INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, JANUARY 17, 2018

The full Interagency Autism Coordinating Committee (IACC) convened in Bethesda, Maryland, at the Bethesda Marriott, 5151 Pooks Hill Road, at 9:00 a.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

PRESENT:

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

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

DAVID AMARAL, Ph.D., University of California, Davis (UC Davis) MIND Institute

JAMES BALL, Ed.D., B.C.B.A.-D, JB Autism Consulting

JAMES BATTEY, M.D., Ph.D., National Institute on Deafness and other Communication Disorders (NIDCD)

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

PRESENT: (continued)

JUDITH COOPER, Ph.D., National Institute on Deafness and other Communication Disorders (NIDCD)(representing James Battey, M.D., Ph.D.)

SAMANTHA CRANE, J.D., Autistic Self Advocacy Network (ASAN)

GERALDINE DAWSON, Ph.D., Duke University (attended by phone)

RUTH ETZEL, M.D., Ph.D., Environmental Protection Agency (EPA)

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

LAURA KAVANAGH M.P.P., Health Resources and Services Administration (HRSA)

CINDY LAWLER, Ph.D. National Institute of Environmental Health Sciences (NIEHS) (representing Linda Birnbaum, Ph.D.), (attended by phone)

LAURA MAMOUNAS, Ph.D. National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.)

DAVID MANDELL, Sc.D., University of Pennsylvania

KEVIN PELPHREY, Ph.D., George Washington University and Children’s National Medical Center

PRESENT: (continued)

LOUIS REICHARDT, Ph.D., Simons Foundation Autism Research Initiative (SFARI) (attended by phone)

ROBERT RING, Ph.D., Vencerx Therapeutics (attended by phone)

JOHN ELDER ROBISON, College of William and Mary

MARCELLA RONYAK, Ph.D., L.C.S.W., C.D.P., Indian Health Service (IHS)

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

ROBYN SCHULHOF, M.A. Health Resources and Services Administration (HRSA)(representing Laura Kavanagh, M.P.P),

STUART SHAPIRA, M.D., Ph.D., Centers for Disease Control and Prevention (CDC)

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation

PRESENT: (continued)

CATHERINE SPONG, M.D., Eunice Kennedy Shriver National Institute of Child Health and Development (NICHD)(representing Diana Bianchi, M.D.)

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University (attended by phone)

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

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

CARRIE WOLINETZ, Ph.D., National Institutes of Health (NIH)(representing Francis Collins, M.D., Ph.D.),

TABLE OF CONTENTS

PROCEEDINGS

DR. JOSHUA GORDON: Good morning and welcome to this meeting of the Interagency Autism Coordinating Committee. As many of you know, I am Joshua Gordon, Director of National Institute of Mental Health and the chair of the IACC. With me is Susan Daniels, designated federal official.

Thank you for making it here, those of you have done so, despite the weather this morning. Apparently, schools in Montgomery County are closed, which astounds me as someone who spent years in Minnesota. I am glad all of you could make it here.

We have a full agenda today, encompassing committee business, including our Summary of Advances Discussion, discussion of the workgroup that is forming, and some other items.

We also have presentations on the Indian Health System and on Autism Screening efforts, as well as our usual public comments.

So thank you for coming. I am going to turn the mike over to Susan, who will conduct roll call and passing the minutes.

DR. SUSAN DANIELS: Good morning and welcome. Glad to see you all here and glad so many of you could make it in spite of the inclement weather. I will go ahead and take roll call. Joshua Gordon.

DR. GORDON: Here.

DR. DANIELS: Jim Battey.

DR. JAMES BATTEY: Present.

DR. DANIELS: Diana Bianchi.

DR. DIANA BIANCHI: Here.

DR. DANIELS: Cindy Lawler or Linda Birnbaum, I think were by phone.

DR. CINDY LAWLER: Yes, I am here.

DR. DANIELS: On the phone?

DR. LAWLER: Yes.

DR. DANIELS: Carrie Wolinetz.

DR. CARRIE WOLINETZ: Here.

DR. DANIELS: Ruth Etzel.

DR. RUTH ETZEL: Here.

DR. DANIELS: Tiffany Farchione.

(No response)

DR. DANIELS: Marguerite Schervish for Melissa Harris.

(No response)

DR. DANIELS: Jennifer Johnson.

DR. JENNIFER JOHNSON: I am here on the phone.

DR. DANIELS: Laura Kavanagh.

MS. LAURA KAVANAGH: Here.

DR. DANIELS: Nina Schor for Walter Koroshetz.

DR. NINA SCHOR: Here.

DR. DANIELS: Laura Pincock.

(No response)

DR. DANIELS: Marcy Ronyak.

DR. MARCELLA RONYAK: Present.

DR. DANIELS: Stuart Shapira.

DR. STUART SHAPIRA: Here.

DR. DANIELS: Melissa Spencer.

(No response)

DR. DANIELS: Larry Wexler.

DR. LARRY WEXLER: Here.

DR. DANIELS: Nicole Williams, on the phone.

DR. NICOLE WILLIAMS: Here I am.

DR. DANIELS: In person. David Amaral.

DR. DAVID AMARAL: Here.

DR. DANIELS: Jim Ball.

DR. JAMES BALL: Here.

DR. DANIELS: Samantha Crane.

MS. SAMANTHA CRANE: Here.

DR. DANIELS: Geri Dawson, on the phone.

DR. GERALDINE DAWSON: Yes, I am here.

DR. DANIELS: Thanks. David Mandell.

DR. DAVID MANDELL: Present

DR. DANIELS: Kevin Pelphrey.

DR. KEVIN PELPHREY: Here.

DR. DANIELS: Edlyn Peña.

(No response)

DR. DANIELS: Louis Reichardt.

DR. LOUIS REICHARDT: Here by phone.

DR. DANIELS: Thank you. Rob Ring.

DR. ROBERT RING: Here by phone.

DR. DANIELS: John Robison.

MR. JOHN ROBISON: Here.

DR. DANIELS: Alison Singer.

MS. ALISON SINGER: I am here.

DR. DANIELS: And Julie Taylor by phone.

DR. JULIE TAYLOR: Yes, I am here.

DR. DANIELS: Thank you. So we have the minutes, the minutes from the last meeting. The draft is in your folders. We sent that out in advance. Does anyone have any comments or anything that they feel needs to be updated before we finalize those minutes?

DR. BATTEY: Move to accept the minutes as written.

MR. ROBISON: I will second it.

DR. DANIELS: Thank you. All in favor of accepting the minutes as written.

(Chorus of “ayes”.)

DR. DANIELS: Any opposed?

(No response)

DR. DANIELS: Anyone abstaining?

(No response)

The motion carries to pass these minutes and we will be posting them to the web soon after this meeting. Thank you.

DR. GORDON: I want to, in particular, welcome Nina Schor, who is a brand-new Deputy Director at National Institute of Neurological Disorders and Stroke, representing Walter Koroshetz. Glad to have you here.

Now we will move right into the program then. So it is my pleasure to introduce Dr. Marcella Ronyak, who is the Deputy Director of the Division of Behavioral Health at Indian Health Service. She is going to be talking to us about advancing behavioral health in the Indian Health System.

DR. RONYAK: Good morning everybody. Thank you all for taking the extra effort to get here this morning. It is an honor to be here this morning. I was extremely excited when Dr. Daniels requested an in-house service to do a presentation. But before I get started into the presentation, can I see if the audience – how many in the room would say they know extensively what Indian Health Service does or how we even deliver services. I have a few. Excellent.

What I did with the presentation just to give you the lay of the land of how we are going to move forward with this one is I am going to talk a little bit about the overview of Indian Health Service. I, myself, am a consumer of Indian Health Service. Now, that I have moved to DC I am considered an urban Indian and no longer a consumer of tribal services, but could be a consumer of urban Indian Health Services. I want to talk about the difference of that because that does change how services are delivered and how resources can meet the community. We will talk about that a little bit.

We will also talk about our current behavioral health initiatives. I am a little pressured in what we have going on because I am the deputy director, the Division of Behavioral Health. I am a member of the Colville Confederated Tribes, which is in

North Central Washington. I moved from Washington to Washington. With that, it was very interesting to see how services were delivered when I was actually born and raised. I was raised in California in Sacramento. I again would be considered an urban Indian, if you will, because there were no tribal reservations around us. Once I moved back home what we would call to our reservation, I went in as a social worker and then got my clinical degree in psychology, and started as a tribal psychologists. I have seen quite a gamut of services. I want to talk about that as well during the presentation because I think it gives a different lens as to not only being a consumer, but being a provider and then being a provider that had to deal with the proverbial wall of lack of access to care, which brought me to Washington, DC. I will talk about that as well.

The third piece that I will roll into is discussing our impact of telehealth and tele-behavioral health services. Indian Health Services made dramatic leaps and bounds and that is part of how we are able to reach our population. I want to wrap it all together. Feel free to ask questions as we go along, or we can have questions at the end. I am okay with either way.

If we talk about Indian Health Service, our mission really is to raise the physical, mental, social, and spiritual health of American Indian and Alaskan Native populations. With that, the amazing piece out of that is we are looking at how do we ensure that we have not only comprehensive services, but culturally appropriate services. Many in the room will know that everything we talk about is evidence-based practices. The problem that we have is evidence-based practices may not always work within tribal or diverse communities. Not only do we want to think about how can we adapt evidence-based treatments to whatever population we are working to, but we really want to think about culturally how does that impact somebody.

I would honestly say that everybody in this room brings something unique to the table. When we are looking at treatment, we need to look at the unique options that would be for that individual, that family and that community. That is one thing that IHS really tries to do.

The other piece of it is Indian Health Service was put in place by lots of legislation, which I have here on the right part of the screen. It really is to uphold the federal government's obligation to tribal sovereignty. When we talk about tribal sovereignty, it is a government-to-government relationship. The federal government has a relationship with all of the tribal governments. On the next slide, I am going to show you how many tribes we have, which is 567 federally recognized tribes. I will also talk about the difference between federally recognized tribes and state tribes.

IHS has four main priorities, which are people, which are our service population, our partnerships, which are everyone here in this room, including other federal partners, private sectors and also if we think about like tribal organizations, those are considered our partners as well. We are very much about quality. It is improving quality and services and also about resources. Those are our four main pillars that we work from.

When we think about the tribal population, IHS actually serves 2.2 million American Indians and Alaska Natives within the United Nations. If we think about that, that is a lot of people and we have to think of uniquely how that is different.

Up in the top left, you can see we have different areas. They are hard to see on here so my apologies for that. IHS is broken up into 12 IHS areas. Each of those colors has an IHS area and each area operates what we call our direct services or service units within that area. Mind you, we are one IHS. It does not mean that we have one cookie cutter model that covers all of IHS. We truly work with 12 different models because it depends on what the needs are within that community.

