INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

Thursday, October 14, 2021

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

PRESENT:

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

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

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

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

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

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

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

PRESENT: (continued)

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

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

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

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

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

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

CRAIG JOHNSON, B.A., Champions Foundation

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

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

PRESENT: (continued)

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

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

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

YETTA MYRICK, B.A., DC Autism Parents

MORENIKE GIWA ONAIWU, M.A., Rice University

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

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

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

JALYNN PRINCE, Madison House Autism Foundation

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

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

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

PRESENT: (continued)

ROBYN SCHULHOF, M.A., Health Resources and Services Administration (HRSA)(representing Lauren Raskin Ramos, M.P.H.)

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

MATTHEW SIEGEL, M.D., Tufts University

IVANOVA SMITH, B.A., University of Washington

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

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

HARI SRINIVASAN, University of California, Berkley

MELISSA HARRIS, B.S., Centers for Medicare and Medicaid Services (CMS)

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

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

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

PAUL WANG, M.D., Simons Foundation

PRESENT: (continued)

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

STEPHEN WHITLOW, J.D., Merakey

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

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PROCEEDINGS

DR. JOSHUA GORDON: Welcome everybody again to the second half of the fall Interagency Autism Coordinating Committee. We have another full afternoon. I appreciate members of the committee for joining us and I welcome members of the public and NIMHers and others, feds and non-feds alike to today’s event. I am going to turn it over to Susan Daniels. Dr. Daniels.

DR. SUSAN DANIELS: Great. Thank you, Josh. Welcome to everybody. We are really looking forward to today’s discussion and really appreciate all the wonderful input that committee members shared with us yesterday as we had our discussions. We have three sessions we are going to be going through today. The first one is going to be an update on Kevin and Avonte’s Law, which with the last committee, the committee had asked about this. Now, we have a great new update on that.

We also will have a public comment session and a session on mental health. Toward the end of the day, we have sometimes set aside for round robin, but we also will give the committee a chance to weigh in on whether we prefer to go back to some discussions about the strategic plan instead of round robin. So we will see how we are doing toward the end of the day.

But at this point, I would be very pleased to introduce to you Kristie Brackens from the U.S. Department of Justice and Joy Paluska from the National Center for Missing and Exploited Children, who will be presenting us an update on Kevin and Avonte's Law and what DOJ and NCMEC have been doing recently. Welcome Kristie and Joy.

MS. KRISTIE BRACKENS: Thank you and thank you for the opportunity to speak to the committee today. I am really excited to share with you all some of the things that we have been doing under the Kevin and Avonte program over the past couple of years.

Next slide, please.

DR. GORDON: Are we running it from here? I think so.

MS. BRACKENS: While we are getting that slide up, this is my first time speaking to the committee. I am sure you all are aware of how the Kevin and Avonte program came about with the law. Congress created the Kevin and Avonte's Law in response to the two children with autism who went missing. It is named after those two boys, I am sure you all are aware. We have 9-year-old Kevin Curtis Wills, who wandered from home and slipped into Iowa's Raccoon River and drowned in 2008. And then we have 14-year-old Avonte Oquendo, who wandered away from school and drowned in New York’s East City River in 2014. As a result of that, Kevin and Avonte’s Law was enacted in 2018. For the past couple of years, the Bureau of Justice Assistance – we have awarded grants in support of that law.

In 2000, -

DR. GORDON: Kristie, sorry to interrupt. It looks like the slides did change. We are back in control of them. Just say next slide whenever you need the next one. Can you see them?

DR. BRACKENS: Yes. I see that. Thank you. I apologize. This is my fault for the technical difficulties. I was on vacation from October 1 through October 13. I missed the prep. So I apologize.

DR. GORDON: No worries. Welcome back. Welcome back to work.

DR. BRACKENS: Next slide.

When we look at the history of the programs enacted in 2018, as I was just saying in honor of these two boys, and although we focus on the children who have autism with the Kevin and Avonte’s program, we also have funds available to support programs for adults that wander as well.

Next slide.

There are two objectives with the funding. One objective is the proactive programming. We want to be able to get information in the hands of people so that we can prevent where we can the instances of wandering in adults and children that are prone to wander. And we also want to work with law enforcement and other entities to get locative tracking devices in the hands of law enforcement and others that can also aid in the successful recovery of those that wander. To do that, again, like I was saying, we have a grant program, the Kevin and Avonte grant program. There are two categories under that program, one being the locative technology and the second being the proactive programming, prevention programming.

Next slide.

This slide gives you an overview of where we are at as of right now with the program. We have made 26 awards since the inception of the program. In October 2019, we made 13 awards, totaling almost $1.8 million. One of those initial awardees that you see noted here, was a West Fargo Police Department. And with the locative tracking devices that they received funding for, they were able to successfully recover a child. That is one of the early successes that we saw in the program.

In 2020, we made 13 additional awards, totaling about $1.8 million as well. What we found, one of the things that we do when we make these awards is we track the performance of our grantees and the people that we are making awards to, and what we found is that when it comes to the average number of hours lapsed between a report of wandering and the location of a vulnerable individual in our grant program per se, those with locative tracking devices, we found that it was five hours on average that these individuals are able to be located and without locative tracking devices, it was 72 hours. That tells us that putting this locative tracking device in the hands of those who need it has been very successful.

Like I said, we have had 26 active grantees. I wanted to highlight a few sites for you all under both categories that are doing some really good work.

Next slide.

The first site – this grantee of course, is being awarded under our proactive and preventive programming. It is Alzheimer’s Community Care, which kind of highlights how we also work with some of the older adult populations. And what is unique about this one is that just in this past year, they have serviced over 500 patients. They have been able to get the ID bracelets of these patients. They have 126 active ID bracelets. And where there has been a case of wandering, they have had 100 percent recovery rate. Again, getting these bracelets and getting this information out there is really working.

As we go to the next one, I would like to highlight for you, it is the project program ReUnite that is the partnership with a couple of sheriff’s offices in Florida. With their program, they have been able to enroll 228 participants in the past 10 months, with their goal being 300. They are almost there.

They have been able to – of the people who have been reported missing in the Lee County Sheriff’s Office, the ones that were part of the ReUnite membership were all found safely, were located safely. We see that. It is a five-county area there that they are partnering in, but it is good to see that with the grant funds that they are able to actually enroll people in the program and although we do not want to see folks go missing, but of the ones that did who were a part of this collaborative, those folks were all found safely as well.

Another part of the component with our proactive programming, if you go to the next slide, is the education component. We want to make sure that we are providing educational materials to our first responders. When we look at the work that is happening with the Mental Health of America of the Midsouth, they have conducted 15 trainings, trained 389 first responders. They are providing life cards to over 5000 Tennessee residents and continue to distribute information across their 13 counties in that region in that Midsouth region.

We continue to see with these grants that the locative technology piece is being successful as well as getting the educational materials out there and in the hands of the folks that need it.

Next slide, please.

Working with our police departments and getting their locative technology, we have the bracelets, that they are able to do with the grant funds. Just lifting up the Boston Police Department is one example where they continue to enroll new clients in the program. We see it working there.

Next slide, please.

I wanted to highlight the Osceola, I’m going to pronounce it wrong, Sheriff’s Office, because, again, you see with these grant funds that they are successfully finding people. They currently have 30 clients enrolled in their Project Lifesaver Program. They have had two successful finds when someone has gone missing.

Something unique also to their program that they do is that they change out the batteries and they check on the clients every 60 days once they get them this equipment in their hands.

And then our final one that I would highlight for you all is the Sumter County

Sheriff’s Office. Next slide please. Again, with the locative technology since the inception of the grant, they have distributed 59 devices and they have had nine participants who have been located and brought back home safely. Even with the zoning alerts, which we also want to be preventive, caregivers reported getting the zoning alerts, which helps avoid a wandering incident. This is six examples out of the 26 active sites that we have that I thought really speaks to how well the program is being implemented.

With that, another part of the grant program recently by way of update – when the Kevin and Avonte’s Law – a part of that legislation, next slide, required us to work on the development of standards and best practices as it relates to the use of tracking technology. So in order to do that, we convened a Locative Technology Roundtable earlier this year, with the 26 active Kevin and Avonte’s sites. The goal of this roundtable was really to help us in developing these standards. We wanted to get an understanding for how our sites, our grantees, what is their process for determining the locative technology that they are using, how do they use it, how are they defining standards, what are some promising practices that they are using, what are some of their existing standards, how are they working with their communities, how are they working to train law enforcement, caregivers, things of that nature, on the locative tracking technology.

And then we also wanted to use this as an opportunity to look at non-invasive examples that we can also work with these sites on.

Another aspect of this Locative Technology Roundtable was also looking at some of the proactive programming and understanding, which I think Joy will get into a little bit with you all later in her presentation but understanding wandering in children and adults. Why do they wander? What are some things that we could be doing to better get the word out? What are some of the considerations that need to be made when it comes to communicating about this population, victimization, credibility? What are some things that we could be doing to help improve the interactions among law enforcement, community, business, individuals, things of that nature, to help prevent and as well as identify an individual who has wandered?

So we had a two-day Locative Technology Roundtable that focused on all these things that I just mentioned, with our sites, and some of the key takeaways - next slide, please, as a result of that roundtable, which was a very good conversation with our sites, but some of the key takeaways that might be of interest to your committee was, one, that there needs to be a creation of federal and national standards for the use of tracking technology to locate missing individuals who have wandered due to their conditions and that we need to make sure that we are including the perspectives of everyone that is affected by those standards. So not only looking at law enforcement, but families, special education teachers, experts, the manufacturers, making sure that we are including the voice of people who have had lived experiences.

Another key takeaway was that any standards created for the use of tracking technology to locate missing individuals who have wandered due to their condition need to be flexible and adaptive to different departments and jurisdictions. There can't just be like a one size fits all approach.

Something that came out of that I personally hadn't thought of, but I think is critical, is that locative technology should be used as a last result. There are other sorts of prevention methods that should be utilized first in making sure that as we develop standards that we are including those other methods first and making sure that we are getting the word out about those other methods first.

During the roundtable discussion, there were examples provided like placing a stop sign on the front door or changing the height of where you place your door lock.

We also, another key takeaway, was that looking at the various causes of wandering and understanding that every individual has a unique pattern of behavior. It can be difficult to generalize across this very large population and so being conscious of that as we develop standards.

And then finally, the final takeaway, key takeaway, was looking at training for officers, first responders, 911 dispatchers, **(17:21)** dispatchers focused that training on identifying key characteristics and behaviors that are associated with this population of folks and making sure that we are able to direct folks to the appropriate services. That was our focus at the time for the Locative Technology Roundtable.

The way that we continue to work with the Kevin and Avonte's sites is through the provision of training and technical assistance to these sites. We have quarterly calls with the grantees. We have brought them together for a grantee meeting. We brought them together for this locative technology meeting that I just mentioned. But we are supported through TTA for these sites through IACP. They serve as our direct training and technical assistance provider for the sites. NCMEC is also a partner and the Arc. They are also partners. What NCMEC and Arc bring to the table is their resources and their subject matter expertise to work with the sites as we help them develop these comprehensive plans around using this equipment.

Our goal is not just to put locative technology in your hands and not have the site have a plan for how they are going to use that equipment, how they are going to be proactive when it comes to spreading the word about that equipment, how they are going to work with engaging their partners. So we continue to engage with our TTA partners around this issue and supporting our sites.

One of our things that we have also developed through IACP as a part of the TTA, is Home Safe. Next slide, please. The Home Safe page on the IACP website – when you go to the Home Safe page, I encourage you all to take a look at it. You will find information about the Kevin and Avonte sites, any resources that we have as far as the training and technical assistance is there. We have a library that contains webinars, workshops, tools, other tools, publications, articles.

Through our Kevin and Avonte’s sites specifically, we have a peer sharing, a secure online peer sharing community, which is our Home Safe connect that our grantees are able to use to talk amongst themselves. One of the things that we took from the listening session that we had on locative technology is that they were really craving for the opportunity to be able to talk amongst themselves and share some of the challenges that they were facing in implementing the grant, as well as some of their successes.

We recently had a webinar on the resources that NCMEC has. I think that Joy is going to go over that, so I will not go into that. But those sorts of eLearning opportunities that we have for the Kevin and Avonte sites – those things will also be placed on the Home Safe website so that anyone can take a look at those and get the same information that we are providing our sites.

And then we are also working – COVID has impacted our ability to travel at the department and to be able to support travel, but we are committed to working with the grantee sites to connect them to some peer-to-peer learning opportunities so that they can see what the best practices out there that other departments may be doing or other agencies may be doing that are working that might help them as they implement their program back at home.

Next slide.

I see that I am running out of time, and I do not want to get into Joy’s time. I will be real quick and finish up here. As we think about fiscal year ‘21 and what is beyond for the Kevin and Avonte program, we plan to make 17 new awards this year. We received some additional funding this year for the Kevin and Avonte program. So we are able to make more awards this year. We are going to be making about $2.3 million in new awards. We are also planning a bigger stakeholder workshop in spring 2022. That workshop will build on the Locative Technology Roundtable that we just had so that we can continue to work on the development of those standards.

And then as far as the Kevin and Avonte program itself, as we think about what it is going to look like going forward, we are in the process of developing the solicitation for next year to solicit for more grantees to be able to support through this program.

One of the things that I would like to do with the program is to develop a prevention toolkit. One of the things that came out of the Locative Technology Roundtable is that we tend to always go to locative technology, and what are some of the other things that we can be providing to the Kevin and Avonte sites to fulfill that aid in prevention as well. We are going to be working with IACP to develop a prevention toolkit.

Also, enhancing the focus on public education and awareness and beyond. And then also the final thing that we will be doing with the Kevin and Avonte program, proposed to do with the Kevin and Avonte program, that came as a result of the webinar that we had with the NCMEC resources, is to look at how we can better support this population when it comes to kids and their online, who are being exploited online because that is not something that we had really addressed before with the Kevin and Avonte sites. What are some resources? What are some things that we can do to be more supportive in this specific area where these kids are being – they are more prone to be exploited online. So how are we dealing with that?

That is it as far as the BJA update on the Kevin and Avonte program. I hope this information was helpful to you all. I welcome any questions at the end. Thank you.

DR. DANIELS: Thank you so much, Kristie. And now, I would like to welcome Joy Paluska to join us.

MS. JOY PALUSKA: Thanks, Dr. Daniels, and thank you, Kristie and Dr. Gordon. I am really honored to be here. My name is Joy Paluska. I work at the National Center for Missing and Exploited Children.

There are three areas that I support at – we just go by our acronym. I am just going to say NCMEC when I speak. But I support disaster preparedness and response, our outreach to children of color, Native American, children in indigenous communities, and also children on the autism spectrum. I just want to put that out there because a lot of work sometimes intersects in different areas. You will have my contact information after today, if you want to stay in touch or if you have questions or anything like that. Really grateful for the opportunity to be here with the committee.

I just wanted to also say when I first started at NCMEC a couple of years ago, I did a cold email to Dr. Daniels and said, hey, I am Joy. I work at NCMEC. This is an area that I support. She has been super responsive and helpful to me as I have grown and learned about these issues in terms of how we can best support children on the autism spectrum. I just wanted to give a warm thank you to Dr. Daniels, and also to Kristie, who is also really giving strong support to NCMEC through the grant that we are working on.

With that, let me advance my slides. Today, I am just going to talk through the mission of NCMEC and our history very quickly, some of the data that we see with missing children and the resources that we have, our resources for reducing child sexual exploitation and preventing future victimization.

Our mission here at the Center is to find missing children, reduce child sexual exploitation and prevent future victimization. We are a nonprofit organization, and we were founded by John and Reve Walsh. Some folks on the call may remember that their son Adam went missing in the early '80s and he was later found murdered. They really have taken the worst tragedy that could happen to a family and have transformed the landscape in terms of how we search for missing children and support missing and exploited children.

Sometimes in my presentation, I will talk about different programs that have the name Adam. When I make those references, we are referring to Adam Walsh. I wanted to acknowledge that.

In terms of where I work, I am in the Missing Children Division. Earlier this year, some of our colleagues put together a report on what we see in terms of missing children on the autism spectrum. Some of the important things that I just wanted to pull out from that report, it is on our website and available. I am sure Dr. Daniels can share that as well with the committee. But one of the big data points that we have seen now and historically is our drowning deaths of our children. I am just talking about children on the autism spectrum in all of this data.

What we have done in terms of our own outreach and awareness, and we train law enforcement, that is the big thing that we do as an organization. We really focus on that data and it impacts the search protocols that we put together for law enforcement and also our training. We are always saying, any time I talk, if you leave – one thing to search water. Even if we have asked the family if their child is attracted to water, maybe they do not know yet. We always are encouraging our law enforcement partners to search water and now not just to search water, but to have someone stay at that location so that we can prevent these drowning deaths that we see with our kids.

Again, the data that we have collected – we had a little over 1500 children on the autism spectrum reported to us during that 10-year period. One thing that we always talk about with our data is that not everyone reports to the National Center. There are certain instances where there is a requirement to report. A couple of years ago, a law was passed to mandate that child welfare workers or children who are in the foster care system, any kind of state care, if that child goes missing, they are mandated to report to NCMEC. Unfortunately, we still do not have all of those reports that are coming in. We are always working on educating our partners in this space about that mandated reporting. So again, there may be many more children. We are just dealing with the data that we have here at the Center.

