to the autism community. I also thank you for your earlier considerations and discussions around the issues of the autism community as it pertains to the COVID pandemic and also in the discussion and responses after the public comment. You have given a lot to think about in terms of what issues we might want to address as a committee over the coming months and indeed years.

Fortunately, we have a really crack staff that Susan runs, who are going to look over all these comments and come up with suggestions for what to address next. But she is not going to be working alone. She is going to be working with all of us in order to do that. I encourage you to keep the lines of communication open as we think about what to address at our next meeting in the fall.

Again, I really thank you for this free exchange of ideas. I found it to be respectful. Although I understand that sometimes we cannot always be as clear in our language as we would like. I hope that we continue to engage in these kinds of fruitful discussions.

DR. DANIELS: Thank you so much for this wonderful day of robust discussions and we really appreciate everyone's participation and also our viewing audience, everyone that is participating by just viewing and giving comments. It has been terrific.

I did want to remind everyone that there is a round robin document that has been placed on the website and is available for the committee. We had all the committee members share their updates here because given that we are such a big group going around at the end of the meeting like we have in past years may not be completely practical. Please look through these carefully. There have been a number of members who said that they had some really important links and events and various types of information to share. Look over that. And anything that was received today that was added there, we will put it into the round robin document later too. We will make sure it is completely updated. Thank you again for your attention and for being with us.

We look forward to our next meeting, which is on October 13 and 14, 2021. It will also be a virtual meeting. Be on the lookout for announcements about that. Thank you.

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