Like Ed mentioned, we do have 567 federally recognized tribes. That is who our tribal obligation and federal obligation is to. There are state tribes and the difference between that is federally recognized tribes are tribes that the federal government has recognized due to blood quantum and due to legislation and the fact that you do have federal land that is their reservation. State tribes often do not have a reservation per se and may have not had the same blood quantum. Those folks may not also receive direct services.

DR. GORDON: I am wondering, can you define what blood quantum is?

DR. RONYAK: And please ask any question. A blood quantum is a percentage of our actual blood that would be within a federally recognized tribe. For myself, I am Colville. I have over 25 percent, which is the minimum for my tribe to be federally recognized, but it does not mean I don't have other blood quantums from other tribes. My daughter – she has blood quantums from the Yakama Tribe, from the Oneida Tribe and then from Colville Tribe. She has more blood quantum than I do. And then people with various blood quantums depending on if they have 25 percent of each tribe would then have to choose to be enrolled in one of those tribes and that is where you would call your home tribe. Thank you for the question.

When we think of Indian Health Service, one of the pieces I just want to spend some time on is the bottom of the slide. We do have IHS hospitals that provide direct care. We have 26 hospitals and 22 tribal hospitals. And the difference between an IHS hospital means it is run by IHS directly in funds. That includes staffing. And tribal hospitals are run by the tribes. Tribes can choose to what we call compact or contract. That is where a tribe would come forth and say we believe that we can provide services better than IHS or we choose to provide services rather than let IHS run the facility. And we, as a tribe, would like to pull shares or monies down from the Indian Health Budget, which I will talk about in a few slides. And we will take those funds and we will provide those services that are needed for our community. You are going to hear me talk about IHS facilities and tribal facilities. That is how the funds get separated and that also depends on who is managing those programs.

Then we also have health centers, which are not full hospitals. We have 53 IHS and 289 tribal. You are going to notice some of our numbers are very lopsided and we are going to talk about why.

In Alaska Village Clinics, there are 150 just in Alaska. That is in addition. And then in our urban communities, we have 34 IHS facilities within our urban communities. And then we have what are health stations. Health stations are small, stations where providers either come in remotely and so there is a lot of telehealth or they may have just one provider that are operating the entire clinic and it is really kind of a checkpoint, if you will, that someone would come in, have an assessment and if they needed to be referred out then they would be referred out to a hospital or a bigger health center.

And then we have school health centers. Because IHS is a federal system, one of the things we also have to think about is we do have partners with Bureau of Indian Affairs and Bureau of Indian Education, which are both part of the Department of Interior. We have schools that are called BIE, which is Bureau of Indian Education. And within those schools, there may be health centers that are placed there for the students to have health care right there on campus.

I happened to be placed when I was a tribal psychologist at one of the schools that was considered tribally ran, but we did get BIE funds and we did have a health center, if you will, in our school, which was amazing because students could see a nurse immediately. We could make contracts or MOAs with our surrounding what we called regional providers that could come in once a month or once every week and do physicals for our athletes, do health checks for the students. We had dental come in. This way students were not transported away from the school, but services were provided there within the school.

When we talk about the budget, IHS has a budget that I kind of want to separate out two different things. We have a discretionary budget, which is $4.9 billion. And then you would add for our special diabetes program for Indians, which is $147 million. Part of that programming was because clearly it was identified that within American Indian and Alaskan Native populations, diabetes is one of the medical conditions that we work with and we focus on. Clearly, many of us in the room know that when there is a medical condition onboard, there is often behavioral, health, what we would call mental health conditions as well. There are other feelings that come along when we have a medical diagnosis. It was really important that we got additional funds.

Right now, our '17 budget was $5.1 billion. And the reason I bring that up is now we will see how many funds we put towards mental health and alcohol and substance abuse. For alcohol and substance abuse, in particular, we have $2.1 million, and for mental health, we have $94 million. So a total of $312.4 million. If we look at that in comparison to the billions that we get, it is a very small budget. We really have to focus on that people and that partnership and the quality and our resources, which are our priorities within IHS because we have to really make our efforts count. We have to look at how are we going to have outcomes with the funds that we have.

With that, we will talk about how that is split up. On this particular slide under mental health, you will see the dark piece on the bottom. What is important to notice is that 60 percent, which is the green up on top, are the funds that are sent out to the tribes. Out of our IHS budget for mental health, we send 60 percent of our money out to the tribes to run their tribal facilities that we just talked about.

When we look at the alcohol side, we only hold 20 percent give or take a little bit as IHS. The rest are over 80 percent is sent out to the tribes. Again, if we are looking at how do we make that big impact, it is very difficult when people say well IHS is not doing enough or IHS is not able to do enough. If you think about it, many of our funds are sent out to the tribes. IHS takes a different role as far as advocacy. We will talk about that in just a minute. We really have to think about how can we use those funds to our best of our ability at our IHS facilities and how do we provide enough resources and partnerships with our tribes for them to be able to reach out to others to help them as well.

When we look at our system and I just want to go quickly because I know we have a lot to talk about. We have over 2000 IHS, tribal and urban Indian mental health and alcohol providers. That is a lot of providers. But when you think you have 2.2 million in your population, this is where the waiting list comes in. This is where it becomes difficult to provide all the services, let alone to get passed the stigma to have someone come in for those services.

We also have 500 mental health and alcohol and substance abuse programs across all of our American Indian and Alaska Native communities. And then we have 12 of what we call our Youth Regional Treatment Centers. One just opened up in Southern California. We also have another one that is being built in

Northern California right now. Some of those facilities are run by tribes and some are also run by the federal government.

When we talk about the Division of Behavioral Health, that is where I am the deputy director and Dr. Cotton is the director, we have a huge umbrella. When I originally started there in 2013, I want to say there were six employees. As of next Monday, we will have 29 employees. We have grown tremendously. And part of that is the initiatives that I am going to talk about next because IHS has recognized that to run the initiatives, we need to have a representative within the office that is running that. But one of the pieces that is important to talk about with the initiatives is some of the initiatives are manned or “womanned” by one person nationally. It does not mean we have a whole staff of 29 people to do one initiative. We have one person that is still trying to assist everyone. That is part of why we really look for our partnerships to look at how we could have the biggest impact.

What we focus on is policy development, programming, budget formulation, our support and resources, our special initiatives and then we have some grant funding that we are able to put out for tribes, tribal organizations, and urban Indian organizations.

With the Division of Behavioral Health, coming back to our 12 IHS areas that we talked about, each area has a behavioral health consultant. And that behavioral health consultant is really the go-to between Indian Health Service headquarters and direct services on the ground for that area. Again, that is a party of one, taking care of an entire area.

However, those are folks that provide us advice that advise us in what is needed in the area and they are literally invaluable. It is just amazing to work with them.

When people ask for services in a particular area, we immediately connect them to their behavioral health consultant. They know their areas and resources so well. They are just an amazing partner that we have.

Some of our special initiatives that we have and some of the things that we have even talked here at our committee meeting is focused on trauma-informed care. Indian Health Service has taken a stance that there is inter-generational and historical trauma that has impacted not only American Indian and Alaska Natives, but many populations.

Part of what we do now whether it is resources, training, or any type of referrals is we are looking at how do we address trauma-informed care.

We have two major programs. One is Family Spirit. Family Spirit is a program that is culturally based and it is connected with the Johns Hopkins Center. It has been fabulous. Basically, what happens in a nutshell is they take community I will call them champions that have behavioral health backgrounds. Some are really maybe associate degree or could be a layperson. And they are an individual that will then go into a home health center with the family and it is usually with a mom or a dad that has a child that is birth to three. Their purpose is to build better relationships to teach those parents how to parent, how to take care of themselves, how to look for symptoms early on, how to reach out and make those referrals. This home health-based care – it has been phenomenal. It is one of the pieces that we have really tried to take and push forward because, again, it is taking funds from the national level and really getting them down on the ground so we can make an impact and improve the health of our younger generations.

The next one that we have is Pediatric Integrated Care Collaborative. This is one of our new initiatives. This particular initiative is really talking about integrating mental health or behavioral health within primary care. We are looking at the pediatric population in general. Right now, we have ten projects, pilot projects that are just getting off the ground and getting started. We are looking forward to what those pilot projects are going to tell us so we can also take that information and look forward into how we are moving that out in the upcoming years.

When we talk about some of our youth-focused initiatives, we have the Generation Indigenous, which came from the Obama Administration. With that, we have over 100 projects that we have funded right now that are really looking at improving our youth, the resilience, looking at how do we improve their self-esteem, how do we get them active, how do we get them to find their own voice and be leaders within their community.

And then the next piece that we have added is we have the Children and Mental Health Services within schools. How I had mentioned that there are BIE, Bureau of Indian Education schools, and there is also BIA, Bureau of Indian Affairs that puts in some funds for some schools.

What Indian Health Service has done is done some memorandum of understandings and agreements with the schools to be able to increase behavioral health in the schools. What they are doing is at the local level is if there is IHS service areas that can reach out to those schools, they are making a contractual agreement between the school and the IHS service unit, so providers can go into the schools and provide direct care at a school. I will talk a little bit more about that as well.

And then the last one under our youth focus is the Boys and Girls Clubs of America. Those are our Native Services. IHS has provided over $100 million to I believe it is 11 Boys and Girls Clubs of America. They have just taken off. They have been amazing. We have a Native Youth Lead, Minette Galindo, which is part of our staff, who just went to one of the recent Boys and Girls Club of America meetings. It was amazing. She put some of her videos on our Division of Behavioral Health Facebook and it literally had the most likes that we have had in the last two years. People love seeing the videos of the youth. They love seeing the activities. They love seeing the youth be empowered. That is one of the investments that Indian Health Services has been very excited about.

Here is one of the pictures of Dr. Cotton who is in the middle. This is when they were signing one of the MOUs. They are trying to build those partnerships. It will be interesting to see how many more Boys and Girls Club will be open. I have to say even my tribe opened a Boys and Girls Club. Here I am in DC because it has been needed. And actually, when I did my dissertation on my tribe, which is one of the things that was my recommendation from my dissertation. It was very exciting to see that happen.

Some of our Behavioral Health Grants that we have – we have a lot. It has been amazing how much funds that the Division of Behavioral Health has sent out to the tribes. We have some funds that support our Substance Abuse and Suicide Prevention efforts. We have some funds that support Domestic Violence Prevention. And then here we have our Behavioral Health Integration. We call it our BH2I. We have the Zero Suicide Initiative. I am going to talk a little bit about each of these. And then we have our Urban Indian Health Education and Outreach, Preventing Alcohol-Related Deaths, and then finally we have our Youth Regional Treatment Center Aftercare.