The other kind of data that we have noticed as an organization is just this spike that we see for children missing during the summer months. Of course, in January/December, it is kind of around 6 percent. And then there is this pretty significant spike during the summer periods.

But what I really want to always drive home with folks is we have a 98 percent recovery rate for these cases. That is huge.

We are just really trying to encourage both families and our law enforcement partners to report the child to our organization so that our resources can be utilized. I will get into those next.

How does NCMEC help? Once a call comes into our organization through our call center, which is 24/7, we take those calls from either law enforcement or from the guardian. We also will take them from other folks. We just provide a little different support depending on whether it is law enforcement or the parent or guardian. We are going to then connect that child’s case with a case manager. They are going to do a variety of things. One of them is to create and disseminate posters, which I will talk about in a moment, help create leads for law enforcement through all the resources that we have at our organization, provide referrals to our family advocacy services, which I will touch on also a little bit in terms of what we have that is available to folks who are experiencing a missing or exploited child.

We are going to coordinate all of the resources that we have through – if necessary, our Team Adam Consultants – I will talk about those folks in a second. But also, we have lots of federal liaisons. When we were in a non-COVID environment, everyone kind of sat together in our shared space, but we have all of our federal partners sitting with us and sharing information. Now, we are all at home for most of the time, doing our work from those spaces. But we have those longstanding relationships and connections and can help local law enforcement, which there is about 18,000 law enforcement organizations in the US and most have less than 50 on staff. We have this incredible amount of staff who are available to provide the technical support to law enforcement and can really assist.

I mentioned our Team Adam Consultants. These are some of the folks – they are mostly retired law enforcement, but we do have some other folks who we have been adding to our Team Adam Consultant team and those are odontologists and forensic folks so really an incredible group of folks who can do a few things. They can deploy on site to a critical missing child case and provide their particular expertise. We have some folks who have search and rescue expertise. They are incredible individuals who can deploy on site and help the local law enforcement in that search for the missing child.

We also have folks who can provide long-term case assistance. I did not mention it, but it is on our site. We never give up hope.

I have hope on my T-shirt here. We have folks who are looking at these long-term missing cases and can go in and help law enforcement do some organization analysis. There are all kinds of new resources that are now available through DNA and forensics that were not available just in the even recent history. We can apply those NCMEC resources to cases. Just an incredible free resource that we have.

We also have our poster distribution. You can see that we have over 200 partners. You may see our posters in Walmart. They are a huge partner.

I just want to say that before I worked for NCMEC, I walked by these posters. I worked for the Federal Government. I walked by them every day in the cafeteria and I had a friend that worked at NCMEC. It was just kind of there. When I started to work in the missing children division, I really started to learn how these posters actually recover children.

The story that stays with me because it is from when I first started. We had a child that was missing in New York – went missing in a subway. We deployed one of our Team Adam Consultants. They postered the subway and really got that information out there so that the public could assist in the search. We had an individual call our call center and they said I am looking at this poster of this child – the caller was just saying I am looking at a poster and I am holding the hand of the child. What should I do? There are just dozens of stories. We get all of those at the missing children division. We always hear about the recoveries of our kids through our posters.

Another way that folks can engage is through – programs. You can sign up. That is a partnership with – you can sign up to receive those posters. They are geo-targeted. If there is a missing child and we believe they may be in your location, you will get that notification and the public can participate in that. Of course, Facebook helps us out and all of our other partners as well.

Another incredible resource that we have is the analytical support that our Analytical Services Division can provide to law enforcement. You can see on this slide that there are all kinds of different resources that we have that are donated to the National Center.

There is also a lot of open source out there. You can see Facebook, Instagram. There are a lot of things that are available just open source. We also have partnerships with these organizations as well.

But the unique thing is that we can take all of these different pieces of information through our partnerships that are public and private and we can put them together for law enforcement. As I mentioned, most have less than 50 on their staff and most may not even have an analytical services unit in their law enforcement. And even if they do, we have an entire team of folks who are devoted to this and who have incredible expertise.

Everything that I am talking about we could talk about for probably an hour or two in terms of what these folks are able to do. Like I said, our Team Adam folks, when they get trained, they come on board. They are with us for almost a week, getting trained on all of the free resources that we have. Just dusting the surface here.

But I also mentioned our family services division. These are really special human beings. A lot of the folks who are part of our Team HOPE that you see here have experience of missing or exploited child in their life. I know that I talked to a parent who had a child on the autism spectrum. Unfortunately, she was taking a shower. Her child bolted. She was later found deceased. Horrific. But she has taken that tragedy and works here at NCMEC and provides that peer-to-peer support when we have a parent who maybe experiencing this same experience. Just really incredible. Really special.

We also have a lot of resources through the Family Advocacy Division that can provide support and they are all free and they never go away.

Here are just some of the federal partners that I mentioned. We have the US

Postal Inspection Services. I am going to talk about them, I think, in a second. We have our Homeland Security, US Secret Service, ICE, just an incredible amount of folks who have their expertise and capabilities that we are able to link up with because we are a nonprofit organization, but we are mandated through Congress to carry out a lot of our functions that we are going to carry out, which I am going to talk about momentarily.

Earlier this year as part of our outreach and awareness, really focusing on our law enforcement partners. We have done a couple of trainings. One is how local law enforcement can build an outreach and awareness program. I am sure a lot of folks who are part of this committee are familiar with Officer Laurie Reyes. She is a leader in this space and has been an incredible friend and mentor to me. She gave a presentation talking about how easy it is to build these programs for our local law enforcement. These are just the core components that were an outgrowth of that training, just officer training, which I know Kristie mentioned was also brought up in our Roundtable earlier this year. It is just not something that most law enforcement officers are mandated to learn about. There are just pockets of different organizations. I know Illinois has some. There are different states that have different requirements, but it is so essential that we get our officers trained so that we can have those safe interactions and swift recoveries so not just children on the autism spectrum, but as Kristie mentioned, our wandering communities, including Alzheimer's.

Some of our outreach and awareness that we have tried to build over the last could of years – a lot of this is on our website, but I just want to draw your attention to it. We try to elevate model programs like Officer Reyes in Montgomery County so that law enforcement organizations have those resources that are available to help not only their organization, but their communities. We have those on our website. We have a lot of materials like our missing children on the autism spectrum search protocols for law enforcement. We just updated that last year. I believe I reached out to Dr. Daniels on that also. We have the report that I mentioned and referenced some of the data.

Our NCMEC CONNECT resource is free and available to anyone. You just have to like anything register for that and get vetted and figure out which category that you are in.

The How to Search for and Protect Children on the Autism Spectrum is closed. That is only for our law enforcement partners, but this other one is available, and we are going to do another one in a couple of weeks that will be called Resources for Caregivers of Children on the Autism Spectrum. We can talk with our caregivers about different things that we have learned from our law enforcement partners, including - and I do not think I have it on the slide so I will just talk about it. Just the importance of calling 911 and calling NCMEC, but of course 911 first when your child is missing because time is of the essence. The longer our kids are missing, the more likely that we are to have an unfortunate outcome.

What we have learned is that sometimes parents do not want to call because they feel they are ashamed or they are going to look like a bad parent. But part of our job at NCMEC is not just helping law enforcement understand these children and how to search for them and interact with them, but also giving that support to our families and our caregivers so they can start to build those relationships with law enforcement and say my child is on the autism spectrum. They have these characteristics. They may run. They may bolt. I need your help. I need your support in keeping my child safe. When law enforcement has that information and understanding, we can again have those positive interactions and positive outcomes.

We have done some blogs on swimming safety and searching water. We have a great relationship with Lori McIlwain from National Autism Association. I am not sure if she is tuned in today. Similar to Dr. Daniels, Lori – I reached out to her two years ago. She has been an incredible friend and mentor and incredible partner for NCMEC. She actually can report missing children that she has seen come in terms of news. She sends that to our call center and says please assist. And our call center folks get on that and immediately reach out to law enforcement so really an incredible human being and organization.

Of course we have our partnership with the International Association of Chiefs of Police and the Bureau of Justice Assistance. We are really thrilled about that partnership and all of the things that we are learning all of us together in ways that we can better support our families with wandering populations.

Next, I am going to talk through some of the issues that we see around reducing child sexual exploitation and also some of the prevention materials that we have. This slide just describes what is sexual exploitation. I am not going to go into too much detail. These terms are all taken from the legislation that talks about this issue and defines how we carry out our mandate as part of the CyberTipline.

One thing I just wanted to draw folks' attention to is this terminology of child sexual abuse materials. I will say in the law in different laws, we still have that terminology of child pornography, which as an organization, we do not use that language. We call it what it is, which is child sexual abuse material. If you interact with folks at NCMEC on a regular basis, we call that CSAM and I will probably reference it later on, but that is what we are talking about.

In terms of online enticement, I am just going to read this straight from the screen. This involves an individual communicating with someone believed to be a child by the Internet with the intent to commit a sexual offense or abduction. It is important here – believes to be a child also because some of the work that our organization does is make sure – we are making that determination that a child is involved. And of course, once we know that, all of these different things are going to come into play in terms of our support for these kids.

This slide talks about our CyberTipline Workflow. The number – I will share this number at the end, but it is 1-800-The-Lost. We share the same number. Missing or exploited child. It is the same phone number. It is easy to remember. 1-800-The-Lost. These tips can come in through our traditional phone, but also folks can make these tips online as well.

The little diagram here has an individual and computer. This image is really – this could be the child that is reporting the abuse that happened to them. This could be a parent. This is really anyone from the public. Anyone can make this report. And also, electronic service providers. That is a fancy name for different things like Facebook. But our electronic service providers. They are mandated by law to report child sexual abuse materials to NCMEC.

Once those come in, we have our CyberTipline folks who are going to take that case and they are going to prioritize E1, 2, or 3. E is just that has come in as the electronic service provider so (indiscernible). And then Priority 1 is this child is in imminent danger. We have to act immediately. Priority 2. We believe that the child is going to act or there is going to be something that is going to take place. And then Priority 3 is unfortunately, something has already happened. This has taken place. This has happened in the past and we want to go in and start providing the different resources that we have.

When we get our prioritization, our analysts are going in and they are trying to connect all of the different dots from the information that is then reported to NCMEC. We say in all cases both missing and exploited children's cases. The more information that an individual has no matter how small it seems, every piece of information is utilized and it can help connect the dots. As you can see in that next little picture there, we are figuring out where in the world is this taking place literally. Where is the child, where is the offender so we can then start putting together our analysis and get the right jurisdictions and folks involved in getting that information to law enforcement so that they can continue. They are the investigators just to be clear. We are providing the analytical support and our law enforcement partners are doing all of that boots-on-the-ground investigation and not always boots on the ground. Sometimes the computer also.

Something else that I wanted to bring to your attention. Some of this information is available again on our public website. We just have it sometimes in different ways. But what is important here is that in the cases that are reported to us when we look at the relationship of the exploiter to the child, 50 percent had direct access to the child. That means they are known. Look at the names: guardian’s partner, babysitter, mentor, coach, other relative, neighbor, family friend. You never want to get too like oh this is terrible. This is so scary. But there is a piece of us that wants to say this is a little bit scary. These are folks who are known to the child and who are in what we would call traditionally trusted adults. It is just something to be aware of and why these next materials are so important for folks to be familiar with and know that they exist.

This just has the latest data that we have seen and that increased from 2019 to 2020. Of course, the entire world started being at home, being online at this elevated level all of last year continuing this year. We have seen this incredible spike in terms of the report. Just staggering numbers.

The other thing just to keep in mind when we are thinking about online enticement is that perpetrators are looking for easy targets. This is true in anything. But perpetrators are looking for easy targets and many of our kids can fall victim to that manipulation. It is a very human need to want to feel loved, to want to feel connected, to want to feel listened to. These are things that are normal and that all of us feel, child or adult. But our children have more trouble discerning bad behavior or danger, which increases their risk. Children who feel excluded or are seeking a connection are at risk.

At our organization, we have started to take a look, not at just our search protocols when we are thinking about kids on the autism spectrum, but also the other vulnerabilities that they may have. It is just another lens that we are using as an organization and something that we are trying to raise awareness with the folks who are supporting and caring for children on the autism spectrum.

I talked a lot about some hard topics in terms of the exploitation that we see. I just want to walk through some of the incredible free resources that we have for families and for children. We have our NetSmartz, which is our online safety program for children and families.

I just want to say one other thing that a colleague mentioned to me when I was preparing for this particular presentation, and I never thought about it this way and I think it is really resonating with me. We do not put seat belts on our children when they are 18 years old. We do not wait. We do not wait until they are 18 years old to put their seat belts on when they are in a car. We do that immediately. The minute they can go in a car. They are in a car seat, a seat belt. And that seat belt is on for life hopefully. It is that same thing. We do not want to wait for our kids to talk about all these different issues particularly online safety. We want to start having these healthy conversations at a young age. We have these great resources that are on our website. Some of them are activity guides. Some of them are online games. We have presentations that can be downloaded. There are tip sheets. There are videos. Our Into the Cloud series is really great. It is something that is very engaging and talks about important issues at the level that our young folks need to hear it. Just great resources.

And there are also resources for how folks can ask for help. They just walk through all the things that we do, even when we are trying to do our own presentations. Practice. Be clear about what you want to talk about. Be honest even if it is hard. I was trained by another person to know that bad news does not get better with time like not addressing something does not make it go away. We want to have these conversations and focus on what we can do going forward and again, being calm, which is really difficult to do when we are talking about these issues.

I have talked about a lot of the prevention materials that we have that are available for free. But there are instances sometimes when something has happened. When there is something that has happened to a young person, we have the capability of our organization to help them remove those images and the comments online. We can provide that technical support. We can support that emotional support. If a young person shares their picture with their partner, boyfriend, girlfriend, whatever, they break up then this person wants to put that information out there. These are things that actually happen. We have the resources that can provide comfort and support to the young folks and the families who have experienced that.

And then we have our Office of Legal Counsel, who can provide assistance and guidance through this process. And then, again, we are always working with our law enforcement partners and other folks to help in the response for CSAM if someone has experienced that.

The last thing I think on here is just again a lot of free resources are available on our – it is called NCMEC CONNECT site. You can take a much deeper dive in understanding child sexual abuse material and its impact. We have an introduction to child sex trafficking, which I did not even talk about today and then our other child safety resources and also those presentations that I mentioned about how law enforcement can build outreach and awareness and also the search protocols. Just an incredible wealth of free resources that are there.

Again, my name is Joy. That is my email information. If you leave with anything, of course, 1-800-The-Lost. I answer all my emails just like Dr. Daniels. Please, if you have any questions or want any more information, do not hesitate to reach out. I really want to help folks in any way that I am able. That is what I have, Dr. Daniels.

DR. DANIELS: Thank you so much, Joy and Kristie, for that information-packed session. We really appreciate your presentations. We would like to take a few minutes for questions. I see that we have one hand up, a second hand up. We are running a little over so I won't take a whole lot of questions because we do want to move to public comment, but I do want to give you a chance for a little bit of discussion.

First, Hari.

MS. PALUSKA: You are on mute, Hari.

MR. HARI SRINIVASAN: There is also underreporting of wandering by school districts and potentially service providers and organizations. In one of my elementary special education classrooms, a kid went missing. I think the classroom staff were trying to look for him as the rest of us had to stay indoors. Later in the day, an old man found him wandering a mile away and returned him to the nearest school. The main conversation I overhead amongst the classroom staff was on how to not let the family know. So the family never knew their kid was missing for most of the day. The questions this raises are what if that guy had not been a Good Samaritan, at what point would the family and law enforcement have been involved? How frequent is this situation?

MS. PALUSKA: That is a terrible thing to hear about definitely. At the end of the day, law enforcement only know if it is reported. It is just like us. We only know if there is a report. To answer your question, thank goodness this person was a good citizen, but this is one of the dangers. It is unfortunate that those folks had that approach of not sharing that with the family, but that we want to engage law enforcement and the National Center as quickly as possible and to encourage that to our school administrators also.

We do have some outreach that we do with schools, right, so sharing that information. A lot of time when we are talking to schools, we are talking more on the exploited side, but it is an important point to note that we need to – when these young folks do go missing and they do go missing from schools. That is some of the data that we have across the board is that is where a young person might go missing from. It is something that we are constantly working on in terms of getting folks to call 911 and NCMEC and of course informing the family, definitely.

MS. BRACKENS: This is Kristie. I would only add to that that with the Kevin and Avonte grant program, one of the pieces that we want to do is work to educate the public to recognize the signs of an individual that might be missing. We are working with our sites to do that. So in the situation that you described, we would want this person that located this young man that had gone missing from school, that others would be able to recognize that the businesses would be able to recognize signs of individuals who may be in distress and missing and then be able to also contact law enforcement in a way that this individual did. There is a big education piece to the Kevin and Avonte program that we are working on.

DR. DANIELS: Thank you. I am going to take questions from a couple of people who didn't have a chance to speak yesterday. First, Morenike, you have a question.

DR. GORDON: Morenike, if you are speaking, I think you are muted. I can't quite hear you.

DR. DANIELS: Or if you are taking a moment to type something into the chat, we can move to Craig Johnson for a moment, and come back to you, Morenike.