I am going through these very quickly. Our Substance Abuse and Suicide Prevention Initiative was established in 2009. Right now, we actually have 175 total projects to a total of $27.9 million. They are on a five-year funding cycle. We had a pilot project initially in 2009, and now we actually have the demonstration project has moved into an actual initiative. They have an evaluation that they are working on. We will have reports. We will be able to have outcomes. We are really looking forward to what the data is going to tell us and how we can see what the outcomes are of the initiative as it rolls out.

This one does have four purpose areas, to basically say it in a nutshell. I made sure I left a slide so people had it for reference later. We are meeting the tribes where they are at. Some tribes are really in the organizational and strategic planning effort. We wanted to make sure that tribes that needed that had that particular funding stream and were not competing against tribes that were already at the prevention piece.

Then we have those who are looking at suicide prevention, intervention, and postvention versus substance abuse prevention, treatment, and aftercare. Tribes may have both, but they may have only applied to one or they could apply to both. Again, we wanted to be able to provide options for tribes so where they felt that they really needed to start is where we could meet them.

And then the fourth area is the Generation Indigenous, and that is very youth-focused. And actually, a lot of the tribes that have those funds have actual youth councils that they have started. It is kind of exciting to see that happen.

As far as the Domestic Violence Prevention, this came one year later. This was in 2010 when it started as a pilot project. And now we have 83 projects to the tune of $11.2 million, and again this is on a five-year funding. It is set up very much the same way as far as the evaluation as the substance abuse and suicide prevention.

And this one has two areas. The two specific areas, one is domestic violence and sexual assault and then there is a prevention, advocacy and the community response versus the purpose area number two, which is Forensic Health Service. I am going to pause right there. Does everyone know what Forensic Health Service is? Does someone not know? Thank you. I found that out my last time I was talking about this.

For Forensic Health Service, for me, the layperson way of saying it is really when there is someone that has a need that has been sexually assaulted that needs to have an exam where our providers are trained in the facility to be able to do that exam, to be able to document the exam, to be able to work with law enforcement, to ensure that the process of the evidence is moved forward. Therefore, if there is a prosecution that we can ensure that we have that for the law enforcement.

One of the pieces that we have found through the Forensic Healthcare Service is that in rural populations, if an event happens and there is someone that has been sexually assaulted, they have to go miles away for an exam and oftentimes they are not willing to do that. Part of this initiative is to really train our forensic health providers. We have actually developed a forensic health care website on IHS. It has all of these free training modules that folks can go to. Again, that is for all IHS tribal, urban organizations. And some of them are also in-person trainings, but there are a lot of online trainings that assist with forensic health care.

On our Behavioral Health Integration Initiative, this is a new one that just came out. It literally started September of 2017. Our staff was extremely busy because I believe we found out in July that we were pushing this money out. We hustled and made sure that we were able to put out $6 million for 12 awards. Each awardee got $500,000 a year for a three-year term. It is really focusing on integrating, like we talked about earlier, health within our primary care. And we are looking forward to seeing what our evaluation pieces look from this so we can make our next steps forward.

With that, again, you see here in November. These were all happening at the same time. The Zero Suicide money came up. We were able to put out funds for the Zero Suicide. It is really to reduce the risk of suicide for all individuals. This is not about screening one individual or improving screening, this is about a community response. This is looking at how do we reduce suicide rates within an entire community.

What we have done is we have funded eight sites to implement the Zero Suicide model. Each of those sites will have $400,000 for the next three years to be able to put that money to use. We started with ten pilot sites. Of those ten, eight said we are ready to actually implement this model within our community. That is where we are at right now.

As far as our Behavioral Health Grants, for the urban Indians, one of the pieces that is really important is that we put out $75,000 to the National Council on Urban Indian Health. That is to focus the increase of raising national awareness and visibility of behavioral health within urban Indian Health Centers. There are not a lot. There are 34 urban Indian Health Centers. If you think about it, there are only 34. We have to raise that awareness. Many tribal folks do not even know where to go for urban Indian Health Center or what services are offered. Part of that is raising that awareness and increasing their partnerships to help raise that awareness too.

One of the very difficult pieces for me to talk about personally is our preventing alcohol related deaths. This came forth because of a lot of the situations that were occurring in particular in the Navajo country where folks were actually dying on the streets from alcohol-related deaths. It would be folks who were intoxicated and literally freezing to death because there were not detox centers, because there were not services that were provided. IHS responded with some funds. We have awarded $500,000 to Oglala Sioux Tribe, which is in our Great Plains area, and also $1.5 million that we put to the Navajo area because it will be focused on the entire Navajo area. Those projects started in September of 2017. As you can see, September, November – we were busy little bees making sure we got all of these funds out to the tribes.

The focus of this is really providing social detoxification services for alcohol for that community so we can look at really preventing the unnecessary deaths.

Then we go to one of the uplifting grant programs that I am just exciting about, is our Youth Regional Treatment Center Aftercare. We have awarded one already, the IHS YRTC. We were awarded the tribal, but we are working on the IHS YRTC, which is the federal one. They will get $810,000 for three years, which is a total of $1.6 million for the two awards.

This is a new initiative that we brought forth. We recognize that our youth that are in treatment centers – once they leave that treatment center and move back home, we lose them. We do not have case management to follow them. We are not sure how they are getting supported services. We had to figure out a way of doing this.

Part of our aftercare is that we have two facilities that are going to pilot how they are going to follow folks, how they are going to evaluate that and then we can look at really what the outcomes are of the treatment and they will share that with our other YRTCs to be able to implement that as well.

Now, I am going to move into how IHS has taken all of these initiative funds and funneled it through, if you will, are TeleBehavioral Health Center of Excellence. The TBHCE sits within our division as well, and is run by Dr. Chris Fore. He and his staff provide tele-education in tele-health, including technical assistance for all of our 12 IHS areas.

Again, that is available for IHS federal facilities, our tribal facilities, and our urban providers. They all can come in on any of the presentations and take continuing education.

Some of them have really taken advantage of managing noncancerous care training. We call it our essential training. They provide telebehavioral health services right now in nine of the IHS areas. Some of those are done between IAAs. With that, the IAA, the Intra-Area Agreements, what we have tried to do is he is connected with the University of New Mexico who has reached out to a lot of our continuing education folks for whether it is psychology or social work or the medical field, and they provide the CEUs or the CMEs for our providers. They are able to utilize those contracts so they can reach out to a variety of areas.

I have decided to put a map, I am a very visual person, of where we are. You will notice down in the South, we have a whole lot of them because they are sitting down there. We are starting to spread out. We do have a lot of requests to add additional sites. The issue has been funds. Again, we are having to be creative of how do we build this, how do we build our partnerships so we can get either tele-health equipment there on site and be able to get providers and/or hire the providers and be able to have them on board to provide services?

If we look at the services provided when we look at our patient scene just by tele-behavioral health, they saw over 8000 patients. This was just in FY17. Those are 8000 patients that would not have been seen. There is a part of us that were like yeah. We are actually increasing the access to care through this. When we look at the number of hours that they have provided services to or we look at the amount of sites that they have provided services to, it is very exciting to see that we are starting to expand that.

What I was more excited about personally was the types of service. They saw more children than any other population. When we are thinking about reaching out to our youth and we are talking about breaking through the stigma, our children are more likely to come for services because they do not know all of the stigma as some of our adults. Those are our children that we are hoping to change the future. That was really exciting.

And then the other piece of course near and dear to my heart is counseling was the reason that they came in for services. Of that, 21 percent of it was for addiction. And then we have 18 percent for adults. It is interesting that our children are almost twice as much as our adults for coming in for service.

I just wanted to provide just a quick overview of what we do for tele-education. They do support a lot of our educational webinars. I know at our last committee meeting, we were talking a little bit about what are some options of how do we raise awareness of this committee. How do we get out to providers? This would be one way that Indian Health Service could partner and providing those educational webinars out to our providers.

When we look at continuing education credit, if you go down to the third bullet, we have 4336 continuing education hours. For me, as a provider, for my licensure, I have to maintain 36 hours for my social work and then 40 hours for my alcohol and substance abuse hours. If you think about that if I could do these where I am remote, it would save me tremendously, which means I can provide more patient care. When we think of those types of ways of being innovative, it is just very exciting to see how we are able to make a change.

This is really where I want to go with the conversation. One of the things we have started is our Indian Children's Program and we call it our ICP. We are all about acronyms and Indian Health Service. I apologize upfront.

We do provide training. Here are three areas that I felt were very important to talk about. One is our focus on autism. We do have six series on autism. It does not seem like a whole lot. They are still working on some more and actually we have some that are in the pilot phase right now that we were just having a discussion about yesterday.

We have six series webinars on autism for our providers to have awareness. And the reason we talk about how important that is is because if the providers cannot get away to actually go for autism-specific training, at least they are able to get it remotely.

We also have five series on Fetal Alcohol Spectrum Disorders. And many of our providers have talked a lot about when folks are coming in and they are starting to recognize symptomologies, which is when they are going maybe I really need to refer someone out for a specialist. Maybe I need to look for a developmental pediatrician. They are starting to have more conversations. They are starting to have more awareness. That is exactly what we are talking about with our tele-behavioral health. Raising that awareness so those flags are raised right away so we are not waiting years down the road for somebody to be referred off for confirmation of a diagnosis.

And then the last piece is for our ICP Pediatric Neuropsychology Consultation. I am going to look at my notes here real quick because I do not want to tell you the wrong age groups. With that, what we have set up are consultations that we provide to all of our providers. Again, this is to Indian Health Service, our tribal and our urban providers. Those providers can actually request a consultation for any patient that is between the age of 1 and 23 years old. We are having conversations about expanding that age group.

But they are scheduled every second and fourth Friday of the month. They have a four-hour block. They ask for consultation for 15 minutes. Within that consultation, what will happen is they will already pre-fill out a referral sheet for the consultation and then the provider will have that to be able to look at it and kind of have some thoughts before they have their consultation. That is really to help them clarify and differentiate diagnosis so they can provide behavioral health interventions that are not only for the individual that is 1 to 24, but also for the family.

One of the pieces that we have noticed with tele-behavioral health is this has really helped the families also deal with a diagnosis being given. Also deal with the stigma that comes with that. The extra stress. The concern about what do I do now. I do not know what resources I have. This is part of the pieces that our primary care needs to step in and provide those resources and provide the follow up.

For one of the pieces that we are looking at is that the more that at headquarters we can identify those resources and we can build our websites so we have those resources readily available for anyone electronically, the better we can prepare our providers to deal with any diagnosis that are coming, to deal with questions and be comfortable with referring out as necessary. That is kind of the direction that Indian Health Service is moving forward with.

What I tried to do, and I know this slide is a little bit hard to see, are some of our consultation clinics. The main issues have been on Fetal Alcohol Spectrum Disorder, on Autism Spectrum Disorder and ADHD. Is that a surprise to anybody in this room? No. But what is exciting is that we are able to follow that. We can say these are three areas that have been really hot topics for us. And then we can go down and we talk about intellectual disability and learning disorders, which run along with our TBI. And then we start talking about other disorders going down.