MR. CRAIG JOHNSON: Hi, Joy. One of the things that I think – I am a father of an autistic son. One of the things we face is really educating us as parents on our child if they are running or if they take off or if they happen to get lost like that. Do you provide any training for parents in working with our kids and showing them what to do when they get lost or when they are in a dangerous situation because I think that would be really helpful. Because once they are there, it is really challenging for the children that they put themselves in dangerous situations at times and do not know what to do and can even hide themselves or be unable to respond to rescuers. So is there any type of education that you do for parents to work with our kids on what to do in those situations?

MS. PALUSKA: Thank you for the question. In a couple of weeks, we are going to have really that first webinar where it is focused on caregivers of children on the autism spectrum. Like I said, we are always training law enforcement, our law enforcement partners. But to your exact point, that is something that we really want to address as an organization.

I just took a note because I am still working on the presentation. I am talking to Lori McIlwain tomorrow about the presentation itself. I hope that you are able to tune in and I appreciate the feedback because I have all these things that I want to talk about in that presentation. We have some different folks who are going to talk from the law enforcement perspective and my colleague, Lauren, will do kind of what I did in terms of the exploited stuff. But this is a good point, and so we can make some kind of concrete information for families.

What we tend to focus on is to call 911. We have a 911 script. I am sorry. I know I am taking up too much time. But Craig, if you take my email, I would love to chat with you afterwards about how we can build an even stronger presentation. I hope you reach out. I do not want to take up time. I forgot that I went over my time anyway, sorry.

DR. GORDON: Susan, I am wondering if we can hear from Morenike and then I think we will have to put the other questions on hold. Maybe we will have more time for this topic if we can get through the public comment.

DR. DANIELS: That sounds great, Josh. I do have a comment here from Morenike. Morenike says, "thanks for your presentation. It was very thought provoking and addressed an extremely important issue for our community. It was helpful to receive hard data and also details about future programming. It was also encouraging to learn of some of the successes in terms of children being safely reunited with their parents as a result of some of the resources that have been provided to various entities as a result of your program.

I do have to share that I have a great sense of ambivalence about this. As an educator, I will never forget the immense sense of dread that I felt years ago when I was notified that a child from the campus where I was employed at the time was missing. And as a mom who knows from personal experience that alarms, locks, gates, and cameras help, but do not necessarily prevent one’s child from finding their way outside of your home. I know this is an important topic for many families.

Elopement and wandering have been concerns of ours for some time because it is something our family has dealt with. However, I am also a black autistic parent of children on the autism spectrum, as well as a child with an intellectual disability who are also black. I am extremely fearful about the implications of surveillance and tracking devices at the macro-level.

When they are looking at my children or me, before the world sees an autistic person, they see a black person and the likelihood that a disabled person of color will have challenging encounters with law enforcement is high. I realize that you have mentioned that this would be a last resort option. But I believe that there are a number of police reforms that need to be made before we consider these types of tools. Respectfully, they are still profiling and killing us for the color of our skin, neurology aside.

I do not know that I feel confident that there is competent developmental disability knowledge and skills nor sufficient cultural competency to entrust individuals with such authority.” That is the comment. And Kristie and Joy, you are welcome to respond.

MS. PALUSKA: I can respond just from the space that I also support that I mentioned at the National Center, which is our missing children of color and indigenous children.

We definitely see some data that we are concerned about as an organization. I know that when I was speaking earlier, I was talking about how we are trying to encourage safe interactions and swift recoveries, right. That is kind of what you just touched on. Forgive me. The individual who just raised that, is there are instances where police are responding and we are – not we, they, our law enforcement partners are coming with all kinds of things that we are trying to address in terms of racial biases and prejudice. We do a lot of training on that also. So definitely an important issue that we are definitely looking at the National Center. I will just pause for Kristie because I think you were --

MS. BRACKENS: Thank you for your comment, first of all. I would say that with the Kevin and Avonte program, there is a big focus on training our law enforcement. That is a big component of it. There are two categories to the program. One is the proactive prevention kind of training piece of it, and the other is the locative technology. I think we are cognizant of that fact that we do need to do more training with our law enforcement.

I would say for a big picture though, at the Bureau of Justice Assistance where I work and where the program is housed, we have all sorts of programs that we have stood up over the past year that are very intentional when it comes to training for law enforcement. We have our crisis intervention training. We have our justice and mental health collaboration site. There are programs that we have out there that help to address some of the issues that you mentioned.

I know we have been – there is an increased focus on constitutional policing in community violence reduction strategies. I think that several things that you touched on are things that we are working at BJA to improve as far as making these sorts of training available. The instances that you talk about that you speak of are less frequent. But I am happy to talk to you offline about that as well.

DR. GORDON: Thank you. I know Morenike had an additional question. I am just afraid we do not have time for anyone else right now, but please feel free to reach out to the two speakers. If we can finish with the public comment discussion early enough, we can get back to this topic if our speakers wouldn’t mind hanging on. Or if not, we can forward questions to them also by email as well.

MS. BRACKENS: I will be available.

DR. GORDON: Thank you very much. Great.

Susan, I suggest we take a four-minute break until 2:10 just because people need to take care of their biology and take a moment and then start up the public comments at 2:10, about ten minutes late. Is that okay?

DR. DANIELS: Sounds good. Thank you.

DR. GORDON: See everyone in four minutes.

(Whereupon, the Committee took a brief break starting at 2:07 p.m., and reconvened at 2:11 p.m.)

DR. DANIELS: I want to get us moving forward on our public comment session. Welcome back, Dr. Gordon, too. We are going to be going through public comment today. We have a few virtual commenters, and we appreciate them being here with us live to be able to give their comments. You will also note that on the meeting materials that are listed on the website, you can find the full text of the written comments that were received for this meeting and in addition, a special packet of comments related to a specific topic. You can go to the IACC website under today's meeting, and you will find all those materials if you scroll all the way down.

With that, the names of the five commenters we are going to be hearing from today are Adrienne Robertiello from Children's Specialized Hospital of New

Jersey, Crystal Hernandez, Julia Bascom from the Autistic Self Advocacy Network, Eileen Nicole Simon, and Shannon de Roches Rosa. I am going to go in that order. I would like to call on Adrienne Robertiello to share your comment. Welcome.

MS. ADRIENNE ROBERTIELLO: Hi. Thank you, Dr. Daniels. Can everyone hear me okay? Great. Thank you. Thank you to the Department of Justice and NCMEC for bringing the intentions of Kevin and Avonte's Law to fruition. I am a parent of an autistic child and a community educator at Children's Specialized Hospital. Through my work and as a part of efforts made possible through an Inclusive Healthy Communities Grant from the New Jersey Department of Human Services, we have found indications of notable safety risks. And many of these are compounded with issues of intersectionality and factors involving communication and hearing, vision, IDD, physical impairments, mental health, and more.

Some examples of safety incidents include severe kitchen burns or pedestrian injuries or accidental poisonings, which may occur because medication instructions were unclear.

Calls to poison control centers do not record if a caller is autistic or other potential factors, which might influence poisoning with no records of repetitive episodes.

Neither qualitative nor quantitative measures of occurrence are available for most safety incidents. By identifying patterns and frequencies of significant injuries in households and communities, we can develop aggregate data for more effective prevention and safety education.

Looking at the problematic interactions between law enforcement and autistic people and related intersectionality issues, these incidents are often documented with elements of bias. Baseline data related to the quality of safety education in autism training from law enforcement, from emergency responders, and students are mostly anecdotal. We must study the efficacy and impact of current and emerging safety education to determine safety risks, identify disparities and inform the development of effective safety education and professional training.

Functional data for autism safety are most often subjective, inadequate, discriminatory, inaccurate, or unsubstantiated. We must begin to identify and quantify injuries and analyze outcomes to implement prevention practices and services.

This needs to be done equitably and ensuring data are gathered in methods that prevent misuse and bias. These efforts are critical to empower autistic people to better understand and safely practice life skills. By identifying potential correlations and patterns of injury and identifying the efficacy of safety education, we can establish substantiated safety interventions, further increase safety, improve services, and enhance the quality of life of autistic people. Thank you.

DR. DANIELS: Thank you so much, Adrienne. We are going to have each commenter just give your comment and then we will have the discussion period after we have gone through everything.

Next, I would like to call on Crystal Hernandez. Thank you so much.

DR. CRYSTAL HERNANDEZ: Good afternoon, IACC members. My name is Dr. Crystal Hernandez. I am an autism mother and ally, Cherokee and Latina. I serve as a tribal mentor parent, serving on various support groups and panels, working with local and national organizations on tribal inclusion projects and research. I see and hear stories from grandparents and parents, communities and individuals struggling to find suitable service and varied treatment for their autistic loved ones. I see continued disparities in access to quality care within communities, underrepresentation, and cultural exclusion. We must do better.

It is a pivotal moment in our world, where Tribal Nations are not just being looked at, but rather are starting to be seen and included. But there is still much work to be done. Autism in Indian Country is overwhelmingly underrepresented in national and state data, due to non-inclusive methods of measurement and often distrust of the measuring systems.

We must focus on improving culturally relevant diagnostic tools and screening instruments and train in meaningful ways, those working within the field on cultural humility and responsiveness. There needs to be a focus on embedding appropriate culturally relevant screening practices in a variety of conventional and unconventional settings, such as health clinics, daycares, community centers, nutrition programs, Head Starts, and behavioral health care settings. A focus on community and extended family compositions in system build and design is desperately needed. We must change the narrative within communities and learn from those walking the journey. Representation matters in all the places where decisions are made, not just in theory, but in continued practice.

There is a great need to improve access to care in community settings, meeting the person where they are, removing barriers to treatment and support. We must look beyond gap analysis and instead focus on actionable items for continued system overhaul. We need to allow culturally rooted care to be viewed with the same fidelity and reimbursements that all mainstream treatments are. Giving honor to language, customs, beliefs, values, and practices is the only way forward.

The vast array of Tribal Nations throughout the United States are not here to be served, but rather we are here to be part of building meaningful systems of service.

Thank you for this opportunity and if I can be of additional service, please let me know. (Indiscernible)

DR. DANIELS: Thank you so much, Crystal, for that comment.

Next, I would like to invite Julia Bascom to share a comment.

MS. BASCOM. Hi. Thank you so much. My name is Julia Bascom, and I am the executive director of the Autistic Self Advocacy Network. Thank for this opportunity to present key themes from our written comments.

ASAN is deeply concerned by the lack of comprehensive research aimed at ethically supporting autistic people who lack an effective means of communication, who struggle with self-injury or aggression or who otherwise require intensive support. As IACC is aware, the vast majority of autism research focuses on studies that are not aimed at supporting the quality of life of autistic people. Even within the small amount of research that looks at services and supports, shockingly little attention is paid to urgent human rights issues such as the need for effective communication. We urge the IACC to use your leadership roles to change this.

As we noted in our comments, there are troublingly few studies, which examine how best to support non-speech forms of communication for autistic people. Given that approximately one-third of autistic people do not develop usable oral speech, it is imperative that significant research dollars be dedicated to understanding and scaling effective AAC approaches.

And there is a robust body of evidence showing that AAC is highly effective for individuals with disabilities that impact speech in general, including people with significant intellectual disabilities and including autistic people and that access to effective communication is key to reducing challenging behaviors and improving quality of life.

However, research is much more limited on best practices, to support autistic people specifically with our associated motor and cognitive and language processing differences. Very little guidance exists for families, educators, or autistic people ourselves, looking to access the level of communication that would allow us to say more than simple requests.

ASAN, therefore, recommends that the IACC prioritize the development of substantial research on best practices for supporting robust and effective AAC for autistic people.

The other thing I want to raise is that currently autistic people who struggle with self-injury or aggression especially autistic people with intellectual disabilities or limited communication lack access to accessible mental health services and are typically only offered behavioral modification programs or medication with little attempt to address our underlying needs. This is an urgent human rights crisis. In all cases, autism research to address challenging behavior should attempt to understand and address the root causes of that behavior, but that is just not what we have seen.

ASAN recommends that the IACC lead the charge in funding research that expands the number of options available to us as a people struggling with challenging behavior. Some possible research topics could include best practices for identifying and addressing underlying medical, mental health, and communication needs in people with IDD who struggle with self-injury or aggression, effective provision of community-based mental health services with people IDD especially people who lack an effective means of communication, pilot programs of particular services and supports that may address these underlying needs on an individualized basis, and then scaling effective approaches and building the capacity of providers to support people with IDD who may struggle with challenging behavior safely and humanely in the community.

This research should be conducted to the maximum extent possible in partnership with autistic people, particularly autistic people with co-occurring mental health disabilities or intellectual disabilities, autistic people who use AAC and autistic people who currently or by history struggle with self-injury or aggression. Thank you so much.

DR. DANIELS: Thank you very much, Julia, for that comment.

And next, I would like to move to Eileen Nicole Simon. Welcome.

DR. EILEEN NICOLE SIMON: Thank you. My autistic son was nearly 6 years old before he learned how to speak. Language disorder is the most serious handicap of autistic children. Social disorder is the result of the language disorder. But since the 1980s social disorder has become the focus of most research. This has led to recent claims by many people who believe they are autistic, but that their autism was missed when they were children.

I want to urge the IACC to maintain the focus on developmental language disorder and its causes.

Infants begin to learn language through the sense of hearing. Professor Roger Brown at Harvard determined that speech begins with the use of stressed syllables. Stressed syllables become more and more difficult to detect during the first ten years of life. This is why learning a new language becomes more and more difficult.

Language development should be the primary focus of research. Use of single syllables should be encouraged in attempts to teach autistic children to learn to speak.

Please discuss language development as the most important focus of research with autistic children. Thank you.

DR. DANIELS: Thank you, Dr. Simon.

And next, we have Shannon de Roches Rosa.

MS. SHANNON DE ROCHES ROSA: I am no longer on mute. Hi. My name is Shannon Rosa. I am the mother of a 20-year-old high-support autistic young man, and senior editor of the autism information and advocacy community Thinking Person’s Guide to Autism.

My son is a thinking, feeling human being just like you. He deserves a good life. My husband and I love him dearly, enjoy his company, and do our best to help him feel happy, healthy, and safe. However, it is challenging for families like ours to give our autistic loved ones those lives they deserve, as current public and private autism efforts focus disproportionately on theoretical unborn autistic people, rather than investing in best support practices for existing autistic people like my son. Per the

IACC’s own analyses, autism research funding is primarily funneled into risk factors and biology with less than 10 percent prioritizing lifespan issues and services. I do not understand how this is considered acceptable.

My son and the wider autistic community, deserve to be living their best lives, now. They deserve family, caregivers, and therapists who understand how to help autistic people thrive, now. They deserve access to well-trained and paid educators and support workers, now. They deserve medical professionals versed in best practices for treating autistic people, now. In one year, my son and his peers will age out of the school system, yet no existing federal, state, or local framework exists to transition to or support them in fulfilling and dignified lives as adults. We need those frameworks, now.

Even so, my family is lucky. We have decent autism services in our area, and we have the language, know-how, and socioeconomic advantages needed to access those services. At the same time, we all know that less-advantaged autistic people and their families are missing out on services, partially or entirely, as are autistic people perceived as lower support than my son, yet who still requires significant accommodations. This is unconscionable.

Finally, we need to formally recognize that autism issues must have autistic guidance. My son’s quality of life improved dramatically once we all had access to autistic insights on supporting autistic people, and every autistic child and adult in this country deserves the same opportunities and benefits. I applaud the IACC for seating more autistic members and hope autistic priorities will have a proportional influence on the IACC’s outlook and directions. Thank you for listening.

DR. DANIELS: Thank you, Shannon. And thank you to all our virtual commenters for taking the time to be here and share your thoughts. We also have people that sent in written comments. I would like to take a moment to just acknowledge those comments. I believe that you can see my screen.

We had several written comments that came in. You can find the full text of these comments on the IACC website under the meeting materials for this meeting. I am not going to go through reading off every single name as it is a long list of names. You can see them here and you can read the actual comments.

We received comments on a number of topics, including program supports and housing options for autistic individuals with high support needs. There were a number of commenters that commented on that.

Another group of comments that were generally about concern about medical practices and potential causes of autism.

There was another group of comments about the role of the IACC and the Federal Government.

We had some comments on service needs, resources, and policy implications, the needs of the direct support professional workforce individuals, the treatment of autistic individuals in medical settings, services and supports for adults with autism or on the autism spectrum, and comments for the IACC Strategic Plan update. I will refer you to the actual whole text comments and I know that the committee received those in advance and has had a chance to read them so will be prepared to respond.

In addition, we have a packet of comments that are about concern about the use of graduated electronic decelerators or GED devices. We talked about this a little bit at the last meeting, but this is the full list of all the commenters that sent in comments about this topic and the full text is available on our website and we also welcome people to discuss that if you would like.

At this time, we have some time now for the committee to have some discussion about all the public comments received.

DR. GORDON: Thank you, Susan, for overseeing the comments. Thank you very much to our oral commenters for coming to us today and presenting your comments to us directly.

Are there questions or comments or follow up from any members of the IACC? Tiffany Farchione.

DR. TIFFANY FARCHIONE: Susan had actually asked me to follow up with FDA about the electronic stimulation device issue. I did check with our litigator. Just as an overview, the FDA had banned the use of these devices and then the ban was overturned by the DC Circuit. But it was just the three-judge panel at the DC Circuit and two of those three judges voted to strike down the ban. Now, the FDA has appealed that decision. FDA and DOJ, actually, have appealed that decision. It is now just pending a decision by the full DC Circuit for all 11 judges. That is the current status of that issue.

But I did pass the entire list of comments, the whole document to our team of lawyers so that they are aware of all of that information and everyone’s concerns.

DR. GORDON: Thank you for the update, Tiffany. I really appreciate it.

Dena and then Alycia.

MS. DENA GASSNER: Good afternoon, everybody. It is so nice to be here. Can you hear me? New headphones. I cannot even hear myself. Sorry.

I just wanted to address some of the things that came in. I want to thank everybody for their comments truly. Dr. Robertiello. I should know how to do that. My husband is Italian. I just so appreciate your comments and I just want to express that for your comment and so many others. I am very sensitized to the needs of high-support needs individuals. I think most of us are. All of us are. We seek to be at least. It is just important for us as a committee and for us as a community to remember that not all high support needs issues are subjectively observable. Not everybody can see them. When it comes to looking for housing, mental health services, safety training, better interventions to prolong and enhance the quality of life for autistic individuals. I just think it is so important that we stand as a unified body on these points and recognize that together we can do more.

I wanted to mention to Peggy Kilty, who submitted a comment about IEP. If you reach out to IACC, they will put you in touch with me. I think I can help you with some things.

I just wanted to point out that while we continue to hear how one side of the community is leaving out people with high-support needs, I point out the ASAN testimony today whereby over three-quarters of it was focused on exactly that population. We need to really come together as a community. I just cannot express that any stronger.

In terms of safety needs going back to our early presentation and then what we have heard from today, I have not heard much about training autistic individuals to be safe in the community. Obviously, there are no guarantees. But all of these programs really need to invest in equal amount of time on not only hearing from autistic people about safety needs, but also educating autistic people on how to be safe in the community.

We did hear from one of our members about informing parents. But many autistic individuals have never had an opportunity to learn functional skills because they have been in academics. Many times their functional skill set is substantially lower because we have not given them any instructions. I just wanted to emphasize that. Thanks so much.

DR. GORDON: Thank you, Dena.

Alycia.

DR. ALYCIA HALLADAY: Hi there. Thank you for allowing me a chance to comment. I want to echo the fact that there were two amazing presentations about safety today and at least one if not more public comments about safety. I think that this might be a topic that the IACC needs to further address beyond incorporating what other people have said and what has been done with Kevin and Avonte’s Law has been absolutely miraculous, but I think there is more that could be done and we should continue that discussion.

I want to also point out a couple of comments that were not on the oral comments. They were on the written comments, but there was more than two of them that have to do with the urgent need of families who have individuals in their family who are desperately seeking help because they end up in a hospital environment. There is really no hospital type environment or there are very few of them that can help people with autism. I know that there are a lot of projects to help train hospital personnel. But we are really talking about crisis care situations.

There have been some pilot programs across the United States to help those with severe mental health needs. I do not think they have been piloted with autism yet. But this is an issue that continually comes through Autism Science Foundation. I am seeing it on the written comments that we ought to maybe think about having further discussion about crisis situations and how to handle crisis situations and what needs to be done to manage them.

DR. GORDON: Thank you, Alycia.

I have Ivanova next and then Morenike.

MS. IVANOVA SMITH: This is Ivanova Smith. I just am very passionate about making sure that autistics who like to explore that they get support to get to explore. I think it would be really cool if these programs funded nature walks or things or ways that people can get support to explore in their community, get swimming lessons so that they can swim in water safely. My parents made me get swimming lessons after they adopted me from that institution. It took a couple of years for me to learn it, but I eventually learned how to swim. It has made my life so much better because I am able to be safe in water and I even got to do Special Olympics because I did swimming. If people with intellectual disabilities cannot swim, we just need to be given the proper support to learn how to be safe in water and explore our communities.

Many of us love to go hiking and like to go on adventures in the woods and nature and explore things in nature. We should get support to do those things. That is what I would love research in and supporting us and doing those things safely in our communities in a way that makes us happy.

I also am very passionate about not using these GED devices on autistic people that cause pain. We have experience pain just like anyone else - putting us in pain to make us do certain behaviors is cruel and unusual punishment, which is in the Constitution. So I encourage that we support the FDA in supporting the ending of those devices on autistic people because they cause us much pain. Thank you very much.

DR. GORDON: Thank you, Ivanova, for that perspective. I very appreciate it. It is very important that we hear it.

Next, I am going to read a comment from Morenike. Morenike, if you wish to make the comment yourself, please unmute and go ahead and do so. “Thank you for your poignant message.” I believe this is in reference to the first commenter. “Thank you for your poignant message and for emphasizing the importance of accurate safety data. In theory, I agree with much of what you shared.

In actuality, I could not ethically advise most individuals or families I am acquainted with to report the frequency of these events. Disabled families bear a disproportionate burden with regard to involvement with child protective services. Why would we voluntarily give more ammunition to those who are already convinced that we are uncapable of managing our households? That would be like a stream of blood in a body of water filled with hungry sharks. Until there is better integration of equitable services and practices of what practical benefit would reporting these incidents be to an autistic parent and/or a non-autistic parent or caregiver of an individual on the spectrum.” Thank you, Morenike, for the comment.

Lindsey and then Sam and then Scott and then Jenny and then Judith. That is who I have across the top. We have time, I think, to get to all of them. Lindsey, go ahead.

DR. LINDSEY NEBEKER: Thank you. I had to pre-write this because otherwise I lose track. But I wanted to provide some remarks in response to the written comments, a combination of oral and the written comments that had been presented to us for this meeting as well as part of the past full committee meeting.

I had gone back and forth on whether to even mention anything about this. And I will be very honest with you. I am somewhat hesitant and nervous, but I think it still needs to be addressed.

One of the themes that had really popped up with me when I was going through all of the public comments is the unfortunate reality of toxicity and division that exists within our own community. I just want to echo the point with my own observations as a committee member and a brief message for outside audience in the community who maybe frustrated or upset that they are not feeling heard.

Since my first time attending an IACC Full Committee Meeting 11 years ago, I have presented oral comments and repeatedly emphasized the importance of increasing support of access to communication in non-speaking autistic people, which affects at least a third of autistics, a point that Julia Bascom mentioned in her oral comments today.

I want to kindly remind our audience who maybe turning into meetings about a couple of things that need clarified as I was reading the comments. An appointment to a federal committee is a voluntary commitment. We do not receive a paycheck for our time and expertise in serving this appointment. My colleagues and I are here because of the well-being of autistics and their families of all support needs, and it is that important to us.

While I cannot speak for the experiences of my other autistic colleagues who are currently serving or have served in the past, I know that my ability to perform effectively in this work gets difficult when I receive hurtful comments and attacks from people and they do not believe I understand the importance of validating autistics with complex or high-support needs.

I know I am not the only one who has experienced this. This is not about identifying or pointing fingers because when you get down to the core, the who is not relevant. But on behalf of the autistic members of our committee, I would like to kindly ask each of you to please take a moment to learn more about a person’s story before you make your judgment. I understand life can be chaotic and conflicting especially for a community. I can appreciate how much more convenient and easier it can be to develop our own conclusions and express our anger than the additional time it can take to learn about a person’s background or family story involving autism especially if you are not feeling heard. But it is really important to learn about other people.

For example, if you had taken some time to understand my own background, you would have known that I also have an autistic brother with co-existing intellectual disabilities who is non-speaking, does not use AAC, has lived in a group home since he was 16 years old and to whom I have dedicated a lot of my childhood towards helping my parents take care of his needs with love and patience and scars to prove it. You would know at times our experiences growing involved some traumatizing incidents for my family as well as for my brother. He is a significant motivator of my advocacy efforts to ensure the happiness and safety of all autistics, including autistics with high-support needs.

I am mindful that even though I am autistic myself, I am in a position of privilege. I can appreciate and understand why one would be quick to judge and assume my lack of understanding of the diversity of needs of autistic individuals based on my appearance and speech.

Just keep in mind by saying that I or some of my colleagues in our committee have “never seen a truly autistic person” or “hijacked a diagnosis and made an expletive out of it” or “have no idea what it is”, not only are you personally offending me. You are also invalidating the existence of my own brother, one of the most important people of my life. You are doing the very thing you are afraid we are doing to you and your loved ones. We may have our differences and our experiences and our opinions. But I think it is safe to say we are all in agreement that none of us or our loved ones want to feel invalidated. Please open to your heart to the possibility that we as committee members are here to support you and every person on the autism spectrum. And we are all continuing to learn together. That is all I have to say at this time.

DR. GORDON: Thank you, Lindsey. And I appreciate that. That must have been very difficult for you to say it, but I appreciate you saying it.

Sam, I believe you are next and Scott, Jenny, and Judith.

MS. SAMANTHA CRANE: Hello everyone. I actually wanted especially since we are still talking about safety and I wanted to connect it back to some of the discussion that unfortunately got cut a bit short.

One of the things I was really hoping to say and I would love to be able to contact the presenter as well to give her this feedback. I really appreciated the effort that was being made to connect with a lot of different stakeholders on tracking devices for the Avonte’s Law workgroup. But that absolutely has to include autistic people themselves in the workgroup. I did not hear them being mentioned.

In particular, we have a lot of people in our membership who have been labeled with wandering behaviors in the past. Hearing from them about what kinds of interventions hurt, help, and how to safeguard their rights while trying to ensure safety would be really helpful. It is one unfortunate issue that we are running into is that a lot of these tracking devices are being marketed by private companies and absolutely anyone can buy them and use them to track the location of another person who might not be consenting. There is really quite a lot of opportunity for abuse and misuse of these devices. We really want to make sure that that is heard when we are making federal standards for how they are used but with privately and by law enforcement.

DR. GORDON: I believe we still have the speakers from earlier with us. Could you respond? I would appreciate actually a response in two things. Number one, Sam’s direct question regarding whether individuals on the spectrum are included in the advisory groups as you consider what to do forward. And then, second, also I think clarifying some about what roles that you have with regard to missing children versus missing adults.

Joy, I just saw you pop up. I do not know if you want to comment with regard to either of those two issues.

MS. PALUSKA: Sure. Of course, as an organization, our focus is on missing children. There are certain times where we are able to provide assistance to folks who are under the age of 21, particularly if we are working with law enforcement and there is a child missing from care.

I will also just say from an organizational standpoint, we do not – I will say this. Our focus is on the proactive approaches that we can utilize in non-tracking situations just because from what we have learned as an organization and we are still learners is we do not want to track to a death of a child. We consider it a tool in the toolbox that is available, but something that is last resort. And also, I know Kristie will probably speak to some of this. A lot of learning that we have done as an organization is everything that Sam just described. From the NCMEC perspective, we are focused on other ways that we can prevent missing incidents and address missing incidents, but definitely --

MS. CRANE: I also want to clarify because as a low – generally, people on these taskforces might be adults. I want them to be able to also speak to their experiences as children when they were labeled with wandering. There can certainly be situations where these trackers can be used abusively even if they are being used on children rather than adults, for example, when there is a contested custody situation, when it is used to listen in on a private conversation of a teenager, et cetera.

DS. GORDON: Fair enough. Kristie, I wonder if you might respond. Go ahead.

MS. BRACKENS: As far as the working group that we had, the Locative Technology Working Group that we just had, I would say unfortunately no, we did not have that perspective. That was one of the key takeaways that came out of that discussion was that we need to make sure that we are including the perspective of folks, as you mentioned.

As we think about the convening, the bigger convening that is going to be sponsored by NIJ in spring of 2022, I think that is where we can make sure that we have that perspective of folks with autism, childhood experiences with autism with lived experiences. We can make sure that we have those folks represented when we have that bigger discussion in 2022.

I think also as we look at ways like every year, we put funding out under the Kevin and Avonte’s program. I have an opportunity to rewrite the solicitation for funding and add things to the solicitation for funding. Just listening in on the discussion that you all have been having, I am already thinking of ways that maybe we could enhance the work of what we are putting in those categories that people can apply for funding for. I really like the idea of swim classes as something, doing more proactive things, things that we can apply funding for.

I think that we look to the organizations that we fund under category one under some of the proactive prevention programming. We hope that they have that diverse perspective amongst their board members and the folks that they are working through and their organization. But I think we can be more intentional in our wording in how we put things out there to make sure that we are getting that voice. Unfortunately, I do not think we have been that intentional when it comes to making sure that we are having the voice of people with those lived experiences represented.

DR. GORDON: Thank you, Kristie.

Scott.

DR. SCOTT ROBERTSON: Thank you, Dr. Gordon. I appreciate the comments that were shared both in terms of written public comments and oral ones. I first also want to emphasize my appreciation for my federal colleagues over at FDA. I know they are limited in what they can say because of the legal process. But I appreciate the work that they went through to adopt in terms of the rulemaking regulation process to try to restrict devices that are harmful to folks in causing that I would argue as a human rights violation in terms of the electric shock with that. I hope they understand that we have the appreciation in the rest of the Federal Government. I am sure folks outside of the government are appreciative of their continuing work in this court case to try to improve the outcome here in terms of vetting those devices.

I would also say that – I also appreciate some of these comments and discussions on full access to communication and supporting the broader focuses with the health and safety to make sure that autistic people have – that our perspective is included in – and that includes mentioning some of these things like water safety skill development for swimming skills because I think sometimes it is not mentioned as much as it should that I think if we had funding for that, we would have fewer folks who are drowning. I think that is not just autistic people. I think that we need to do a better – health and safety – like the water safety skills that folks may know that there are folks from diverse and underrepresented racial and ethnic minority groups are often less likely to learn swimming and water safety skills in the United States and some other countries. It is a large problem historically as far as the issues there that I think we could do a better job of promoting areas of health and wellness in those focuses for autism, but also for broader lived experience.

And then also, I appreciate some of the comments that were mentioned as far as the American Indian population, as far as the disparities that are there. I will defer a lot of that to our colleagues over at HHS as far as Indian Health Service. Obviously, that is their jurisdiction. I take in mind a lot on that linguistic and cultural competence that I think we have to do a lot better job in that area.

I think that in supporting access for folks from diverse and underrepresented population groups in autism and other developmental disabilities. I think that is part of our charge here in the Federal Government with diversity, equity, inclusion, and accessibility is it aligns very much with the priorities that we have right now under the current administration. I am very glad that folks are emphasizing that and emphasizing the supports that real families need right now and individuals need right now where there are continuing barriers. I think we can do better as far as research and enhancement of supports and services, again, to improve quality of life and access and opportunity and make sure that the voice of autistic people and family members is well integrated into these conversations in all these areas that we are talking about. These are real people’s lives and I think we should never lose sight of that on the committee that I think sometimes especially with the focus is on research that folks forget about there are real challenges that folks are living on a real regular day-to-day basis and sometimes their voices are not being heard and they are not being focused as much in terms of research and practices and services and supports. I think that gives it a lot of opportunity I think for us to inform what the committee I think is going to do as far as with the strategic plan in terms of heeding a lot of these focuses and making sure there is coverage of that in the plan itself. Thanks.

DR. GORDON: Thank you, Scott. We have a number of folks more who want to comment. I think we have a little bit more time, but I am going to ask each of you to keep your remarks brief so that we can give everybody a chance.

Jenny.

DR. JENNY MAI PHAN: Thank you, Dr. Gordon, and also to our two speakers as well, as our public comments that came in.

I will be brief. I just want to echo some of the points that Scott brought up about swimming being an important focus because of drowning incidences in autistic individuals.

But I want to also briefly mention in case any of the public listeners or viewers did not catch the first meeting that we had back earlier in the summer is that I am also a parent to two autistic children who cannot swim. I sought community help to find instructors who are trained to work with autistic children. It was very difficult to find any swim instructors who can work specifically with my children’s needs. I ended up teaching my children how to swim myself. I cannot swim. But I have learned the techniques of swimming enough so that I can teach my children and because I am their parent, I know their needs and I know what their likes and dislikes are.

A lot of these concerns within families do fall heavily on caregivers and parents. I know much of the conversations have been centered on autistic individuals as well as research being focused on autistic individuals. But I also want to I guess add a plug to remember family members and caregiver support being a high priority because a lot of these needs do fall on family members, specifically for autistic family members and caregivers, who they themselves need support and they are not getting their own support as well as support for their children. There are, as we know, disproportionate number of racial minority families who are not getting these services. I do appreciate Scott's comment about making that a priority. Broadening what we mean when we see DEI, what does diversity actually mean and to well define that as well.

I bring in the example of non-Native English-speaking families so bilingual families who may not understand English, but services that may be available to them are mostly in English and they need translators to help understand what these services are actually doing for them and their children. I will leave my comment there. Thank you.

DR. GORDON: Thank you very much.

Judith Cooper.

DR. JUDITH COOPER: Good afternoon, everyone. I and my institute director, Deb Tucci, are both here on the committee. We are with the National Institute of Deafness and Other Communication Disorders. I just want to point out two things related to some of the comments that we heard today about communication and challenges for some individuals on the spectrum.

First, we do have a program on augmentative and alternative communication. And NIDCD has been, I think, a leader over the past five to ten years, encouraging research on minimally verbal individuals with autism. We do have a number of projects that focus on that.

I just would encourage – we were listening very carefully to the comments that we heard, and we want to continue that dialogue. If you have other comments, those of you who spoke on this issue and the importance of it, if you would send those comments to Susan Daniels and she can send them on to Dr. Tucci and I. We can share those with the staff and figure out perhaps next steps. Thank you.