One of the pieces that we are really excited about is that we have acquired providers that can do these consultations because oftentimes within the field, what we hear from are providers are – I think there is something going on, but I am not really sure who I can consult with. I really want to talk through this, but I do not know who I can do that with. Through this system, they can have a consultation and we can assist them very quickly.

Overall, if we look at how we are achieving the IHS mission, we really are taking a holistic approach. Coming back to one of our first slides, this is the comprehensive, culturally-appropriate approach that we can improve the mental health and wellness of American Indian and Alaskan Natives and that is through our YRTCs. That is also through our schools. It is through even transitional living. I was so excited to hear about transitional living when we were here in our committee meeting last time and the time before. That is extremely important.

We also wanted to reach out to the detention centers, the tribal police. And part of that is we clearly recognize that many folks that are in our detention centers that are in our jails, that are in our prisons have not been diagnosed, have not received the help they needed. That is not necessarily the best place for them. If they are there, why aren't we providing a service to them so when they do leave, they have a better opportunity of being more successful? That is one of the pieces that we look at.

The other piece is looking at the rec centers and that is kind of where our Boys and Girls Club come in and our outpatient facilities. And with all of this, this is where we are really looking at the person, the family and the community as a whole. All of our approaches have always tried to be holistic and culturally appropriate.

One of the things I wanted to leave you all with is staying connected with IHS and looking at our missions. We have our website at IHS.gov. We have lots of presence on Facebook now. Social media is the thing. It is hilarious when I am talking about with people of even hiring. I got my job off social media. I am like really. I am not a millennial. Some of that was a little different to me. We do have pieces on YouTube. We are now on Twitter. We are even on LinkedIn. We have kind of stretched out. It is a little bit different for the federal government to say we are going to be on all of the social media networks. However, we have realized we have built some fabulous partnerships. And some of our partners have been able to just find out about initiatives and about our programming just through those means.

And then lastly, I just left my contact information because I know we do share the slide deck. If anyone wanted to reach out to me directly, you would have it. Thank you.

(Applause)

DR. BIANCHI: Hello Marcy. I am Diana Bianchi, director of the National Institute of Child Health and Human Development. Thank you for the presentation.

I wondered how accessible either mobile phones are or computers are, to people in rural areas in the tribal communities. Can you give an overview comment on that? That could be a challenge or it could be a great opportunity, especially for the remote tele-consultations.

DR. RONYAK: Excellent question. Thank you. It is actually kind of funny because most youth have a phone more than they have a computer. Some of the statistics we were working on – we were working with folks from Text, Talk, Act and looking at the mental health application. They were able to identify within rural communities. Most of the youth will have access to a smartphone of some sort. When it comes to the computers, most of the youth will use computers that are either at the school. Some do have them in the homes. There are some tribes in tribal communities that they have very limited access to any kind of Internet.

However, what has been happening is tribes are now applying for federal grants to provide that type of IT infrastructure. We are starting to see the numbers go up.

When we look at areas that are really remote, there is some in Navajo area that is extremely remote. Alaska area that is extremely remote. A little bit in the Great Plains area so more of the Dakota area that are remote. Other than that, we usually have pretty good connection.

When it comes to tele-health, they have not had any difficulties getting in the equipment that has been needed to be able to provide the tele-health. The bigger struggle has been having enough providers to provide the hours that are needed.

Thank you. I hope that answered your question.

MS. KAVANAGH: Good morning. I am Laura Kavanagh from the Health Resources and Services Administration in your building. Thank you so much for the presentation. Can you talk a little bit – building on your last comment, your tele-consultation services. Do you have waiting lists? Do they have access to a multi-disciplinary team? Can you talk a little bit more about that consultation?

DR. RONYAK: Yes. Sometimes there is a waiting list because it is the second and the fourth Friday. You may be waiting. We try to make it very quickly, a short period of time. When they do send in that referral, that is what clicks on which provider that needs to go to with the specialty. If that provider does not have all the answers, they will consult with others before they get on that consultation. Part of what we are trying to do is be able to bring that multi-disciplinary team view to the consultation.

There is follow-up to that. If all the questions are not answered or there are additional questions that are generated during that consultation, they will schedule another one and be able to come back to that. What they try to make sure is that they are able to answer those questions and then follow through with the people.

Any other questions?

MR. ROBISON: You talked earlier about one of your priorities being improving resilience and self-esteem among young people. In light of that, have you funded any research into the role of autistic people in Native societies in history? It would seem to me that you are funding or other Indian agencies are funding studies into Indian culture in general. Have you studied autistic culture with a view to building self-esteem through understanding?

DR. RONYAK: Thank you for that question. One issue and I guess I should have said this. Indian Health Service does not necessarily do research. Part of what our research would come from would be the evaluation of any initiative that we roll out. You are absolutely right. Autism is an area within IHS that we do not have a lot of information even on the number of those who are diagnosed.

I can speak from personal experience that Indian Health Service is not even aware of my son because we are urban. He is not in the Indian health system electronic health records right now. He would not even be counted in the numbers. That is one of the pieces that I have taken from this committee back to Indian Health Service, so we can have those conversations internally about how can we, one, identify our autistic population so we know how many are out there, we know what age group that have been diagnosed. Are we looking at youth? Are we looking at adult populations? Are we looking at somewhere in the spectrum so that way we can also identify where we really need to work on identifying resources for them and then looking at how to write for other initiatives in the future. You are absolutely right. I appreciate you bringing that up.

DR. BIANCHI: Sorry. I have one more question that I forgot to ask. I was interested in the blood quorum that you had mentioned. Is that done via commercial DNA testing? I assume it is DNA testing.

DR. RONYAK: Actually, no. The blood quantum piece – it is a little bit difficult. What they do – each tribe is a little bit different. I can speak to what my tribe does. When you have a child, clearly, they do a blood test whether you are married or you are not married, to ensure that the biological parents are really the biological parents because of the whole blood quantum piece and the 25 percent has become very political because you have to be 25 percent or more.

Once that piece is done then each tribe has historical records as to what the blood quantum is of my great grandparents and great, great grandparents, et cetera. Then they mathematically computate how we are in our family tree.

One of the issues that has happened, and I want to say it was 1967, I could be misquoting here. There was a large fire and when that fire happened, a lot of what we call tribal roles, which are our family trees, that information was lost. There was some legislation that was put forth that if folks knew what their blood quantum was or had a record because we each have – we call it a blue card. It has my blood quantum on there. It has my family tree lineage there –

were to bring it forth and they could recreate the records.

For those that did not, they were able to make an assumption of what blood quantum was from other records, which would be oral conversations from our elders in the community. And after that then they had to recreate all the records for the tribe of where our family lineages start. Then we continued from there.

There can be some problems with that clearly. But the blood quantum is held by the tribe and each tribe has an enrollment department that mathematically figures that out for you and lets you know. And then that is put on your identification card.

DR. BIANCHI: That is very interesting and thank you. But I am wondering about people who are having their DNA tests who now find out they are Native Americans. What happens to them?

DR. RONYAK: So sorry. I forgot all about that whole Ancestry.com. Yes. Those who are doing DNA testing, they may find that they are Native American and they may be able to find what part of the country they would come from. Then it would be up to them to try to go back and figure out with the enrollment department of that tribe or tribes because they may have specific tribes to figure that out if they can that piece. They could use Ancestry.com, the family tree piece, and come back to find out if one of those names match up. But there would be a lot of historical pieces, but they would work with the enrollment department at each of the tribes.

MR. ROBISON: You said that the Indian Health Service essentially devotes all of its budget to delivery of services as opposed to research. Are you saying that you do not fund research into specific issues that the Indian Health Service would address? If you don't, does some other government agency do that or do you actually do that, but it is just a small part of your budget?

DR. RONYAK: Thank you for the question. We do have a research department, but it is more for our folks who are mining our data that is coming in from our electronic health records. It is not necessarily research as we would think from like NIH or CDC. IHS is a direct service organization. We are not a research organization. To answer your question, no. We do not have funds set aside to do specific research activities, but we have funds set aside for our research department that is mining data from electronic health records, which would all be code-able by diagnosis or IDC-9 and IDC-10, things of that nature. It is a little complicated. That is part of why Indian Health Service – we really partner with CDC and NIH and many of those agencies have tribal offices within there. We talk about what research needs to be done. We share research with each other. We talk about what we have learned from our initiatives to help them move forward with whatever research they are working on.

DR. GORDON: John, just so you know, the NIMH, and I think all the other institutes, do conduct research specifically aimed at Native American populations. Most if not all have a Native American office within the institute. It is part of the purview of the NIH to conduct biomedical research in Indian communities throughout the United States.

MS. CRANE: I was curious about the way that the tribes work together to deliver services because you were describing situations where, for example, a mother could be enrolled in one tribe and the daughter could be enrolled in another tribe or a son could be enrolled in another tribe. Since the tribes are administering services directly, do they coordinate in order to serve families that might have multiple different registrations or can this cause issues?

DR. RONYAK: It always can cause issues, but they do work together. For example, the mom – and you brought up a great example. The mom could be from the Coeur d'Alene Tribe and the child from the Colville Tribe and the dad from the Umatilla Tribe. It is, again, remember the blood quantum. They decided where they wanted to be enrolled.

If they were residing on one tribe, what they would do is have that service unit talk to the tribe of the enrolled child with that service unit. They could either transfer the records over and provide services or they would work together and provide services. That goes even within the tribal court systems because it gets a little complicated when they are talking about custody, divorces, and things of that nature. The tribes do work together. Their goal has always been about providing services for the tribes.

When it is someone who is within IHS and IHS facility, we work with tribes to make sure there is continuity of care if they are moving back and forth between mom and dad as well. Good question. Thank you.

DR. SCHOR: I wonder if you could comment on whether there are cultural or stigma-related barriers to individuals seeking the services that the Indian Health Service provides.

DR. RONYAK: Absolutely. Thank you. Excellent question. There are always barriers. Some barriers can be financial barriers. Some can be distance barriers. Some can be lack of provider barriers. It means that they do have access. There is a building, but they just do not have a contractual provider or a full-time provider on staff.

When it comes to the stigma, there is a lot of stigma out in Indian communities. Part of it is the lack of mistrust in general. That would be the very top layer. Then it would be I am not sure I want to know what is really going on with me. I am not really sure I want to go in to find out. Then it is I do not want other people to know.

One of the things that happens in tribal communities is you know everyone's business. The problem we have is some folks say integrated care. Let's put everyone in the same building. Well, let's say you come in on the north end of the building and you walk by my cousin who is sitting at the registration and you are coming in. I am already called on the south end of the building saying she just walked by. I wonder what she is doing here. Unfortunately, that is part of the problem in small tribal communities as being a provider.