DR. GORDON: Thank you, Judith. I will just point out that as we think about some of the comments regarding what we are or are not doing from a research perspective, what we are or not investing from a care perspective as well, when we think about the balance of where things should be, I think it will be important for this committee to become acquainted with the actual data and the portfolio that we actually have at the NIH and elsewhere both from a research perspective and a care perspective. I think there were numerous inaccuracies in many of the public comments and also numerous excellent points. We will want to make sure the committee is appraised as we move along with our strategic planning process of what actually is going on.

We are just about out of time. There are three more people who would like to comment. I going to go ahead and restrict it to those three so Ivanova, Joy, and Morenike. And then we will move on to the next program. I apologize to those who are waiting. I know we were supposed to start at three. We will probably get started at about ten after is my guess. Ivanova.

MS. SMITH: This is Ivanova Smith. I just want to say I was institutionalized for five and a half years of my life. I was non-speaking. I did not understand many things. I did not understand even my own name. It was not until I was started to be taught things and that people really did one-on-one support with me that I started to learn things and I started to gain abilities in being able to be in my community. It is because people did not think that I could not learn. This idea that people with intellectual disabilities cannot learn is a very dangerous idea and it leads to us being harmed. I think it is important to autistics with intellectual disabilities that we get the support to learn. And we need to get teachers equipped. We need to help parents teach their children that we grow just like anyone else. We should be given a chance and the dignity of risk to learn how to swim, to learn how to cross the street. If we need support, if we need one-on-one support to cross the street, we should be given that support to cross the street. We shouldn’t be shut away in an institution just because we are struggling to learn something.

I struggled to read and the school said you will never learn how to read. But my mother, she said no, I will not believe that and my mother sat in the hallway with me every day in the school and taught me to read, to use sign language, to use visuals. She used a different method that the teachers did not use. I learned how to read. It made it so I could have access to academic courses. But that is not fair for people who can’t learn to read to not be given that access and to be denied that access to have to fight to be able to have access that anybody else wants. It is not right.

Just because of an IQ score, we need to stop that and we need to look at people as human beings who want to learn and we need to make sure that everyone has the right to learn and that we all have the right to grow up. We are not mentally children. Autistics with intellectual disabilities are not mentally children. We grow up just like everyone else and we need to learn how to be safe and we need to learn what – if we want to have one of these devices, the GPS devices, we should be taught informed consent. We should be told about what the device does and what we want it to do and what we do not want it to do. And if we want to go explore a community, we should just have somebody help us and support us in the community to explore. If I want to go on a walk near a river, but I need support, have somebody go with me and help me explore. Do not just take away that right for me to explore. That is sad. That does not help an autistic person feel like they are valuable or allowed in their community. We should all be allowed in our community. If we need extra support for that then we should be given it because that is our constitutional right. Thank you.

DR. GORDON: Thank you, Ivanova. I appreciate the comment and I appreciate your passion.

Joy.

MS. PALUSKA: Thank you. There are so many wonderful folks and advocates on here. I am honored to be here. Since so many folks mentioned the swimming lessons, please forgive me. My focus was definitely today on the online safety, but this is definitely an issue that we are going to be talking about with our parents. I want to raise the fact that the Y has done incredible work in terms of inclusive swimming lessons, so that is something that we are going to be highlighting in the presentation. And I love Kristie because she hears different things and thinks about ways that we can raise money and funds. So I think that is definitely something where we can hopefully continue to partner and address that issue because both things, not just for safety, but for the resiliency for folks that Scott talked about. I just wanted to thank everyone for bringing that up. We will continue to advocate for that.

Also, I know I reached out to Dr. Pearce to connect with Crystal, but definitely I want to do more work in that area of our outreach in Native American and indigenous communities. We have a tribal fellowship that is out there. Hopefully, Crystal, if we are able to connect and other folks. Anyone who is able to, please I want to connect with you after this call. Thanks for raising all those issues.

DR. GORDON: Thank you, Joy.

And for the final comment I have a comment to read again from Morenike. I am going to read it word for word. “I am not really certain how to communicate this in a sensitive manner, but I will try. Can you share the mechanisms that are used to distinguish a potential trafficking victim from an individual who might be engaged in consensual sex work and/or transactional sex of their own volition? For a variety of reasons for a sizeable proportion of the autistic community, the adult and sex industry might be a means of survival in a world where there are not a great deal of viable employment and/or financial options accessible. This is especially so for gender-diverse, or queer autistic individuals as well as for those with other intersectional marginalizations.”

I do not know if Kristie or Joy care to comment about either of those points that Morenike raises.

MS. PALUSKA: I will just answer from the NCMEC perspective. I just want to be really clear. I am not in the exploited children division. I do not want to answer on behalf of my colleagues who are experts and would make those determinations.

But I would really encourage you to email me so that I can get you connected with the right folks so that we get the right answers and information and also the feedback that you are sharing so that we can inform our own program.

DR. GORDON: Commercial sex work, not consensual sex work. I read the abbreviation wrong. Thank you, Morenike, for that. And I saw Morenike give a thumbs up when you indicated that she should contact you and you can connect with the people in your organization.

I think that will have to do for the comments on the public comments. I am going to turn it right back over to Susan.

DR. DANIELS: Sure and I would like to make a brief comment as well just regarding all these comments on swimming lessons. I would be happy to connect Joy and Kristie with the CDC program on water safety. They do have a program. I was inquiring with CDC and they said they do not necessarily work on autism, but maybe we can bring them into that conversation to help too.

DR. GORDON: Okay. Given the lateness of the hour, we were scheduled to start the next session at 3 o’clock. We were scheduled to have a five-minute break. I think what we should do is move right into that session, but acknowledge that people might need a few minutes for biology or for mental health. If you need to do so, take it now. You will miss some of the introduction or take it whenever you need it during the next hour.

It is my pleasure to introduce this next session on the National Autism Indicators Report particularly with regard to mental health. We will be hearing from Dr. Lindsay Shea and Jessica Rast, both from Drexel University, followed by Teal Benevides from Augusta University and Stephen Shore from Adelphi University. Dr. Shea is the director of the Policy and Analytic Center at the AJ Drexel Autism Institute at Drexel University. Jessica Rast is a research associate in that Autism Institute also at Drexel. They will be speaking first. And then Teal Benevides is an associate professor at Augusta University in Georgia. Stephen Shore is assistant professor of Special Education at Adelphi University in

New York. I forgot to mention that Drexel is in Pennsylvania.

Dr. Shea, please begin.

DR. LINDSAY SHEA: I am actually going to pass to my colleague, Jessica, for our first slide.

MS. JESSICA RAST: I am Jessica. I am very happy to be here. You just gave a great overview of our title slide. I do not really need to repeat much, but I will tell you our title, Priorities and Potential for Autism and Mental Health Research. And, hopefully, by the time we make it to the end, you will agree with our title.

I will start with a quick introduction to who I am. Thank you for that introduction before so I do not need to repeat. I work at Drexel and the AJ Drexel Autism Institute in the Life Course Outcomes Research Program. I will spend my introductory few seconds to assert that mental health is a vital component of health and following mental health care is an integral part of health care for all people.

DR. SHEA: Thanks Jessica. Thank you to the IACC for having all of us in for the focus on this important issue. We appreciate the time and attention to walk through our research and to have a discussion as well.

I am here today because I am in part the director of the Policy and Analytics Center. And the goal of the Policy and Analytics Center is to seek to understand how the health care system can improve access and services for autistic individuals. That is driven by service experiences among autistic individuals across the experiences that they have, the types of services they use, and how we can best support the professionals who deliver those services. And by taking a whole health care system look, we are able to really emphasize and strengthen the public health impact of our research.

The report you are going to hear about today was first authored by Jessica Rast and is one product from a funded initiative that we have through HRSA, which is the Autism Transitions Research Project. We have several components of ATRP as we affectionately call it. One of those initiatives is also the Transition Odyssey, which is a qualitative effort to understand how that transition into adulthood looks among a diverse group of adolescents as they age.

Why did we do a report focused on mental health? We believe strongly and have seen initial data that indicated that mental health matters in transitions. Transitions set the tone for what happens next in life and by addressing, understanding the needs of individuals through those transitions, we are more readily prepared to support what they may need as life continues on.

We know that mental health matters in systems because often systems address certain sets of symptoms or address certain diagnoses. And by understanding how the data emerge from those systems, we are more ready to help provide input or support those systems in changing to meet the needs of autistic individuals.

We also know that mental health matters in families. Families are impacted and often seek to support their family members.

Mental health diagnoses are also very common in the general population, but even more common among individuals living on the autism spectrum. Understanding mental health among this group and using large data sources, again, helps us to think back to the services that may be needed and ensure work to ensure access.

And we also know that care is complex. When individuals may have multiple diagnoses, multiple needs, multiple types of needs, or ways that they can be supported to meet their own goals per the discussion that we just heard. We need to be able to understand those needs and drive toward the delivery of the services to meet them where they are.

Jessica, I will hand it back to you.

MS. RAST: Today, I want to talk to you a little bit about our most recently produced National Autism Indicators Report, which is to focus on mental health and mental health care. The purpose of our report was to catalog indicators of mental health and mental health care, to highlight areas of needed improvement and practice and in policy.

This report is a direct follow up to one of our previous reports that came out. I guess it has been a little over a year now that was focusing on health and health care. In that report, we found that autistic children specifically had high rates of many mental health conditions and were more likely to see a mental health provider and to use psychotropic medication than their peers with other special health care needs.

We also found that while autistic children had health insurance, almost all of them had health insurance. Fewer than half the parents reported that it covered all the services they needed for mental health. Again, mental health is an integral part of health care and well-being.

The study of mental health is relatively recent in this area in autistic people. But we start from the idea that autism is not a mental health condition. And then we go on to examine why higher rates of mental health might be present in autistic people from both genetic and social origins. We know that parents of autistic people have higher rates of anxiety and of depression than their peers. But we also know that experiences of adversity, isolation, and stigma may place autistic people at an increased risk for mental health concerns.

There is also some emerging evidence that camouflaging that some autistic people use to blend into social situations is associated with increased depression and anxiety in autistic adults.

And then there has been some research into heightened intolerance of uncertainty linked to increased anxiety in both autistic and non-autistic people. And increasingly, clinicians are noting that stigma and lack of understanding of accommodations and access to services are contributing to mental health difficulties.

Then we have a little information about mental health services, which is the other part of the equation. Supporting mental health requires accessible and appropriate care. Providers in the US - primary care providers play a key role in identifying and managing mental health needs. They are often the first point of contact for most people to the medical system. They are well positioned to have a holistic picture of patients and identifying emerging concerns. But they are often not experts and have expertise in mental health care directly especially as needs are complex.

But on the other side, we know that many mental health care providers are inadequately prepared to care for autistic patients. One study found that half of mental health clinicians had no experience working with autistic adults and mental health providers may lack understanding of autism in general and how autistic people experience and communicate specifically in regard to mental health issues. Further, they may hold biased assumptions that autistic people cannot make meaningful progress in improving their mental health.

We have talked about this. I have heard a few comments about this already as I have been listening in today. We know that black and Latino autistic people experience additional barriers that result in late diagnosis and missed diagnosis of mental health concerns due to clinician bias and structural barriers and the historical context of health care in the US. And then in general, some other barriers to care include fragmentation of service systems, high cost, and stigma.

Here is the data that we use for this particular report. For children, we use two national surveys to look at mental health care and services and experiences. And then we also looked at a national source of hospital and patient stays as well as Medicaid records for people enrolled in Medicaid.

And then for adults, we looked at two of the same samples. We have this hospital sample and then we also use Medicaid files. In addition, we used a sample of adults that receive – that are insured by Kaiser Permanente Northern California. This was some previously published research from some of our colleagues that use that data.

I include this because it is important methodologically to understand how we make our conclusions, but also because one of the things I really like to point out is that we have a lot less information about mental health or really much of anything for autistic adults at the national level. This is a really strong data advocacy argument. I like to point this out of the limitations of what we have available to us.

And then also, I would like to say that we are using this combination of data to try to build an emerging picture of mental health across the life course in any way that we can. This is the way we went about that.

First, I will share some results about conditions. The most common co-occurring condition, mental health conditions in children were behavior and conduct problems, ADHD, and anxiety. And these things did vary by race and ethnicity, which is the reference showing here.

I would like to highlight a few things about this graph. I know there are a lot of numbers on here, but the first thing I want to point out is anxiety. Anxiety was more commonly reported by parents of white autistic children than it was for any other children of any other race or ethnicity. About half of parents reported this compared to about a third of parents of children of another race or ethnicity.

And then the other thing that I would like to point out is the relatively low rate of parents endorsing these conditions when they had Hispanic autistic children. About two-thirds – I say relatively low because it is still a pretty high proportion. Two-thirds of parents of autistic children who are Hispanic had one of these conditions or more compared to 73 or 80 percent of children of another ethnicity.

And then here is some information we have about adults. We know that - this is from Medicaid, so adults enrolled in Medicaid. About a quarter have any one of these top four bars here so anxiety, bipolar, ADHD, and depression.

And nearly all of these conditions were more common in autistic adults than in adults with an intellecutal disability and no autism with the - depression was the exception here. But all of these conditions, all seven of them, are more common in autistic adults than in adults in the general sample population without autism or intellectual disability.

And then we also had the opportunity to examine some components of mental health risk. Here, we are looking at adverse childhood experiences or abbreviated as ACE or ACEs. These are experiences that happen during childhood that carry with them an increased risk of mental health impacts later in life.

Just over half of autistic children experience at least one ACE, which was similar to other children with special health care needs, but about 20 percent higher than children with no special health care needs. And approximately 12 percent of autistic children experienced at least four ACEs.

The most common ACE for autistic children was difficulty covering basics like food and housing on the family’s income. And this finding is aligned with some of our previous research from other members of my team that look at funding insecurity in families with autistic children. Some of the potential contributing factors to that are high cost of care and employment uncertainty and burdens. Just to name a few that are related to this work.

And then there are many unmeasured ACEs that are important for autistic children and other adverse experiences that are important for children and adults, including some of the things that I mentioned like discrimination and marginalization, isolation, and potentially, camouflaging.

The management of mental health concerns is important for health, quality of life, safety, and most aspects of life. When primary treatment of mental health is not adequately addressed, these conditions can lead to crisis and crisis level.

We found that nearly half of autistic children receive some sort of treatment or counseling from a mental health professional in the past year compared to about a third of children with other special health care needs and treatment is more common in older children than in younger ones.

But we also found that more than half of parents reported that it was difficult for them to receive this care, which is the graph I am highlighting here. Over half said that they had difficulty getting their mental health care their child needed. This is about an opposite flip of what we see for children with special health care needs and many more than we see with children with no special health care needs where only about a third of parents report this difficulty.

And then these graphs show inpatient hospitalizations for autistic children on the left and autistic adults on the right. I have highlighted in orange the hospitalizations for mental health conditions. This is an important consideration when we look at these conditions that could be adequately treated in outpatient care or even in primary care. We see the most common reason for hospitalization in both children and adults is mood disorders.

For children, we also see disruptive and conduct disorders in the top ten list as well as schizophrenia. And then for adults, we see mood disorders as number one and schizophrenia as number two. I just really quickly will point out that we do notice differences in race by the most common reason for hospitalization where schizophrenia is more likely to be the primary reason for hospitalization in black children and in black adults than it is for white children and Hispanic children.

As we just saw, mental health conditions are common. When we think about how to address these concerns for people, we know that psychotropic medication is an important consideration in condition management and ideally, it should be a part of a more holistic management plan that includes psychosocial interventions and trauma-informed care principles.

Psychotropic medication was common in autistic children where half of children took some sort of psychotropic medication in the past year and that use varied by co-occurring conditions. That is what I am showing in this graphic here.

Children with depression and autism were the most likely to use the psychotropic medication so 79 percent used the medication in the past year. And then we see decreases from there.

And then we do know a little bit about adults from the Kaiser Permanente Northern California results. We see here that about two-thirds of autistic adults use the psychotropic medication and that was more than their peers with ADHD or a sample of the general population without either of those conditions.

We know that with the right support, people with mental health challenges can improve their lives and become more resilient as a result of their experiences. We also know that mental health providers can support people in connecting with developmentally appropriate activities, which could be things like playing sports or organized activities. It could be more engagement in the community. It could be community service or employment, all these sorts of things.

We also know that participating in these types of activities has a positive impact on people’s health and well-being so a positive cycle here.

In this graph, we are examining the relationship between the receipt of mental health care and the involvement of these activities for – this is for autistic youth ages 12 through 17. We found that autistic youth who receive all the mental health care that they need or that their parent reports that they need are the most likely to participate in these three activities. The first bar here is children who have received all the care that their parent recorded they needed.

The second bar highlights those who did not receive any care and also did not report needing any more care. And even these youth are less likely to be engaged in some of these activities than youth who receive all the care they need. And then the bottom row is those who have an unmet need for mental health care. These findings may suggest that those who receive all the care they need are having more support to participate in their community.

To wrap up some of these findings, we saw the need for mental health services and supports are critical in autistic people. And addressing the needs of the population often requires changes to policies that impact access, provider training, and resources. Changes in these policies can impact what is covered, who is covered, where, and how.