When I was the tribal psychologist, everyone knew where I lived. Not the safest thing. Everyone knew where I lived. They knew how to find me. They knew my cars. They knew my husband's cars. They knew my children. It is complicated.

It is really important for the providers to build that trust to set those boundaries. I think as we set those boundaries with our patients, they clearly will respond, and they respect that. And oftentimes, that helps them get over that stigma because they realize we are there to help them.

Thank you for that question.

DR. GORDON: Thank you very much, Marcy, for a fantastic presentation.

(Applause)

DR. GORDON: Thank you to the committee for an active discussion. Hopefully that will continue as we move into the committee business portion of the morning, the first component of which is the summary of advances. You will notice in your folders that you have three different packets for the summary of advances. I am going to let Susan describe those to you and then we will go into the discussion.

DR. DANIELS: Thank you, Marcy, for your informative presentation. We appreciate it. You have three different packets in your folders. One is the combined summary of advances nominations for the entire year of 2017, which we provided just in case someone wants to see everything under a particular category.

We have a packet that says summary advances nominations vetted January through October. These are the ones we went over in previous meeting and they were basically accepted by the committee as nominations.

And then the one that we will be discussing today is the one labeled October through December 2017. These are the newest nominations that we have not yet discussed, but we are about to discuss.

DR. GORDON: Are you going to go over the process?

DR. DANIELS: Yes. To get started, I just want to briefly go back through what the processes for the Summary of Advances especially since we do have some new committee members who have joined since we last did this. The Summary of Advances is a statutory requirement under the Autism CARES Act and it provides a summary of research advances, informing Congress and the community of what has been happening in terms of advances made in scientific and services research.

The format for the Summary of Advances that we prepare in response to this requirement is a booklet with lay-friendly summaries of the top 20 most significant advances in ASD biomedical and services research that were selected by the IACC. This typically includes articles addressing all seven topic areas of the IACC Strategic Plan.

The process we have been going through over the last year is that we have been sending out monthly emails to committee members to solicit article nominations from all of you. You have been sending those in along with justifications.

We have compiled quarterly – these different advanced nominations and we have discussed them at IACC meetings. You have them here in your packet. Today, at our meeting, we are going to be discussing the top articles. At the January meeting, we are going to be discussing the top articles among those nominated. Actually, we are going to be talking through the ones that were nominated this time and vetting those.

After the meeting is over, we are going to be voting on the top 20 articles to be included in the 2017 IACC Summary of Advances, the ones that will be highlighted and written up. We will be sending out written ballots to all and you will have a chance to vote on what your top 20 are. We will take a tie-breaker vote if necessary.

Once you have selected the articles, we will provide summaries of each of those articles, short summaries that are in lay language that anyone can understand.

The nominated articles that were not selected will be listed in the appendix of the document so that all of the nominations will have some recognition. About March, we will be sending out a draft of the publication for the committee to briefly review. And then the final publication will be presented at the April 2018 IACC meeting, which will happen during Autism Awareness Month. That is our process.

Any questions about that?

To go over what has happened in the last year, we have had 11 different IACC members submit a total of 81 nominations and across the questions of the Strategic Plan, we have some statistics here of how many different articles were nominated in each of those categories.

Now, we can move to the set of nominations that came in this last quarter.

DR. GORDON: We are going to go ahead and proceed with a discussion. Typically, what we have done here is allowed those who have nominated articles to speak up about ones that they particularly would like to bring up to the group, to highlight them for the eventual voting as well as any comments from any members who feel that there are – the articles that are nominated that perhaps should be left off the list or argue against consideration in the final list.

We usually go through it question by question. We will go ahead and start with Question 1 and ask if there are any committee members who want to speak up about any particular articles that are included here.

DR. DANIELS: For those following along on the phone, these documents are available on the web.

DR. GORDON: Go ahead, John.

MR. ROBISON: Actually, Josh, I want to raise a concern about your nomination of Race influences parent report of concerns about symptoms of autism. It is on page 2. I agree with you that this is an important paper. You say that disparities in services between black and white communities are a significant issue, which I think we are all aware of.

Then you point out that this report shows that black parents had significantly fewer concerns about autism in their children in general than white parents. And the obvious implication is that that leads to fewer services being rendered in the future. I guess that is a reasonable hypothesis.

But what worries me is that we do not have a companion study to this, looking at differences in concern between autistic and non-autistic parents and their children. When I think of my own parenting experience as an autistic dad, people told me that I was unconcerned about things that I should be concerned about and my kid did not get services and of course I did not get services. I am not sure it is as simple as a black and white thing. I think that this is a significant paper, but to me this is a paper that strongly suggests that we need to break these communities down and understand what it means.

I do not think, for example, that my feeling that autism is not so terrible a thing when it is diagnosed in my son should lead to my son getting fewer services or me getting fewer services, but I recognize that is the truth of it. What are we going to do about that?

This is an important paper, but it is important because it points to what we need to do next. I would like to suggest that we make that clear in our summary.

DR. GORDON: Thank you. That is a helpful comment. I have one point to make with regard to the issue of awareness of all health issues, which I am not sure is exactly essential to the point you were making, but there is a control built into the study, which is that the black parents were as likely to note concerns about non-mental health issues in these same children.

It seemed to be at least specific to the – their underreporting of concern seemed to be relatively specific to the autism-focused symptoms. But I agree that much more work is needed.

I think in general, we find in our mental health disparities research portfolio that we have a lot of evidence for disparities and not have a lot of evidence about exactly why or exactly what to do about it. I would say that it is good that you point that out because these are the really important next steps that the disparities research community and that NIMH, really needs to be able to address.

MR. ROBISON: I think that it really is something that the community does not recognize. In my time, serving on these government committees, I have come to recognize that I suffer, and suffer is the correct word, from a number of co-occurring conditions that accompany autism. You know I lived my whole life in ignorance of that because it is the way I was from birth.

When I see a paper like this, I think what you said – yes, that is an important point that the black and white disparity did not exist with respect to other differences, only autism, but I think it can affect us very much and in ways that we cannot recognize and we need outside help to understand if we are going to get help and get benefit later.

DR. GORDON: I appreciate that, John. Are there other comments about this particular paper?

MS. CRANE: I would like to add. I certainly agree that this study should be in the Summary of Advances. But since we are talking about racial disparities in autism, I think another thing we have to consider is that sometimes if a culture is not very concerned about a particular manifestation of autism like repetitive behaviors, for example. That might not mean that they are wrong that they should be really upset about repetitive behaviors. They should be really concerned about that and we need to educate them that they should be concerned. Maybe instead we need to tailor services so that they actually emphasize and respond to the things that parents actually are concerned about like academics, emotional development, disruptive behaviors, and other things that are also potentially signs of autism, but are not getting talked about as much in outreach to parents.

DR. GORDON: Thank you, Samantha. Are there other points about either this paper or any of the other papers listed in response to question one?

DR. DAWSON: Hi. This is Geri. I would like to make a comment on the second paper.

DR. GORDON: Go ahead, Geri.

DR. DAWSON: This is the paper on looking at the vineland Adaptive Behavior Scales. I am at a little of a disadvantage –

DR. GORDON: Can you say which page that is on?

MR. ROBISON: The first paper, Vineland Adaptive Scales.

DR. DAWSON: -- what I hear and what I see is out of sync. I am a little at a disadvantage. But I am pretty sure I saw a slide that had that large analysis of the Vineland Adaptive Behaviors Skills and minimally clinically significance difference paper.

DR. GORDON: Yes, we have it. It is on the first page.

DR. DAWSON: Right. I just wanted to make a comment on that. First of all, I am not sure this is the category it should be in. What this was is that, as you know, one of the biggest challenges in evaluating the efficacy of novel new treatments is the ability to measure whether the treatment had an effect.

Many people have been working on the novel ways of assessing outcomes. And one of the measures that has promise is the Vineland adaptive behavior scales, particularly the socialization subscale.

But the challenge is that there is development that goes in a trial. For example, if you are with a five-year-old, over six months, you are going to see changes on the Vineland that are just due to development. You have to disentangle that from the treatment effect.

What was done here is they gathered all of the Vineland data available in the literature, and this is thousands of children and adults, and then looked at what is the natural course and then made a decision on how would you determine what would be the minimal change that you have to see in order to say that this treatment was effective. That was a huge amount of work. It is actually pivotal for the field, and many of us are using the Vineland as a primary endpoint in clinical trials. This study is just hugely helpful in being able to conduct trials.

I just wanted to give a context for that, and also suggest that perhaps that you go in the treatment category.

DR. GORDON: Any dissent regarding moving into the treatment category? Okay. Thank you. Laura, did you want to say anything else about it given that you --

MS. KAVANAGH: No. Thank you, Geri, for that overview as well. I would support the movement to treatment as well. I feel like it could be in either, but the implications for treatment are quite remarkable.

DR. GORDON: Other comments about anything in Category 1, which is the first four pages?

MR. ROBISON: How many studies are we going to publish in our summary? Just one study for each question or more than one?

DR. DANIELS: It is a total of 20 and it can be divided among the seven. There have been some years when one of the seven questions had no final selected articles.

DR. GORDON: David, I had a question about one that you put forth. It is not a question to raise doubt about whether it belongs here, but just a follow-up question to it. As I am looking at it, which is – the study, as you summarize it, demonstrates differences in children at risk versus children at lower risk for autism, in imaging findings, particularly in cerebrospinal fluid amounts. Have these authors looked at whether that predicts risk for a diagnosis later in life?

DR. AMARAL: That was the findings. Increased in extra-axial at 6 months was associated with diagnosis at 24 months, actually.

DR. GORDON: How many individuals were in this study?

DR. AMARAL: This is the IBIS Network. It is a big study. There were 55 children that ultimately had a diagnosis of autism out of I think 347 that were studied.

DR. GORDON: This is then another aspect for early screening akin to the study that we highlighted I believe last year, of brain growth patterns in 6 to 12 months. Is that from the same group or is this a different group?

DR. AMARAL: Same group. I think the importance and significance in my mind is that it again shows that brain changes at six months are predictive of a later diagnosis of autism. That is number one.

Number two is it highlights the fact that disequilibrium of the cerebrospinal fluid system might actually be associated with – it turns out that in this paper and the previous paper, children that had more severe autism when diagnosed, had increased level of extra-axial fluid over those who had less severe. The correlation between the amount and the severity of autism, suggesting that having this problem with cerebrospinal fluid might actually have some causal relationship, although that has to be demonstrated.

MR. ROBISON: I have another study that I think asks a similar question that is worth reporting. Jennifer Johnson nominated parent-reported strengths in children with autism. In that study, Parent-reported more strength in cognitive functioning and personality characteristics.

I think what that study points to is that parents are recognizing autism as exclusively a behavioral or cognitive difference in their children. So they recognize certain cognitive strengths in children. We have seen what I would regard as very powerful evidence of substantial general health problems among autistic people later in life. I think it is very reasonable to ask if early recognition and intervention for those vulnerabilities, could be very, very helpful for us autistic people.