I am going to end with a few recommendations that we made based on this work. The first is to make care more equitable, which I am happy to hear something that has been coming up on the call today. I am going to talk about this in the context of two groups. First, racialized communities. We know that there has been a historic dis-investment in non-white communities and their health care, and this has resulted in unequal access to care, unknown and unequal treatment effectiveness and lower treatment relevance in these communities.

Another point that I want to take the time to make is that the mental health workforce is disproportionately white, which makes receiving care from same-race provider difficult for people who are not white. And care from same-race providers adds a degree of cultural competence that improves care, which is a really important aspect of care.

The other thing is evidence-based practices. We know that autistic people are underrepresented in mental health research. Recent review of – well, it was not too recent now, but a review of 300 clinical trials found that people with intellectual and developmental disabilities were represented in only 2 percent of trials and these trials are how we build an evidence base for these evidence-based practices. We also know that racialized groups are underrepresented in mental health research as well.

But I do want to mention that some therapeutic approaches are proving at least somewhat effective in autistic people. But approaches to care may need to be different in different populations. And research into practices in diverse populations is something that is really necessary. Engagement across autistic stakeholders continues to be needed to inform these funding policy priorities.

Second is the problems of location. Many people access care through either their primary care provider or through referrals from their primary physician. But primary physicians often do not have expertise to manage complex mental health concerns especially in their autistic patients.

One potential policy solution is the integration of mental health care into primary care settings, which can improve access for people to high-quality mental health care. This includes – integration includes the co-location of primary care providers and mental health providers in the same place. But it also is a little more detailed and includes integration of medical records, scheduling, billing, care planning, all the aspects of care that are important for comprehensive and continuous care.

Primary care specialists often work in silos from mental health care specialists where everything is separate. Medical records, training, and funding are all separate. And time for coordination of these efforts is often not accounted for in current payment and insurance models.

Another consideration here is that insurance plans sometimes carve out mental health care, which means that those services are contracted through a different insurer that has their own network of providers. And when this is true, primary care providers are not reimbursed for any mental health care or any mental health diagnosis.

And a lot of these barriers can be addressed through policy changes and maximizing incentives to change to this type of model. We can introduce pay-for-performance methods. We can adjust individual payments for care complexity, and we can reward practices that are using these methods.

The next recommendation is to improve systems of care. And the first thing I mean is that systems of care should be connected. People are not responsible for carrying their records, carrying their responsibility from system to system. The service systems isolate in silos, which makes it hard for people to connect. But people are receiving services and care over a lifetime and the service system should follow that to provide whole person and continuous care.

The second thing I will quickly speak about is the mental health crisis care system in the US of which there is not an integrated one. That is a problem that certainly comes up a lot and something that should be addressed.

We need a crisis care system as part of a well-functioning, whole system of mental health care. There are a few organizations out there that has suggestions for the core elements of a crisis system and how to go about creating and implementing those.

And then the last thing I want to talk about is training providers. Training in the intersection of autism and mental health is a consistent need noted by policymakers and advocates and providers. There is a need for increased competence and accommodating autistic patients within practices of all sorts and the need for mental health providers who manage mental health conditions specifically in autistic patients.

And then there is also a need for trauma-informed care – policies are focusing on short-term mental health therapies without adequately addressing the needs of people that have more complex or more trauma-related challenges and particularly relevant in autism.

I am going to – I believe I am going to cut this one short. I have lots to say about training providers. I will move on so I know

I am getting close to time. We can also incentivize provider training in many of the same ways that I discussed and incentivization about integration of care before.

I will hand it over to our presentation partners.

DR. GORDON: Thank you very much, Jessica. And we are going to have questions and discussion that we will hold at the end. Next, we have Drs. Benevides and Shore from Augusta and Adelphi.

DR. TEAL BENEVIDES: Thank you so much, Dr. Gordon and Dr. Daniels and to the entire IACC for your welcome. My name is Teal Benevides. I am an associate professor in the Department of Occupational Therapy at Augusta University in Augusta, Georgia.

I am here to share our mental health priorities to guide research in autism along with my colleague, Dr. Stephen Shore, and colleagues representing our community council in our project Autistic Adults and Other Stakeholders Engage Together.

Dr. Shore.

DR. STEPHEN SHORE: Thank you very much, Dr. Benevides. It is a pleasure to return to the IACC. Having sat on the IACC, I think it was a four-year term. It has been great to see the work that IACC has been doing over that time and continues and now the focus on mental health for autistic people and the meaningful involvement of autistic individuals.

We will flip to the next slide. You have all of the disclosures that you need to read. I will leave that to you to read at a future time.

We will move on to the next slide that emphasizes the fundamental need to involve autistic people in research. What we found is that – and I have always been mystified by this. Why would we spend only 3 percent of the research budget in addressing lifespan issues when the average adult period as an adult is 60 to 70 percent of a person's life? Autistic children and we have heard variations on this grow up to be autistic adults. Autistic adults grow up to be autistic seniors. If we consider the paucity of what is available for autistic adults, just look at what is happening for our senior folks.

We need to ensure that autistic people are driving the process. If you are researching about autistic people, it only makes sense to involve autistic people for reliability and validity. We also found a lot more needs to be done on involving autistic people in setting priorities. There is a little bit of research there including the work that we did with AASET. There needs to be a lot more.

Flipping to the next slide, here is our Community Council. When Dr. Benevides and I first started talking about this project, we both knew that there had to be equal autistic involvement so whether it is the project team where half the people are diagnosed on the autism spectrum or the Community Council, made up of mostly autistic people and other relevant stakeholders such as AANE, GRASP, Autism Society of America, Autism Speaks, the AJ Drexel Autism Institute when Paul was here, AASPIRE, Christina Nicolaidis and Dora Raymaker, so as wide a net as we could cast for relevant stakeholders and diversity in stakeholders, the better off our research will be.

How did we enhance engagement of autistic parties? We did this through our published compensation engagement guide. Here are some of the accommodations that we made so that everybody who was involved had an equal chance of meaningfully and authentically engaging in our work. Just taking a couple of these. One is email. We developed an email template, or I should say we used an email template that minimized words and emphasized action. We have a header, purpose of email. That might be to share the results of the year one meeting, to request feedback on conference summary and we have short summary. Details. What are the specifics that we need people to do in response to this email? Maybe it would be like feedback on year one meeting results.

And then actions. What do you have to do? That way instead of burying action in a long email manifesto that might be hard to read, we get right to the chase. And what that means is that, for example, an email might be written by Dr. Benevides and then I go in and de-manifesto-ize it. And it is also run the other way around. I send emails to Dr. Benevides and she has improved what I have started – in true collaboration. You have to have a deadline. It has to be clear. We have an entire category for that. When is it due? And then the other information that follows that.

Another area of focus was the opportunity to use different interaction modalities depending on need and context. Many people understand that some of us maybe talkies and we can engage using spoken word just like I am doing now like many of us do. There will be others where speaking is just not a primary way to communicate. We have to make accommodations for those who use AAC devices and other means and that also suggests that some people may need more processing time for questions and we need to provide that processing time.

What is also key here is depending on need and context so today I may be the best orator – maybe tomorrow perhaps due to sensory issues resulting from the environment, some sort of anxiety of stress, the spoken word is not working for me and I may need to switch to another type of communication. Every single one of you has done that when you have been in a noisy location where it is too loud to talk on the phone so then you resort to text.

As we move on, other areas that we mentioned in our compensation engagement guide, finances. One thing that is really egregious is when I see conferences paying nice keynote speaker fees to scientists, doctors, and others and then they say we need to be inclusive. We are going to invite an autistic person to speak and give a keynote and they may not even get reimbursed for expenses or paid much less. The way I look at it is equal pay for equal work.

On the next slide, we put a lot of effort into avoiding tokenism, building trust. There is a lot of broken trust between researchers and autistic people.

Now, we also need to be open to change. We thought Facebook was a great idea for capturing priorities. But many community council members were concerned and raised these possible issues. What does that mean? No, we do not jam through doing what we said we were going to do. We make modifications because what is primary, what is supreme is the information and the data we get from autistic people.

Respect. Providing opportunities to do everything that every other researcher does whether it is initial planning, whether it is authoring and co-authoring products, whether it is dissemination of information. Equal opportunities. Equal pay for equal work.

And then finally, we need to have multiple options for support. Often, I have met autistic people who say no, I cannot do it. I do not know what to do. Forget it. I am not coming. If we have a sort of menu, would it be helpful if we have provisions for communicating using an AAC device? Would it be helpful if we found a way to fund your what to most people a mere $12 or $20 to get on the train to get to the meeting and back for a population who is chronically under and unemployed. That is some of the work that we did.

I am now going to turn you over to my colleague, Dr. Benevides, to talk about priority setting for health research.

DR. BENEVIDES: Thank you very much, Dr. Shore, for sharing what we did to authentically engage our autistic research partners in this process. I just want to acknowledge all of our Community Council members for their hard work. And we are sharing this information on behalf of our entire team. It really was a team approach.

What did we do to gather information about priorities that autistic adults felt were valuable? We used a multi-tiered process that happened over a period of two years. We first asked autistic adults who were attending a conference, an autism conference, to join us the day before that large autism conference and work with us to understand gaps in evidence as well as areas that they wanted to see further research on.

In this year one large stakeholder meeting, we used breakout sessions and other keynote talks to allow conversation to occur around ways that we could promote autistic involvement in research and areas that we might want to ask about in future priority setting activities. The year one meeting was composed of primarily autistic adults.

As we proceeded, we worked closely with our Community Council and other members of our stakeholder team to identify methods to engage the autistic community. As Dr. Shore mentioned, we originally were going to use Facebook. But our Community Council noted that there were probable dangers associated with the news of the Cambridge Analytica scandal that was happening around the time of our priority-setting activities.

We, therefore, in collaboration with our Community Council, began to work on an online survey to solicit priorities from autistic adults. We worked hard to ensure that autistic people who were responding to this online survey had opportunities to use non-spoken language to respond as well as visual response options to promote understanding of the questions. We pilot tested the survey questions in collaboration with our Community Council, revised the questions, and then launched the survey.

We also wanted to engage autistic adults who may not have the opportunity to answer online surveys. And we developed focus groups that allowed us to understand experiences of people who were living in rural, suburban, and urban settings. Through these three face-to-face focus groups, we asked similar questions and engaged priority-setting activities.

We finally involved a large number of other stakeholders, including researchers, advocacy organizations, community academic partners as well as autistic adults and caregivers to understand all of the information that we gathered and to help draft and prioritize specific elements of priorities for future research and practice. That meeting happened the day before the AUCD annual meeting and involved a large number of individuals who contributed for which we are very grateful.

I want to take a brief moment to illustrate some of the methods we used to enhance participation of individuals who may not use spoken language to participate in these priority-setting activities. On the survey, we used visual sliding scales such as the one pictured in the top left, which allowed people pictures to respond to the questions.

In focus groups, we also ensured that people using AAC devices and people who may have inconsistent speech had an opportunity to participate. We used index cards as well as movement around a room to use sticky notes to invite participation with the questions and the priority-setting activities.

On the right-hand side, we have images of infographics and white boards in which we invited people to use sticky notes to rate different topic areas that were important to them. These did not require spoken language, nor did they require people to express anything that they felt was important to them. They just needed to move around the room and use sticky notes to indicate their preferences. These approaches were felt to be useful in the people that we talked to in terms of ensuring that everyone had access to the activities.

The results of our priority setting revolved around three areas: mental health interventions and outcomes, which I am going to share with you shortly, as well as access to health care and the needed accommodations to get care. Further, we also learned about gender inequalities in diagnosis, treatment, and sexual health. Those priorities will not be presented, but they also relate to mental health in many ways.

In our survey and focus groups, we had a range of people with different genders. Approximately 23 percent of our sample was male, 59 percent were female, and 18 percent identified as non-binary. We had 4 percent of our sample identifying as Hispanic and approximately 13 percent identifying as non-white. Our demographic questions were at the end of our survey and so we had quite a bit of drop off at this point of the survey.

Moving into our mental health priorities. The top priority that we learned about from autistic adults was what is the impact of trauma on mental health outcomes among autistic individuals. Many people reported experiencing trauma, adverse childhood experiences, post-traumatic stress disorder and wondered what the best indicators or measures of those experiences were for autistic people.

Further, we heard many people ask for evidence-based approaches to help them effectively address the trauma that they experienced across their lifetime. Trauma-informed care came up in nearly every conversation and was often mentioned in our survey.

One respondent from our focus group said I want you to write sexual assault on the white board. Straight up, let us just be real.

Another person on our survey stated, I have bene diagnosed with post-traumatic stress disorder when actually I think the symptoms are due to persistent bullying while I was growing up. The impact of trauma was consistent across nearly every response that we received. This is an important priority to consider for future research and practice.

The next mental health priority focused on the impact that society has on autistic people. This priority reads what is the impact of social isolation, stigma, discrimination and other forms of marginalization on the mental health and well-being of autistic individuals. Autistic people experienced so many forms of isolation, stigma, and discrimination. And they felt that research needed to focus on the impact that society's attitudes have on their mental health and well-being. We heard this yesterday in Dr. James Cusack's presentation from Autistica that one of their areas of focus is on societal attitudes towards autistic people. We found a similar priority.

One example from a respondent stated, part of the issue was stigma. We do not have positive representation of people who have been successful with autism and we need to tell those stories and see that as part of the wellness.

A second person said, I want to see research on how society is trained to include, accept, accommodate, and value our neurodiversity.

And a third person indicated, trying to be normal was a futile waste of time so what does that do to a person’s mental health.

Issues related to camouflaging and masking brought up by Jessica and others weigh in heavily around this idea around social isolation, stigma, and discrimination.

The third mental health priority that we learned about was when, for whom, and under what conditions do self-managed interventions and preferred activities result in improved quality of life and reduced mental health symptoms. Autistic people reported that they wanted evidence on things that they could self-manage without having to go to a gatekeeper or another mental health provider. They wanted access to things within their communities and evidence to support how that could help them improve their own mental health and well-being.

Community available approaches included things such as peer-led approaches, exercise, physical activity, yoga, mindfulness, medication, tai-chi, animal-assisted therapy, and others.

Further, many individuals brought up medical marijuana and other available treatments that they could seek out on their own.

One example from a respondent stated, if interventions are to be employed, they must always be self-motivated. Otherwise, they might as well be someone else’s goals or desires. People wanted evidence that they could use to help them self-manage their own mental health and well-being.

The fourth mental health priority revolved around long and short-term negative side effects or adverse outcomes of currently recommended therapies and interventions. These included outcomes and side effects of social, behavioral, and pharmacological interventions that are being used on autistic people.

One respondent asked, does negative self-image occur due to current childhood therapies.

Again, another person wondered, does long-term use of depression drugs increase the risk of fractures in autistic people.

We heard from Jessica Rast and her colleagues at Drexel that autistic people were significantly more likely to be using psychotropic medications. And this question directly gets at how those side effects and long-term outcomes of currently recommended therapies are being evaluated in autistic people over the long term.

The fifth mental health priority was about outcomes and measuring autistically preferred outcomes. This question wonders, how can we better develop measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults.

One example respondent indicated that we need to measure the interests and priorities of autistic people and those interests should be respected and considered valid even if it does not line up with what "normal" society considers most important.

Autistic people indicated that the outcomes that were currently measured as a result of research were not the things that they felt were most important. We asked people to rank order different outcomes that they felt were important for mental health on our survey.

Among the outcomes that people indicated mattered to them. The top ten included quality of life, anxiety, depression, social well-being, sleep, interpersonal relationships, suicidal ideation and suicide attempts as well as the crisis response availability, and level of participation and activities of daily living and work.

To summarize, mental health is seen as an essential component for overall well-being and quality of life. And we need evidence-based practices to equip people with the skills to live a fulfilling life and the information to help them self-manage their own mental health needs.

Further, we need a paradigm shift in society to create spaces and places where autistic people have a sense of belonging and are supported to pursue their interests and goals.

Jessica, I am going to turn it back over to you.

MS. RAST: Thank you. Hi again. Thank you, Dr. Benevides, Dr. Shore for a great presentation.

I now have the opportunity to introduce - bring back the four of us. We want to take some time to draw some comparisons between the work I just presented and the work you just saw to highlight some comparisons and then a few notable takeaways when we did this side-by-side comparison.

As you have seen, we took two different approaches to our work to studying this issue. And while we asked different questions, we ended up with a lot of information that we think can be used together to hopefully move the field forward.

We thought about how to contextualize these findings from both works within an integrated framework for mental health research and mental health care. As we thought about this, we ended up at this conceptual framework for helping to advance research. This was something suggested by Dr. Benevides. We adopted this to help explain a few things. How can we understand the difference between what we find through the national data and what autistic adults are prioritizing? How do we find commonalities and how do we use what we are starting to know in order to move forward? The ultimate goal here is to improve mental health and the context that we support mental health.

The framework we are using has three phases that give us structure to this conversation and potential research moving forward. The first step is to detect and make measurements. As we like to call them in our work, create indicators and identify who, how much, where, when, all these sorts of questions.

The second step is to understand the indicators found in stage 1 by looking for determinants and causal pathways and relationships. And in mental health, it is very integral to consider determinants at multiple levels because we know and we have talked about a few times now that context is a huge determinant of poor mental health.

And then the third step is to reduce disparities. For this agenda, we may better refer to this as improving mental health. This involves intervention, policy changes, systems changes, and implementation and translation.