I think, in particular, this study suggests to me broad parental ignorance of the likely medical problems that autistic people are wrestling with.

We talk here about how pain might cause us to act out and be misinterpreted as a psychiatric problem, when in fact it is a response to pain. This study to me suggests that we need to address that in a more focused way in our research.

DR. GORDON: I must confess I am missing the connection. Are you suggesting that parents focus on the cognitive symptoms and strengths of their children, and therefore are missing the physical health manifestations early in life?

MR. ROBISON: Yes, exactly. I am suggesting that the fact that the overwhelming thing parents report here is cognitive strength and cognitive issues suggest to me that parents are totally ignorant of what medical things may be lurking in the background in autistic children.

DR. GORDON: That is certainly something we would want to look at. I think that is an interesting hypothesis.

MR. ROBISON: I guess it is sort of a contrarian interpretation of what the scientists reported, but I believe it to be likely.

DR. GORDON: Laura, you had a number of them this time. I wonder if there are ones particularly in Group 1 that you wanted to highlight as one or more that you really are --

MS. KAVANAGH: I am realizing that we were quite generative in our submissions.

DR. GORDON: It is wonderful. But I am also thinking that given that you probably submitted almost 20 this time alone that you might want to highlight a few that you really feel strongly about.

MS. KAVANAGH: I think of the Vineland and I think both Jennifer and I recommended on page 4, the Moody screening for autism with SRS and SCQ. I think that is significant as well. I think the findings regarding the DSM-IV and -5 are interesting and important. But I would highlight the Moody from the screening and diagnosis section.

DR. GORDON: Thank you. Moving right along, we will move to Question 2, the underlying biology. There were a number of submissions there. Anyone want to speak up about any particular articles?

DR. BATTEY: What pages are we on, Josh?

DR. GORDON: Thank you for clarifying. We are pages 5 through 7. There are seven submissions in Question 2.

I wanted to take this moment to highlight in particular, one of the two submissions that we have put in. Just to mention that the Weir study on page 7, it is the last one on page 7, is one of a rare, but growing number of studies looking at postmortem brains of individuals with autism who died, but donated their brains for research. Which is wonderful and has been an area where it has been challenging to develop large groups of brains. This is not the largest study that has been published, but at 32, David, you might comment as to whether that represents a significant contribution to the literature. It is the largest published to date.

At 32 brains, we might think this is preliminary. Given what we know about other psychiatric disorders, it is probably a challenge to think of this as definitive, but it really represents a step forward for the field of postmortem studies in autism to be able to collect that larger study and to conduct it that rigorously.

DR. TAYLOR: This is Julie Taylor on the phone. I would like to highlight the Duvekot study, looking at bidirectional effects between core symptoms and anxiety. We have had a lot of conversation about how co-occurring mental health problems are such a pressing concern. We just know very little about how those relate to core symptoms and particularly directionality. I think this is a really nice step forward in terms of moving our thinking forward about what leads to what and chicken and egg issues in predictors. I thought that this was a nice paper.

DR. GORDON: Thank you. I wonder if you or David might comment on the methods used to establish the directionality between – the connection between anxiety symptoms contributing to social communication impairments, but not vice versa. That is my read anyway of the justification.

DR. AMARAL: I do not remember the details. Maybe Julie does. Julie, do you remember the details?

DR. TAYLOR: Yes. Correct me if you remember this differently, David, but they used cross-lagged models. They are accounting for the initial level of autism symptoms and internalizing issues of anxiety and looking to see which earlier variable predicts the later variable, controlling for both directions of effects at the same time as well as stability effects.

DR. GORDON: Got you. It is essentially a temporal order and then also I would imagine some sort of prediction method.

DR. TAYLOR: Yes.

DR. GORDON: I think from my own perspective, I would want to take – I am going to try to take a look at this paper for myself just before I would vote. But in general, the methods used for this is to try to look at not just which occurs first, but whether the earlier symptoms in one predict later occurring symptoms in another.

DR. TAYLOR: I was just going to agree.

DR. AMARAL: I wish I remembered the methodology better. What impressed me was that the anxiety symptoms clearly exacerbated the social impairment. The implication was that if you could treat the anxiety component, it would reduce the social impairment and then allow individuals to take advantage of other behavioral therapies that might go to the core symptoms of autism.

I think the other thing that was surprising in the paper was that there was a common assumption that the repetitive behaviors of autism may be actually related to anxiety. And again, not remembering exactly the details of how they concluded this. They found that that was not the case that they could dissociate the repetitive behaviors from the level of anxiety symptoms. Both aspects, I think, are interesting.

DR. GORDON: Do we know how big a study it was in terms of the number of subjects?

DR. AMARAL: It was a substantial number, but I do not remember the details of it. I am sorry.

DR. GORDON: 130, said Kevin, which is a decent size I would think.

Are there any other comments about that manuscript or anything else in Section 2?

If not, we will move along to Section 3. The first paper is at the bottom of page 7.

That section goes through page 11. Question 3 is about risk factors.

DR. LAWLER: This is Cindy Lawler. I would like to bring attention to that first study and remind people that the lead author, Dani Fallin from Johns Hopkins, presented some of this data at the October 2017 IACC meeting.

I am really excited about this study because I think it highlights a new approach to really help us gain traction in understanding results that are --

DR. GORDON: We are having trouble hearing you. Can you speak a little bit louder? We are going to try to adjust the volume on our end, but it would help if you could speak just a bit louder.

DR. LAWLER: Just remind people. DaniFallin who presented this work at the – I think it provides a way for us to gain traction and understanding how common variations from --

DR. GORDON: Cindy, we really cannot hear you. If you are on speaker, could you pick up your phone and talk directly into the mike?

DR. LAWLER: Is that better?

DR. GORDON: A little bit. But I think on our end, we could still turn up the volume more.

DR. LAWLER: I will try to speak loudly. Reminder that Dani Fallin, the lead author, presented her work at the October 2017 IACC meeting. I am excited about it because it provides a new approach to help us gain traction and understanding how common variation or SNPS identified through GWAS can tell us about the underlying biology. As we know with complex disorders usually have a lot of SNPS with each one small effect. It is really hard to do a lot with that. Typically, you just turn to getting larger and larger samples, which has its own problems.

In this case, what Dani's group did is brought together different data sets, epigenetic data, which – methylation maps available in different tissues from peripheral blood, cord blood, lung, as a negative control, and some published methylation data from fetal brains and identified SNPS that control methylation in those different tissues and compared those methylation SNPS, those methylation QTLs with a list of genes that the ASD-risk genes arising from GWAS studies. Looking at that overlap can then – you can do gene ontology enrichment and have some understanding that way.

But as importantly, because you have that genetic variation controlling methylation, you also know something about the target, the genes or the areas of the genome, whose methylation is controlled. Those can become new genes that we can explore as potential – relevant to autism.

I think, again, the advance is really how to bring together data sets to very quickly bring more information out of the data that we have and suggest new leads and also it kind of addresses, which is a really challenging issue, which is we really want to know about gene expression changes in brain. But in human studies, you have to rely primarily on surrogate tissue like peripheral blood. That cross-tissue comparison can help us understand how better to do that.

The study itself was not a large study, but I think it is important because it highlights a new approach that can be very useful.

DR. GORDON: Thank you, Cindy. Any comments about this manuscript? I wonder, Cindy, if you think that given the merging of genetic and epigenetic data that this could also be a way of trying to look at the impact of environmental effects in their interaction with genes.

DR. LAWLER: I agree with you. I am really interested in this because epigenetics is in a great position that sort of mediates the effects of environmental exposures on gene expression data. When you think about the interaction of genes and environments, epigenetics could be a major player and again this begins to help us understand how we can integrate epigenetics and genetic data.

DR. GORDON: Great. Thank you. Other comments about other papers in Group 3?

DR. AMARAL: I would like to highlight the paper on page 10 that Geri Dawson nominated, the Wang and Zhao, the association between maternal use of folic acid supplements during pregnancy and risk for autism. I have read this paper, not in great detail, but it was also impressed that it brings together a huge amount of emerging evidence that preconception used the folic acid in multi-vitamins can reduce the risk of autism.

Again, I think this is in a sense really good news from the epidemiological world; yet, it has not trickled down to common usage. I know some of the conversations I had with my daughter and some of her friends who are in this pre-pregnancy age group during the holidays. None of them were aware of this.

I think to the extent that we can highlight this finding would be a benefit to the national community.

There was another paper on folic acid that was also nominated, but I think this topic needs to really be pushed forward.

DR. GORDON: Does anyone want to speak about the other folic acid paper because I think it is relevant to this discussion? I can do so just from my read of the justification. It shows that not only do you want to give folic acid because it will reduce risk and particularly in my read of it, perhaps who would have initial low levels of foliate in their system. But that there is also a risk of supplementing those who have high levels of folate in the system.

Although I would want to again look at that paper more closely to see how real that risk is. The paper describes a U-shaped relationship meaning that if you start out with normal or high-normal levels of folate then supplementation could increase risk. You would want to balance it out.

I think the meta-analysis clearly states that on a population basis, folate supplementation will overall reduce risk. There is no question that it is useful. And then depending upon the strength of the results in the other paper though, one might want to recommend not just folate supplementation, but actually folate testing before that.

DR. AMARAL: I think it is a good point and I think it is clearly an area that needs to have more research because I do not know what the prevalence of women with high folate levels. This is actually something that came out at the INSAR meeting a couple of years back. I think it actually produced a scare that may be it is a bad thing to take prenatal vitamins. Certainly, it is something that we need to address if there could be a danger for a certain percentage of women. I probably may be wrong about this, but I do not think we have identified which women are at risk and how they would know they are at risk and what percentage of women that is. But the meta-analysis clearly shows that in general, it is a beneficial policy.

DR. GORDON: Laura, do you know about the strength of the finding of the increased risk with high levels?

MS. KAVANAGH: I think these are early findings. I have not read about the strength of the evidence in terms of the high use. I do think it is early promising findings for both the maternal fever as well as the folate – the Boston Birth Cohort is quite a robust group and Xiaobin Wang at Hopkins has been following this cohort for a number of years. I think there is very interesting work that is coming out of the team. I agree with you. I think it is something we want to watch carefully, and from a public health perspective, share findings more broadly. It is not just around neural tube defects and those sorts of things, but there are other implications.

DR. GORDON: Actually, do we know from either the meta-analysis or the study that is not just about preventing neural tube defects and therefore and/or valproic acid toxicity and that it is really beneficial for more than just that? Sometimes it can be lost in things like meta-analysis.

MS. KAVANAGH: My reading of the Wang article is that they talk specifically about we have studied folic acid supplementation to prevent neural tube defects. But this is looking more at suboptimal status and they are looking particularly at this high-risk population. I think that was the focus of this study.