This is our slightly modified version of the framework where each phase is informing the phase before it and then after. In a cyclical way, we can inform better research, better practice and better policy with the ultimate goal to improve mental health.

Much of the autism research around mental health is still in this first phase of our framework and that is certainly the information that I presented today. Looking at what disparities exist, what care people are accessing, and understanding the field.

Now, I will send it off to Dr. Shore.

DR. SHORE: Thank you very much, Dr. Rast and Dr. Shea. What we are finding and again we are just in that first detection stage that there are a number of priorities. We got the first five. The other five are also important. What is good to see is that autistic adults are doing the work. We are beginning to do the work. One with the AASET project that I mentioned earlier. Work also done by Autistica in the United Kingdom, which came up with similar results, which helps validate this research.

Now, what we need to do - once we recognize is we need to find – we need to develop reliable and valid measures of mental health. How can we best do that? We can do that by involving autistic individuals as equal partners in the project and, also, making sure that that squares with what we have now for therapies, strategies, and interventions and understanding the context of barriers that keep us from getting mental health such as accessibility that was mentioned before, discrimination, trauma, being taught poorly.

This is where we need to go. We need to develop our understanding so that we can reach this nice bridge here from understanding to reducing effects of poor mental health and improving – it is hard to over emphasize autistic voice involvement in these areas.

What can we do is we can move to the next slide. Realizing that mental health is an integral component of health. Even in the non-autistic population, there are big differences between what insurance companies will fund for physical health issues as compared to mental health issues. We need to have what is known as mental health parity and something that needs to be embraced. We all embrace it. Now, we have to get everybody else to.

And then in closing, what can we do? We had a number of ideas today on bolstering authentic and meaningful autistic involvement in researchers as partners, as researchers so that we can continue on our work on partnering today for a better tomorrow.

DR. BENEVIDES: Some actionable gaps in the data that will help us address autistic priorities include expanding our ability to harness national data from autistic adults. We need more research on diverse groups especially those who have intersectional identities and those who we were not able to fully reach with our initial priority-setting activities. Further, we need longitudinal data to better understand the people’s outcomes over a period of time. Although surveys and administrative and claims data are important answers to many of the questions, those need to be supplemented with measures of preferences and context that autistic people share are relevant to their mental health.

Innovative linkages of data require funding agency, data source, and researcher collaborations. These are not single group studies. These are multi-site group collaborations that use and harness multiple data sources to tackle these important questions.

DR. SHEA: Thank you, Dr. Benevides. As we put together our work for you today, we really ended up on a take-home point of mental health being a flagship issue for the future of autism research. And that research should continue with the engagement of diverse, autistic voices and support for autistic leadership in research processes, in community processes, and in any capacity on projects, collecting data and then analyzing it.

We also put forward the investment in mental health research and simultaneously in the service system is needed today for detecting, understanding, and improving mental health. That there are entire states, entire providers across the US who are struggling to understand how to move forward and the research that we could conduct here in partnership and with leadership from autistic voices can help move this issue forward.

Thank you for your time and thank you to my co-presenters as well.

DR. GORDON: Thank you very much. I am going to now open this session up to discussion from members of the IACC. I really appreciate the perspectives of the four speakers and I would love to hear from members. I note that many of the themes were echoed throughout other discussions throughout the day.

Let us start with Jenny. And then I have Alycia, Joseph, and Dena and Scott. But keep putting your hands up and we will get to you.

We have a good 30 minutes, 40 minutes for discussion.

DR. PHAN: Thank you, Dr. Gordon. Thank you, speakers, for talking about this very important topic. I truly appreciate the work you all are doing to address mental health supports of autistic people.

My first point – actually, I have three points. My first point is there has been recognition for culturally sensitive mental health care as you mentioned here. This is a developing area of research and training. I would like to know has anyone on your team or know of anyone doing this work on trainings and effectiveness of trainings on autistic specialized mental health care as well as the intersection of culturally sensitive and autistic specialized mental health care.

My next comment is under the category of other race in your presentation, it was not clear what races were placed in that category. Reasonably, when there is not much data on other racial minority groups, aggregating those groups together is a common practice. My hope is that in presenting and talking about underrepresented and underserved racial minority groups that racial – is disaggregated to show its true numbers. There are certainly efforts to increase participation of racial minority groups in mental health studies as many of you have already addressed in your research efforts. I believe it may be helpful to show disaggregated data on racial minority groups even when it may represent less than 1 percent of the sample.

I can be bold by going a bit further and say that this is even more important to show to represent autistic racial minority groups who are well underserved in mental health services.

My last statement may be more directed for grant funders or maybe any of you can speak to this. It is related to one of the research priorities that you mentioned on studying trauma in mental health. I would like to put attention on funding for research on abuse of autistic children, adolescents, and adults. My understanding is that it is a very controversial topic to study and not much guidance having provided to conduct this kind of research study. It would be helpful for funders who are interested in this topic to provide guidance for conducting such studies and to work with the autistic community and stakeholders to develop those guidelines. It is an important topic, given the rates are likely underreported and to know why it is happening. Knowing why will then help to study how to prevent abuse. Thank you.

DR. HALLADAY: Hi. This is a good day to be reminded that this committee is kind of overseen by the National Institutes of Mental Health. We are in very good hands with Dr. Gordon and Dr. Daniels in terms of making sure that we are recognizing the needs of mental health issues, not just in those with autism and their families, but everyone because this is an issue and I have been reminded on social media that this is not just an issue that affects the autism community. These are issues that affect everybody.

The other thing I want to say is after listening to Dr. Shore’s comments, I think we need to reconsider the title of the strategic plan, the lifespan issues. I think it is a little bit disingenuous for us to be thinking of these as lifespan issues. When you think about things like depression and sleep and anxiety, you have to understand what caused them. You have to understand how they are diagnosed in people with autism versus those without and how they are treated and how there are supports.

I think this maybe calls for the idea of maybe we rename lifespan issues because I think that it is possible that these issues are being underrepresented in the categorization of the strategic plan.

DR. GORDON: Thank you, Alycia, and thanks for the shoutout. Let me just mention that one of the things that I appreciate about the presentations that we heard today is this conceptualization, which was really implicit although I do think the word was used explicitly at least once that autism – in terms of mental health coverage, autism can be considered or should be considered perhaps its own form of disparity. That individuals with autism are less likely to get care and the question is when they do get care, what kind of care do individuals with autism need. I think that is the theme that we heard throughout and that is something that we can and should emphasize more in our research approach to mental health that is specific to the autism community.

There were many other issues that were brought up that are less specific to the autism community. I can tell you from personal experience, getting mental health care for my own family. No one in my family has autism, but many in my family – individuals in my family have various mental illnesses that need treatment, and it is hard. It is hard for people with good insurance to get mental health care coverage.

That does not mean that it is not harder for individuals with autism because that is what the data indicate. They are less likely to get care. There are issues that were raised today that are in common with the general – with neurotypicals, let us say, and there are many issues that were raised that are particular to the autism community. I think ensuring that we study both of those from the National Institute of Mental Health perspective is my job.

Next up, I have Joseph. And just to let people know in case you are trying to get your hand up and you cannot, after that, I have Dena, Scott, Hari, and Ivanova. If I did not mention your name and you would like to speak, please message Monica Barnett in the chat.

DR. JOSEPH PIVEN: Great. Thanks. Thanks very much for that talk and that session. It was really terrific. I am a psychiatrist. This is kind of near and dear to my heart.

I want to put in, I guess it is maybe more of a plug than a question. To think about the model that you guys presented about detection and understanding and reduction and sort of move more to the left and put in a plug for thinking about prediction. This is a huge problem clinically, mental psychiatric disorders in autism.

But one thing that was said as clearly is it is very difficult to diagnose often psychiatric disorders in people. People that do not have language, for example, cannot tell you if they are happy or sad, which is one of the key questions we ask as psychiatrists. But sort of predicting who is at ultra-high risk or highest risk I think is something that really, we need to start thinking more about.

One of the most I think immutable findings in psychiatry is that disorders run in families. Just the fact that parents have a history of an affective disorder or depression is extremely important information. Drexel is a research organization. I think it could probably add this to the model in thinking about childhood and adolescent predictors that would point us more towards kids that are at even higher risk for thinking about these conditions. I just wanted to put in a plug for that.

It is not outside of what we think about in psychiatry. I know Diana Robins at Drexel is thinking about early detection of autism. I think this is really just a step beyond that to start thinking about how are we going to predict comorbid or so-called comorbid conditions in autism. Thanks.

DR. GORDON: Thanks, Joseph. And I think that gets to one point I was making earlier about the nature of the research portfolio and thoughts that were made. There was a lot of work being done on early detection of autism. It is not just about trying to figure out – it is not really at all necessarily about prevention, but it is rather about making sure that we can get treatment to those who need it early enough that they can live fulfilling lives.

And your point about trying to predict different outcomes within autism is also a part of the research portfolio that we want to support in order to be able to direct treatments there.

That said, we heard a call today about the need for more treatment within mental health and autism.

JaLynn, I am going to go to you next because I understand you have been trying to raise your hand and cannot get the tech to work. JaLynn Prince is next and then we will come back to Dena.

MS. JALYNN PRINCE: Thank you very kindly. First, I want to complement Lindsay on her comments. I have the highest regard for her and her intellect and her sensitivity that she brings to so many things. Wonderful comments all along.

I am fascinated too. I had a chance to talk to Dr. Shore the other day, knowing that this was going to be a presentation. I am delightfully surprised that some of the things that were included in it are included in it. We fell into an interesting situation a while ago. Our foundation though it actually is more like Autistica in its approach here in the US, we had a farm fall into our laps seven years ago, a 400-acre farm outside of Washington, DC. We thought we needed to learn to be farmers, but we learned many other lessons. We learned about the health and wellness for so many of those that happen to come out to our area.

We are dedicated first to those with autism. We do have IDD. We worked with veterans. Because this is very intentional to have an integrated situation. We have therapeutic riding and general wellness, job readiness, and community engagement. And all of those things have been playing into good mental health and wellness because people are getting to know other people outside of their circles in a friendly environment. And those that are working on work readiness projects are doing many of the things that were listed in I think number three, but being outdoors, being engaged in things outside, being involved with yoga. We have goat and mini horse yoga. We have all sorts of different types of things.

And we found out especially during COVID and I wish we would have had more insight into a pandemic about keeping records, about how people have reacted that had been coming to receive different services or engage with us or community events. During COVID, we even had Zoom calls between riders and their horses when they could not come out. People would understand that their animals were still there, which was great comfort.

We had safaris as people came out in the family cars and saw the animals. Wrote posters and things to one another. The release that people had after the tension and being confined and being outside in a safe way and participating with others with nature.

It has also branched into something else. I am going to make the comparison of the curb cut. The curb cut was put into use for individuals that had a hard time with mobility. But who utilizes it now? Those with strollers, suitcases, benders, bicycles. It is an answer for one situation that is answering many others. We have found with the health and wellness, it was targeted more toward the autistic population and has been helping others because we started something for first responders, those that were isolated in critical care units, those that were behind the wheel in ambulances, police officers, everything that went through their lives here in the Washington, DC area. And they have been able to come out to the farm and enjoy a day of re-envisioning who they are, being empowered, and having a release that has helped them with their mental health.

I would say that the people that we are working with on the farm with autism have reported to us better attitudes than my associates who haven’t had the opportunity to participate in outdoor activities and doing different things of that nature.

I would say that the mental health issues can often be addressed by softer things. It is not always medication. It is being out and doing and participating and having more environments where people are accepted into community and have integration with others with nature and with animals. We have got many horses, goats. Everybody loves beautiful horses. Chickens, you can even put on a leash if you want to, but it is interesting, and it provides something that people need that is beyond their own computer screen or beyond their own homes. I wish there were more opportunities around the country so people could heal in the way that we have had the opportunity to see people heal over the last several months.

DR. GORDON: Thank you, JaLynn. You mentioned Lindsay, and I want to insert a comment here from her before moving on to Dena. My comment or question for the presenters. I want to acknowledge and thank the presenters for a great and informative presentation on a topic that is very important especially when it has become an emphasized issue as a result of the COVID-19 pandemic. I am reassured to know that the research team was mindful of including autistic people as stakeholders in this project.

Dena.

MS. GASSNER: Sorry, I am trying to get oriented here. I checked out for a minute. I just want to say as one of the community members on the project, that the first thing I want to champion Stephen and Teal with is this system for communication, this email system that you featured in the presentation. Having tasks cleanly and clearly delineated has not only helped me with this project, but I have also carried that into other groups that I work with because it is so effective and so much more organizationally defined for people who struggle with deadlines and just like peeling out of the content what is important from what is not.

I did want to bring up an overlap from another webinar and some other research I have been a part of. In the presentation by Jessica, there was a distinct overlap in reporting these basic need deficits that people were experiencing with the reporting we’re getting back about the effects of COVID-19 on the IDD community, specifically, Swartz et al, found that 54 percent of people, sorry, I have to go to my slide or I won’t report this correctly, 54 percent of families reported employment changes because programs shut down, loss of PT, loss of job coaching, organizational shutdowns so they lost their job coaches, and therapeutic support, and then increased transportation issues. This was a very privileged population we sampled. But if it was that bad for the primarily white community that responded, I can only begin to imagine what it was like for other people with other marginalizations.

And then I wanted to add that another research article by Turk et al. demonstrated that because of COVID-19, 51 percent of people experienced loss of income, 38 percent had difficulty paying usual household expenses, 12 percent saw increased food insecurities, and 33 percent reported housing issues. There is a distinct overlap in these mental health issues now as we are adding this new research about COVID.

Lastly, in terms of utilizing these data sets, I think it is really important for us as we are analyzing them, to keep in mind that these data sets depend on a couple of factors that we cannot predict. Number one, we do not know that the people who are in these hospital settings or in these environments we are drawing data from even though they are on the spectrum. They may have been misdiagnosed. We have not begun to look at medical maltreatment and the issues associated with misdiagnosis.

And then we have to remember that if the presenting issue is not an autistic behavioral issue, if they come in because they have been in a car accident, we may not get that information either. Whatever stats we are looking at, you have to guestimate that they are skewed just a little bit to consider these areas where we are not able to get meaningful access to the legitimate information. It is the best we can do, but we just always have to keep that in mind. Thank you.

DR. GORDON: Thank you.

Scott.

DR. ROBERTSON: Thanks, Dr. Gordon, and thanks to the presenters for you all sharing this really important work in terms of improving research and in terms of the research understandings and improving what we are doing in practice and supports in mental health and well-being.

I think a lot of these focuses especially resonate with us as far as trauma-informed care, better partnership and collaboration with autistic people in research, thinking about positive approaches on mental health.

For us at the Department of Labor that this is especially of interest for our focuses or improving access to gainful competitive integrated employment because employment is both a social determinant of mental health and physical health and well-being and in the other direction to that, folks – workers access to – autistic workers’ access to health care supports can be a difference in terms of maintaining jobs, advancing career pathway, et cetera. I think this is really important to informing what we are doing including on our research project on autism and employment.

I especially want to highlight just briefly here is on the positive psychology end. That the research literature is so very limited on optimism, resilience, positive elements on what autistic people can do and others can do to help support advancement on positive elements of mental health and well-being that I think we need to make better strides with that. I suggested there should be something that maybe could be emphasized in the strategic plan is to prioritize when it comes to mental health related research in autism to make sure there is a lot more emphasis again on the positive psychology. It is not just limited to autism. I would say over the last decades, positive psychology has been a very small piece at times of mental health research, but it is something that I think we can make some strides in that area.

And then just lastly, briefly, what I wondered in question to the presenters is – sorry if you covered this already before is the inpatient settings element, kind of the mental health settings. I feel like that is – especially private settings. Sometimes the public settings that are run by state government often have had trainings. For instance, I know in Pennsylvania, some other states, but often the private settings, which in some cases are for profit organizations running them rather than nonprofits. There is often not really good training on autism and other developmental disabilities, and it leads to major marginalization, trauma, major barriers for folks in those inpatient settings.

Can you speak to anything that you are doing right now that inform the work on the report and related activities or are there other activities that may be coming up that may have that focus on inpatient settings and increasing knowledge and understanding for trainings for inpatient service providers for mental health to support and empower autistic people and other folks with developmental disabilities in those settings? Thanks.

DR. GORDON: Would any of the presenters like to comment on the inpatient question?

MS. RAST: I can speak about that first a little bit. As far as the first part of your statement, the data on these inpatient is from all types of hospitals. The coverage is about 97 percent of the US. It is a pretty good representative show of what is happening in inpatient hospitalizations for autistic people.

Dena, your comment is very well received too that this is likely not a full capturing of people who are autistic in the hospital.

We are doing more work looking at this data and we are interested in the experiences of people as they are there. This data is a little bit limited in what we can know about their experience in the hospital. We know what their diagnoses were when they were there and what procedures they may have had. We do have some information about, like you said, restraints and things like that, which is an important consideration here as well especially as we see the high rates of schizophrenia and conduct disorders and other things that can sometimes be associated with violence, or rather, behaviors that maybe inferred in that way.

We also are doing a little bit of work considering the models of care that can be more inclusive of mental health. I have not really considered this in the context of hospitalization, more in the context of primary care. I think that is a really important component.

And it also speaks to the bit about crisis care and why people end up in the hospital and how we maybe could be diverting people to another location if their main concern is something mental health related so they could just receive better or more appropriate care.