DR. GORDON: Thank you. Nina.

DR. SCHOR: It is interesting that many years ago, there was noted and a relationship between increase in serum folate and decrease transport of folate into red cells and fever. I wonder if that is what we are seeing in some of this. I just pulled up an article from the '60s. Sometimes it pays to remember what you learned during residency.

DR. GORDON: That is interesting. It is not something that I have thought about before.

Anything else in Question 3? Alison, go ahead.

MS. SINGER: I just wanted to speak to the study on page 10, that I submitted from Thomas Bourgeron's group, where apparently I failed to provide justification. I apologize.

I thought I had. This is an important study in our efforts to move towards subcategorizing and segregating by genotype for the purpose of trials and also interventions.

This study had 85 patients with different types of SHANK3 deletions, Phelan-McDermid syndrome. Some of them had deletions. Some duplication. Some rearrangements. And it looked to try to determine phenotypes based on those genotypes.

There were really two interesting things that came out of this paper that I recall. One was that there was a subgroup that in addition to having the SHANK3 deletion, also had copy number variations at known autism loci. They had a particular phenotype.

And then finally, there were five girls in the study who had SHANK3 deletion, but no clinical symptoms. This is additional evidence for a female protective effect. I think it is the first piece of evidence for female protective effect in a known genetic subpopulation.

DR. BATTEY: I would like to second that. I think this is among the papers that I have been considering. This one is a very important paper.

DR. GORDON: We will move along to Question 4, which comprises nominations on pages 11 through 14. In this section, I think Laura really outdid herself. Are there comments or questions on any of these?

The one comment I would make is, David, with regard to your submission, that it is a review. We had talked about including reviews only if they really developed some novel idea that is really important to get out there. I am wondering about the rationale for putting that one forward.

DR. MANDELL: Sure. I realized after I submitted, that Geri actually had submitted it the round before. Clearly, we both think it is an important review. I think there is growing recognition especially with the changing definition and the DSM of autism of the importance of sensory challenges and that many people with autism tell us that they are one of the most important challenges. We have very little published data showing the state of the field in treating them.

I think what is interesting about this review is it close to null results. It is very modest gains that do not sustain in addressing sensory challenges for people with autism. I thought it represented an important call to action about where we should be focusing some intervention development efforts more than the usual Cochrane or systematic. It is also very carefully done rigorous review.

DR. GORDON: Thank you, David. Geri, did you want to add anything to that on the phone?

DR. DAWSON: No, I have nothing to add, but I agree that it is an important study.

DR. GORDON: Questions and comments about other articles proposed under Question 4?

MS. KAVANAGH: In terms of just implications, I would want to highlight the school-based intervention. I think it is an incredibly important as a setting for intervention --

DR. GORDON: That is the first one on page 11.

MS. KAVANAGH: I do think it is very early findings and I would sort of not – as important findings regarding the iPhone-based app for toilet training on page 14. I think it is important for families, but I do not think that has the same effect as any of the others.

DR. GORDON: Thank you – a comment that I wrote down too. Important, but it is really a pilot at this point whereas the school-based one is more definitive.

Other comments on the treatments Question 4?

DR. MANDELL: Can I ask Laura about the Metformin studies, which you present three, one of which comprises a randomized trial. The second I think is an editorial and the third is an open label trial. Wouldn't the RCT trump the other two?

MS. KAVANAGH: Yes, it should.

DR. MANDELL: Okay.

DR. GORDON: Usually we would also want to know the number of subjects in the RCTs.

Do we know what the number is in that one? Jennifer, do you know?

DR. JOHNSON: I am having problems with my computer. It has been rebooting. I do not actually have that question in front of me to be able to speak to it.

DR. GORDON: No problem. If it comes up before the end of the discussion or even before the end of the day, it is probably useful for us to hear from you. But this is the Handen article, randomized, placebo-controlled trial of metformin for overweight induced by antipsychotic medication. Really, the question is the sample size.

DR. JOHNSON: 61. It is the 16-week placebo controlled randomized trial in 61 children and adolescents 6 to 17 years of age with autism.

DR. GORDON: And then I guess the other question I would have would be the clinical significance of the weight loss because sometimes one sees weight loss while statistically significant is not clinically significant although that is also the case that sometimes in these studies there are clinically significant weight losses.

DR. JOHNSON: It just says that they have lower BMI z-scores and statistically significant improvements also noted in secondary body composition measures, but not metabolic variables. They were able to maintain their decreases in BMI, but did not have additional weight loss after 16 weeks. The z-score was a change of minus .10, P .004 in the BMI.

DR. GORDON: .1 for a z-score is pretty low.

DR. JOHNSON: That is true.

DR. GORDON: Nonetheless an important issue.

DR. JOHNSON: I am glad I was able to contribute remotely.

DR. GORDON: We will move onto Question 5, services. We have three submissions on pages 15 to 17.

MS. CRANE: I am seeing more than three.

DR. GORDON: Did I get that wrong? Samantha, are you in the packet that is just the October to December submissions?

MS. CRANE: I am in the January through December ones. I will just look at the other one.

I was going to say that the first one and the last one, are extremely interesting and extremely important particularly I would say the last one because one of the things that is most important to the self-advocacy community is our level of self-determination. The findings here are actually extremely interesting and not obvious. The fact that people on the autism spectrum scored lowered in autonomy even after controlling for self-regulation is really interesting.

DR. GORDON: Sorry, which article because this does not correspond to one?

MS. CRANE: I am looking at the one on page 15.

DR. GORDON: I think you have again the wrong packet. There are three packets. Which packet are you in?

MS. CRANE: I was looking at the January through October one. I am sorry.

DR. GORDON: I was going to mark that one anyway for me.

MS. CRANE: I really liked it. And now I am going to go to the other packet. I scored very low on following instructions.

DR. GORDON: We apologize for the confusion. We could have made this clearer.

Question 5, pages 15 to 17 of the packet that says on the first page October to December.

MS. CRANE: The Kuhlthau was another one I flagged actually, the one on 16 on health-related characteristics. Again, it is what John and I have been saying for a long time that these co-occurring health conditions are an absolutely major factor in improving quality of life for people on the autism spectrum. I think those findings would inspire for other research.

DR. GORDON: I think if there is one that really hits the nail on the head for that particular issue is this article, which says that the general quality of life is related to these other issues much more so or at least as much so as it is to the core autism features. I think that really gets John at the point that you have been trying to make, which is peripheral to the other papers that we talked about, but really central to this manuscript.

MR. ROBISON: That point really does deserve mention in the Summary of Advances. Maybe we could say that we have begun to recognize the importance of that, but it will take a number of years to change the course of the ship of research. And that is the reason that we are discussing it here, and yet we have so few papers to report because of that lag and time to do the work.

DR. GORDON: It is an interesting suggestion. I, myself, would feel uncomfortable with that assertion in the Summary of Advances. But I think a more to the point assertion would be that this is really important because it raises this issue. It turns out we have several in this particular cycle that speak to that issue, as you have highlighted.

MR. ROBISON: Which are you uncomfortable with? You are not uncomfortable with the assertion that we are moving towards more lifespan research, are you? We could say that.

DR. GORDON: Yes. That would be fine.

MR. ROBISON: I think if we do not say something like that, I think we will be roundly criticized by the autism community for not speaking definitively about lifespan issues in our report. I do not know. Maybe Alison and Sam can weigh in on that, but that is what I think.

MS. CRANE: I agree that we can talk about moving in the direction of research and also if we want to put it diplomatically, we can that this confirmation of the fact that these are issues that are critical to quality of life should be taken account in further decisions.

DR. GORDON: That is a good way. I do not think it is true that this group or that many of the agencies and organizations around the table have ignored or are not conducting research in this area anymore whereas a year or two ago before we started taking up this issue and before it got incorporated into our overall strategic plan, I think that would have been more accurate. That is all that I am trying to say.

I do agree that highlighting through Summary of Advances – if I was going to pick one to highlight in the Summary of Advances that speaks to the issue of co-occurring conditions and their impact, this is the manuscript that I would want to choose to include. I think it would be great to include in the lay summary how that it is indeed a confirmation of the importance of considering co-occurring conditions and of increase research into these and other lifespan issues. Sound good?

Question 6: Lifespan Issues. This is the final one for which we have nominations this time around. These are on page 17 and 18. There are four submissions.

Julie, I want to make sure that you should feel free to speak up on the phone. I think you had two nominations in this section.

DR. TAYLOR: I would be interested in hearing what the clinicians have to say about the Mandy article, but as somebody who does research that includes adults on a fairly regular basis, something that has been a real issue is not having an informant report measure, diagnostic measure that we feel really good about for an adult population. I thought the Mandy article was really promising in terms of these initial psychometrics of a new informant report diagnostic measure developed specifically for adults of the sample size in terms of their population. They had an autism group. They had a clinical group that had other mental health conditions and then a non-clinical group. I think there were about 40 to 50 per group if I am remembering that right.

But the sensitivity and the specificity were really good. It seemed like it was much easier to administer. As somebody who is not a clinician, I thought that it seemed very promising.

MS. CRANE: This is Sam. I think any study on assessing autism in adults is going to be very interesting to me. It is something that we have been extremely concerned about the fact that we do not have very good measures.

I did find it interesting that people with intellectual disability were excluded. I guess it makes sense if you have such a low sample size, but we really want to make sure that for the research includes people with intellectual disability because this is a group that is also very difficult to diagnose in adulthood and autism gets missed in this group.

I would also be interested – it does not say here, but I would be interested to see what the racial and gender diversity here. It does not have a sample size. But it would be interesting to see if there are variations in race and gender.

DR. GORDON: I obviously recognize the incredibly utility of developing an instrument that would assist in the diagnosis and severity staging of adults. It is not clear to me that this really definitively does it. I would like to see for a summary of events is something a little bit more definitive.

Samantha, I think you raised really important points about the diversity. If it is a small sample size, generally small sample sizes even if they have representation from diverse groups are not going to be able to validate measures in those diverse groups. And even with the sample sizes, it is hard to know how good the validation is overall.

DR. TAYLOR: That is fair. As I am looking a little closer at it again, the sample sizes are even actually a little smaller than what I had – it looks like it is 39 in the autism group, 29 in the non-clinical comparison and 20 in the clinical comparison. It is pretty small. I think I got really excited about the possibility of using it, but you are right. It is probably not a definitive study of this measure.

MS. CRANE: I am really excited about it, too.

I am actually curious about the Sasson article that David submitted. Disclosure of autism. I am reading this as saying that if a person discloses an autism diagnosis, it actually improves other people's perception of the person. David, do you have more to say about this?

DR. MANDELL: This was a study actually not typically developing adults who are presented with characteristics of adults with and without autism and were asked for their impressions of favorable or unfavorable impressions. It was very similar to the old Bruce Link work around stigma.