Did you have anything to add, Lindsay?

DR. SHEA: No, I think you captured it well, Jessica. I think, Scott, your point – as so often, I feel that the points that you make is very important by way of how we are again in lacking the research to help support the people who are doing the real work every day today, not able to wait for the research, who really need this data now. They need all different kinds of data, not just our quantitative data, but also really tested and true training solutions. I think that the paired approach and thinking about the applied nature of how we can move forward is tremendously urgent. Thank you for that.

DR. GORDON: Thanks, Lindsay. Hari, I have you next. Please do unmute. There you go.

MR. SRINIVASAN: – can echo need for alternatives for blind medication. Wonderful set of presentations and data tying in advocacy and priorities. Thank you. It is so true that we do not have mental health parity for coverage. For example, research hospitals like Stanford and UCSF don’t take state Medicaid for mental health. Right now, I am covered by my dad’s work insurance, but what happens to those who do not have that resource? Also, many years back, Dr. Antonio Hardan at Stanford Autism Clinic, said at a conference that psychotropic meds donnot seem to be as effective and work the same way in autistics as in the general population. Yet, these meds are seen as the first line of defense for any autism behavior. If we are going to be medicated, we need it to work with our physiology, and also factor into medical comorbidities. We need research into this.

The other concern is long-term health effects. Studies show that long-term use of psychotropics cause liver damage, weight gain, and Parkinson’s. Other NIH studies show we are already at higher risk for neuropsychiatric disorders. Old age is looking scary on top as we will have to face more issues on top of existing ones, on top of shrinking social supports as we age. An echo need for alternatives to blind medication.

DR. Thank you, Hari.

Ivanova.

MS. SMITH: Hello, this is Ivanova Smith. I wanted to say has there been any research or any research of trying to find alternatives to institutionalization for crisis care like if an autistic person is having a public meltdown, gain of support that are not institutional, like putting them in an institution or ward, but getting them into an outpatient support – services to help them instead of institutionalizing them. Thank you.

DR. GORDON: Thank you, Ivanova. Would anyone from the panel or anyone else like to respond to that question?

MS. RAST: I can just briefly respond to that. I am not doing work related to this, but I think it is a really important point and it is, again, related to the crisis care system that we don’t really have in place in the US to deal with in general mental health crisis and more specifically how those intersect with autism. I don’t have any expertise in that area, but I have seen some work that have suggestions for how that can be created and bettered so the situation is not quite so poor.

DR. GORDON: NIMH does have a research portfolio in the area of crisis intervention services. I do not know offhand of any particular studies that focus on autism. I don’t know if Lisa Gilotty is on the call or anyone else from NIMH who would want to speak up.

DR. DANIELS: Lisa is probably watching on videocast so might not be able to comment.

DR. GORDON: We can get that information if we have any to the members of the committee.

Yetta, I believe you are next.

MS. YETTA MYRICK: This is Yetta Myrick. I just want to thank you all for your presentations and all your hard work. Unfortunately, disparities that you mentioned are not surprising to me personally. I believe that this data further highlights that there is more work to be done. With that said, I made a point – literally, I was like where is the strategic plan and I went and printed it out at the last set and looked at the objectives. I noticed that mental health was not specifically mentioned, and I would like for my IACC colleagues to consider, including an objective that addresses mental health as we develop a new strategic plan. I just want to throw that out there.

DR. GORDON: An excellent point, Yetta. I think it is one that – I see already some thumbs up coming from your colleagues on the committee.

It is 4:33. This is about the time we planned to take a break. Are there any other comments or questions for our really wonderful panelists, who gave us a lot to think about? I will echo that thank you. Thanks, Dena. Thank you very much to the four of you for your presentations, the information they contained and the passion they relayed. And we look forward to the opportunity to be inclusive of these issues in this upcoming strategic plan.

Susan, I think we can afford to take a break now and return at 4:45 at which point in time we will go through round robin updates. Am I right on that?

DR. DANIELS: Yes. We had scheduled a five-minute break originally. We are sending a little bit ahead of schedule. We had talked about a language discussion. I do not know if we want to defer that to next time as that might be a longer discussion or prefer to do round robin. I leave that for you to decide.

DR. GORDON: My own recommendation as chair would be that we do not cut off discussion on language to make it comply with the timeframe that we have left. I feel like there was a lot - there is a lot to be said on that issue. That said, if people wanted to, we could come back five minutes early and try, but I am reluctant to do so given that there is probably a lot to talk about there. Okay, no one is objecting to my approach.

We are going to take - it is 4:35 by my watch. We will return at 4:45. Those of you who would like to alert the committee as to any updates with your organizations or with the community in general, you will have an opportunity to do so and then we will close. For those of you who might need to leave a little early, I will say right now, that our next IACC Full Committee Meeting will be 10 a.m. on Wednesday January 19. It will also be virtual.

We will see you all in ten minutes.

DR. DANIELS: Thank you. If you want to read our round robin updates, they are on the website. We have some that were submitted in writing. Thanks.

(Whereupon, the Committee took a brief break starting at 4:35 p.m., and reconvened at 4:35 p.m.

DR. GORDON: Everyone who would like to report out something from their organization or for the autism community in general, this is now your opportunity to do so for the next ten minutes or so. Like Susan mentioned, we have several announcements already reported out in writing.

Alison, you get to start and then I have Diana, Alycia, and Susan.

DR. MARVIN: Thank you. I just wanted to follow up on the discussion from yesterday’s meeting relating to the presentation from Assistant Secretary Williams of the Department of Labor. SSA would like to share that they have previously worked and are continuing to work with the Department of Labor, particularly ODEP, the Office of Disability and Employment Policy on a number of initiatives. And Assistant Secretary Williams and SSA Commissioner Kijakazi met last month to discuss ways to address common goals and are meeting again this month with the broader group.

At the staff level, ODEP and SSA have collaborated on a number of projects over the last decade and SSA has also worked with other agencies to find ways to promote employment and well-being for all people with disabilities, including people with autism spectrum diagnoses.

I am also happy to announce that Dr. Jeffrey Hemmeter, the Acting Deputy Associate Commissioner in the Office of Research, Demonstration, and Employment Support at the SSA, has agreed to speak at the next IACC meeting and will present information about our collaborative work and other efforts.

And just one other quick item. I wanted to draw attention to the third item on our round robin list on the handout. Essentially, we have the Social Security Administration has listed an open request for information on potential disability insurance and supplemental security income demonstrations in the Federal Register. If you look at that round robin list, you will see a link there and there has never been an ASD-specific SSA demonstration. Now is the opportunity to share recommendations relating to that.

This request for information seeks public input on potential services, supports or DI and SSI policy changes that could achieve these goals. The input we receive will inform our deliberations about possible future demonstrations and tests. If you would like to have a say in that, please share your comments. Once again, that link is in that round robin handout. To ensure your comments are considered, we must receive them no later than November 16. You have some homework. Thank you so much.

DR. DIANA BIANCHI: Great. Thank you. Hi everybody. I am Diana Bianchi. I am director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development. I have three updates to give you just briefly.

First of all, I wanted to inform all of you that NICHD has launched the STRIVE initiative, which stands for STrategies to enRich Inclusion and achieVe Equity. The goal of this initiative is to improve equity, diversity, and inclusion in all aspects of our research and our workforce.

There are three themes. Theme one is ensuring equity, diversity, and inclusion in the NICHD’s internal workforce. Theme two is enhancing opportunities for equity, diversity, and inclusion in the broader extramural scientific workforce. And theme three is planning, conducting, and supporting health disparities research.

We have had an excellent series of five workshops. They were all recorded. The last one was held last week. Basically, if you go to the STRIVE webpage, you will see the links. Rather than read off a long web link, basically you can find it if you just type in NICHD and STRIVE into Google and then you will see the page come up.

We are also looking for ideas and feedback to inform research on health disparities across our entire portfolio for the next five years. This is an idea scale platform and that I will read to you because it is https://nichd.ideascalegov.com – I think it is a hashtag. It is a hashtag. Current/campaign. I will type it into the chat box when I am done.

The second thing that I wanted to mention is that just going live yesterday, an eagerly awaited study by Dr. Sikich et al. about intranasal oxytocin in childhood in children and adolescents with autism spectrum disorder, which went live at the New England Journal of Medicine last night.

The key message, the bottom line is unfortunately despite very encouraging data from single-dose studies in animal studies, oxytocin treatment does not appear to improve social functioning in either fluently verbal or minimally verbal individuals with autism spectrum disorder. It is safe. It does not cause significant adverse events or effects.

There is a significant placebo response in the first four weeks that is similar with both the treated individuals and those who receive placebo. It is possible that daily treatment for 24 weeks is not optimal due to the brain attempting to compensate for the increased presence of external oxytocin. And the baseline level of plasma oxytocin does not seem to influence who is going to respond to this treatment and who will not respond.

There is evidence that the exogenous oxytocin treatment gets into the plasma and increases plasma oxytocin levels. It gets there. But it does not seem to change behavior. Genetic and model system studies to understand the drivers of plasma oxytocin levels and mechanisms of oxytocin function are still ongoing.

The last thing I want to mention is that the application due date for the Autism Centers of Excellence, Center and Network Request for Applications, the deadline is November 9TH, coming up soon. And the ACE program team has released a set of detailed answers to frequently asked questions for the RFAs. But the NICHD contact is Dr. Alice Kau, who is on the webinar. And her email address is kaua@mail.nih.gov. If you have questions, please reach out to Alice. Thank you.

DR. GORDON: Thank you.

Alycia, you are next.

DR. HALLADAY: Hi. I also have funding announcements or funding opportunity announcements and then also a comment about a treatment.

The Autism Science Foundation has announced the new award cycle for not just pre- and post-doctoral fellowships, but we have added a mechanism for post-undergraduate. It is very similar to the NIH post-baccalaureate mechanisms. The goal is to support young scientists who may not or junior-level scientists who may not want to go on to get a graduate degree but want to stay in autism research although we do encourage people to go on and get a graduate degree in this field.

We have also readjusted our stipend levels to become more current. The deadline is December 7. I encourage everyone to go to the Autism Science Foundation website, the

RFAs, and instructions on how to apply are right there on the ASF website. Please spread the word. If you know anyone who might benefit from one of these awards, please encourage them to apply as well.

The other thing I wanted to bring to the IACC's attention is some new information with regards to the use of STEM cell therapies in autism. These are therapies that right now do not have enough scientific backing to show that they are effective for autism. But yet a company is going forward to market them and charge families out of pocket for them. We hope that the IACC can work collaboratively with the FDA. Tiffany is aware of this situation and she is on the IACC. But I wanted your impact on how the IACC can work collaboratively to encourage the FDA to more stringently regulate these sorts of practices or at least within the autism spectrum disorder because the particular company is moving straight from the kind of minimal or equivocal findings all the way to marketing. That is more of a question for you all and a comment.

DR. GORDON: Thank you, Alycia. Let me ask Lisa Gilotty now to answer the question I asked earlier before going next to Susan Rivera. Lisa, I understand you are on and can you answer the question with regard to crisis service for autism adults whether we have research in that area? If you are speaking, you are muted. Maybe you are not able to comment. We will come back to you if you can.

Susan Rivera.

DR. RIVERA: Thank you. I wanted to announce and invite everyone to - UC Davis is holding our Third Annual Neurodiversity Summit on November 5th from 9 a.m. to 12:30

p.m. California time, Pacific time, via Zoom webinar.

This is a summit that is going to include presentations and a panel discussion and a moderated debate. It relates really specifically this year to non-speaking autism and intellectual developmental disabilities. We will have presentations by Erik Carter from Vanderbilt University, Vikram Jaswal from University of Virginia, a panel discussion that will include parents, non-speaking autistics, individuals with intellectual disabilities, and then a really exciting debate on neurodiversity that is going to include interlocutors Shannon Rosa, who we heard from yesterday or maybe today, and Matthew Belmonte.

We really are tackling the idea that neurodiversity is relevant to those who are speaking and non-speaking and at all levels of intellectual functioning. We are really going to directly tackle the issue of experiences of discrimination and stigma. I hope that everyone can join us for that on Zoom webinar on November 5.

DR. GORDON: Thank you very much, Susan.

I am going to ask each of the remaining speakers – we have four more and three minutes, which gives you each less than 45 seconds. Please keep your remarks brief. Scott.

DR. ROBERTSON: Thanks, Dr. Gordon. I will try to keep it brief. I just wanted to emphasize that we are looking for input for the research project that was mentioned yesterday by Assistant Secretary Williams here at ODEP. We invite collaboration and ideas and thoughts in the future. I am glad IdeaScale was mentioned by one of the other IACC members because we use that for online dialogues. And maybe there is a possibility to do an online dialogue in autism focuses and employment in the future so I can connect with folks offline.

And then I just wanted to briefly mention too, and I do not know if we can also connect to this over email. Suggestion for a speaker for future IACC meeting where it may overlap with some of the emphasis of the strategic plan is it has employment in the focus is why I mention it. Maryland is in the process – they may have already hired the person – a state coordinator for autism to handle their strategic plan. It is going to have health and wellness focuses, employment, et cetera. The priority is especially on adults. I think it would be great maybe at a future IACC meeting. Once they get further along on that process, it might be pretty awesome to have IACC to potentially considering having that state autism coordinator from Maryland to come present at some point.

DR. GORDON: Thank you, Scott. I will just add for anyone who has other suggestions for future speakers, they can always be sent at any time via email to Susan or her staff.

MS. GASSNER: Just a real quick update. Zach Williams out of Vanderbilt and some other collaborators from the Autistic Researchers Committee is getting closer to being able to do a launch date for the database of autistic individuals interested in either doing collaborative research and recruiting people who are autistic to be part of research teams or to in other ways engage the autism community.

One of the challenges we have been facing across the board is not being able to diversify our representation – single source system where other collaborators could plug in and maybe be a part of research. If you are a researcher looking for people, we will have that listed there and if you are an individual who wants to participate in research in any capacity, you do not have to have a degree. You do not have to have college to participate. And each organization of course is going to individually talk to you about what they need and what they can provide. We do have a statement of compensation involved as well. Thanks everybody.

DR. GORDON: Thank you, Dena. It is a great resource. I want to make sure to give everyone a chance. We have three more speakers. Jennifer.

DR. JENNIFER JOHNSON: I will just be real quick. I wanted to just announce several new awards that we have made last month. We have a self-advocacy resource and technical assistance center that we awarded, which continues our work in that area.

We also awarded a grant to work on bridging aging and disability services.

We are also funding new projects on community collaborations for employment to support competitive integrated employment.

And then we also funded some grants to address issues of dual diagnosis and bridging the DD and behavioral/mental health systems in states. We have information on our website about those new awards that went out if you want more information about those.

DR. GORDON: Thank you very much, Jennifer.

Sam Crane.

MS. CRANE: Hi. I will just quickly go point, point, point. ASAN has a few new resources. One is called Who’s in Control, which is the toolkit that lets autistic people understand better how to self-direct their own home and community-based services.

We have resources that we published with the National Partnership for Women and Families on reproductive health issues that intersect with disability.

We are asking people to share their COVID-19 vaccine experiences with us so that we can help our community access this vaccination since autistic people do appear to be at higher risk for negative outcomes of COVID-19.

And I know that Hari wanted to raise this, but did not have time. He is doing a study on the experience of awe among autistic people so autistic people who are interested in participating in this study should reach out to him if they are interested in participating. It is a very fun survey that I have already taken myself.

DR. GORDON: Thank you, Sam.

And last but not least, we have Walter Koroshetz of NINDS. Walter.

DR. WALTER KOROSHETZ: Thanks very much. Just two quick things. People may remember workshops we had on GI dysfunction in autism and neurodevelopmental disorders. There is now a call for grants by NINDS, NICHD, and the National Institute of Digestive Diabetes and Kidney Disorders.

Lastly, we have two medication trials in conditions that lead to autism. One is tuberous sclerosis. One is fragile X. Those should report out early next year. Thanks.

DR. GORDON: Thank you, everyone, very much. We are looking forward to seeing you all in January.

Susan, do you have any closing words for us?

DR. DANIELS: Yes. If you could flash the next slide that I had, I just had a slide to acknowledge the OARC staff for all their work in getting this meeting together and also to our contractor, Bizzell, and other NIMH staff who have been helpful and NIH video cast.

Next slide is just the next meeting. We are going to be having our next meeting on January 19. Please join us. And in between respond to our RFI if you are a member of the public and we will be sending the members their own special RFI. Thank you so much. We look forward to seeing you next person.

MS. GASSNER: Are we looking at in person? Is that going to be in person in January?

DR. DANIELS: No. It is completely virtual.

DR. GORDON: We apologize. But the Federal Government still has not opened up for meetings at this point. And given the need to plan ahead, we have to plan for a virtual meeting. Hopefully, we will meet the one thereafter. We will see.

DR. DANIELS: Autism Awareness Month in April. Maybe it could be in person. Thank you.

DR. ROBERTSON: Thank you, all, for your staff, Dr. Daniels, as you emphasized that, I think keeping the trains running, et cetera, in terms of the coordination of the meeting. I think a lot of folks do things behind the scenes that not everybody knows. We all appreciate the hard work you all do at HHS and especially NIH to organize the IACC. It is very important, and we appreciate it very much.

DR. GORDON: Thanks for the kind words. Bye bye, everyone.

(Whereupon, the meeting adjourned at 4:55 p.m.)