When they were told that the adult had autism, their impression of the adult became much more favorable. We have talked about stigma a lot in this group. It is very difficult to do rigorous studies of stigma. I really like that this was an attempt to do that and especially given the challenges I think people with disabilities and disabilities that are not always visible have with regard to whether to disclose that this offered some promising first evidence that disclosure may be useful in environments like the workplace or social situations.

MS. CRANE: Were the – not the subjects, but people presented to the subjects. Were they fictional or were they real people based on real people on the autism spectrum or were they just completely neutral?

DR. MANDELL: I am trying to find the article now.

MS. SINGER: I just want to comment on this article as well. It says in the justification this is the first study to demonstrate this. In fact, there was a study that was presented at INSAR in San Sebastian that we highlighted at the press conference that came out of Wendy Goldberg's group at UC Irvine, that studied actual people, not images, and studied first impressions of non-disabled college students and whether disclosure by college student peers who had autism was positive or negative. It similarly showed that they were received better and had a better experience in their college environment if they disclosed.

DR. GORDON: It would be worth sending that one around, I think. What I liked about this paper in hearing about it and hearing about that result as well is it is actionable. And the question that I would have for those who have read it or maybe even for the authors is if you are a patient or your loved one had autism and they were headed off to college or into the work environment based on the strength of these results, would you say you should definitely tell them that you have autism because you will be treated better because of it? There are reasons why we automatically reflexively think disclosing is going to lead to increased stigma.

In the context of disability that it may not be evidence, but that definitely in social situations affects interactions. Knowledge on the other part of the individual you might understand why that would result actually in improved perceptions. Pardon the pejorative. They are not just weird. They have a disability. I wish we could always think that way about everyone who we think of as weird. But in this case, in particular, this would be evidence in support of it. The question is how strong is that evidence and do we therefore want to put it out there. Because if we put it out there, we are essentially saying the evidence is strong enough that we should think about recommending people disclose or diagnosis.

MR. ROBISON: Josh, I would agree that this is likely a correct observation. I just would challenge the claim first study to demonstrate that disclosure improves the perception of others. The fact is for the entire time we have had master of fine arts degrees in creative writing. The professors have taught that disclosure of vulnerability and weakness makes the writer more appealing. For at least 200 years that has been recognized in the community of writers.

To suggest that autism is somehow new and different I think is disingenuous.

MS. CRANE: I would disagree. That is in some ways new and different because we know that with disclosures of other types of mental health diagnoses that can be very different. If you say this person has schizophrenia, you might have a very different result. The fact that it is different for autism is interesting.

On the other hand, if this is in fact not new and the study Alison mentioned is equivalent to it then --

MR. ROBISON: I just think it is a human condition thing, revealing a vulnerability or a weakness will cause people to treat you with more compassion whatever that happens to be.

DR. MANDELL: Until they stomp on you. I am happy to review the article again within the context of both its novelty and rigor and come back to the committee and to say that this is either the first or second study in an Index Medicus journal as opposed to Shakespearean.

MR. ROBISON: I am not challenging that it is valuable. I just want to put it in context.

DR. GORDON: I think the committee would appreciate if you could come back to us with it. Alison, maybe you could respond when it gets sent around with the Goldberg study because to me any time we have an actionable article, we have two responsibilities. The first is to ensure that we believe the strength of the evidence because people are going to respond to our actionable item. And then the second is to get it out there because we want people to know.

In working with patients in my practice, I always advocated for disclosure, but also always had a very significant conversation with the patients about what the disclosure means and acknowledge that we do not know because I did not treat patients with autism. I treated adults with other illness. At least to my knowledge, they did not have autism. There are always issues about that.

But if I had had evidence that said in a workplace environment, disclosure of diagnosis of bipolar disorder actually improves other people's perceptions of you that would have been – for those listening, we do not have evidence to my knowledge. But that would have been a stronger recommendation on my part. I think getting this out there if it is rigorous is important.

MS. CRANE: I would also want to see the breakdown of perceptions. Is the person seen as more friendly, more trustworthy, more competent, more worthy of respect, more powerful? These are all very different perceptions. As anyone who is self-disclosed will know, you make a calculation about which perception you care about the most. Sometimes you do get dinged on perceptions of competence, but you do not get dinged on perceptions of friendliness or trustworthiness. People might assume that person is not being unfriendly. She is autistic. Then you are seen as more friendly. You might be seen as not someone that is going to be good at a particular task. Those are all things that a person thinking of self-disclosing would want to know about in terms of those perceptions.

DR. PELPHREY: I do not want to beat up on a dead horse here. One of the things that I think needs to be done in this area is more of an implicit assessment of stigma, watching people react in terms of how they state they believe versus what actually they do and how they act, the idea of until they stomp on you versus I am very accepting of you as long as you are not taking an important position or watching the self-disclosure and people's interest.

It kind of depends on what people think of you before you begin the process of self-disclosure and to what end they hope you might be useful. You think about the recent media attention around Donald Trump's physical exam record, for example. Some people were hoping for some sort of mental health diagnosis for different reasons and some people were hoping for a clean bill of health. Would self-disclosure help or hurt? It depends on your orientation beforehand.

I think that that is such a complicated factor that I do not know if this study even if the results were very much true would be actionable because of this whole issue of implicit attitudes toward mental health that are not really measured in it.

MS. CRANE: I still think, especially if it does breakdown the different kinds of perceptions, it gives people information that they can use to make a decision. I think that is very important.

DR. GORDON: I want to point out actually, and we are actually a tiny bit over, but that is fine. I encourage all the committee members before they vote to look into the papers that we have nominated here themselves. Samantha, you should feel free to look that paper up. If you cannot access it because you do not get access then we can access it for you and send you a copy, but just contact Susan's office. To help you make the judgment yourself and you can look into it to see what measures they did measure regarding positivity and certainly those that you are thinking about voting for. If you have concerns about the rigor, look at it yourself before you cast your vote, if you will.

The final thing I would say is that we did not – I hope we would have time, but we do not have time to go over, but remember these are not the only ones that were nominated. That is why you have the packet that includes all the nominations, January through December. That is the packet that I would want you to focus on when you receive your ballot, if you will, and that you choose the papers that you think are most important for inclusion.

When you do so, I will ask you to try to as best you can look at all seven areas. We do like to try to include advances in as many of them as we can get consensus around as possible. Don't just look at your favorite area be it services or etiology. Try to look at all seven and make a determination about the quality and impact of the manuscripts in those sections.

Thank you very much for this robust discussion. We are going to take a ten-minute break. We are going to come back at 11:17 and resume just a couple minutes late for the committee's business.

(Whereupon, the Committee members took a brief break starting at 11:08 a.m. and reconvened at 11:15 a.m.)

DR. GORDON: We now have committee business. I want to let everyone know. I am going to have to leave about ten minutes before noon because I have an appointment on campus during the noon hour. I will be back for the public comment session at 1 o'clock.

DR. DANIELS: Alright. So we are ready for committee business. I just want to start off by again thanking OARC staff. This is my team in the OARC who make this meeting possible and all of the wonderful things you see on our website, our database and other products. Thank you to all of them for all their hard work.

I wanted to give you a brief update on the 2016 ASD Research Portfolio Analysis for the IACC to let you know that our team is currently collecting data for the 2016 Portfolio Analysis and using these data, we are going to be collaborating with the foundation Autistica in the UK and with the Canadian government to do the first International Autism Research Portfolio Analysis and we hope that we will – we are planning to present the preliminary results of this analysis at the INSAR meeting in

Rotterdam in May 2018. We hope that it will stimulate broader international participation in future years. When that information is available, we will be presenting it here at IACC as well. We look forward to that and what we can learn from these other countries that are also working hard on autism.

I also wanted to give you a brief update from my office about the Autism CARES Act report to Congress. This is a report that is required in the Autism CARES Act. There was another report required, which we talked about last time, the report on Transition-Age Youth and Youth Adults. This is the second report that is required. It is due in September 2018. My office is going to be coordinating this. We have begun the preparation of this report, collecting data from all the relevant federal agencies.

When this report comes out, we will also share it with the IACC, but wanted to let you know it is underway and any federal members who are here that have questions about the data can direct those questions to our office. We will keep all of the agencies informed of progress on this.

I also wanted to highlight that the Social Security Administration has a request for information out right now on strategies to improve adult outcomes for youth receiving SSI. And the comments are due by February 2. We have put the web link here on this slide and we also have it up on the IACC website. But if anyone needs it separately, you can always send me an email and we will be happy to send that to you. We can help out our colleagues at the Social Security Administration.

The main topic today that we are going to be talking about is the IACC Working Groups. I did not stop to take questions. Were there any questions about anything I mentioned already?

Talking about working groups. The IACC, as you know, voted previously to convene three working groups on issues of critical importance to the community between January 2018 and the end of this iteration of the IACC, which will be September 2019. Among the three topics, the first one is improving health outcomes for individuals on the autism spectrum. That one is going to be starting now.

And we also in the future will be doing working groups on housing and safety. We will be doing those in a staggered fashion, first getting this one off the ground to get it going on its products.

The co-chairs who stepped forward to help us with this group are Dr. David Amaral and Dr. Julie Taylor. We really appreciate their willingness to help lead this group.

The scope that we discussed includes all of these different topics, including health and general wellness for individuals with ASD, co-occurring conditions and preventative approaches to address them, issues such as obesity, co-occurring mental health conditions, premature mortality, which includes causes such as epilepsy, suicide, and chronic health conditions, patient provider interactions, medical practitioner training, including increasing understanding of autism among physicians, supporting community doctors who provide medical care for adults with autism, and parental and family mental health.

I do not know at the moment if there is anything else that the committee feels is important that needs to be added to that list that is of the same level. If you do have anything to add, let us know. Alison?

MS. SINGER: I would suggest adding self-injurious behaviors, which in many cases leads to inpatient hospitalizations and very negative wellness.

DR. DANIELS: I think that could be an example under the mental health conditions or co-occurring conditions.

MS. SINGER: I do not know that it is a mental health condition. I would just want to see it --

DR. DANIELS: Highlighted in some way as an issue.

MR. ROBISON: I wonder if we should expand that, Alison, to address violent behavior in general because I think that is ignoring autistic people who are aggressive towards others. I do not think we should do that.

MS. SINGER: I think that makes sense.

DR. DANIELS: Those would be a couple of particular areas that you would want to include. Anything else that you feel might not be sufficiently highlighted here?

MS. CRANE: I am not sure that I would consider that behavior to be part of what I would see as overall health. I do not know. I feel like those are – self-injurious behaviors, I would agree. Aggression towards others. I worry that we might get side tracked from other things that people are really concerned about. It is not that it is not a serious concern. I just think that it tends to be addressed in other context other than health and wellness.

MS. SINGER: I think you can make the case so that aggression towards others is another cause of inpatient hospitalization, which there have been several really disturbing journalistic reports about people languishing in inpatient hospitalization and there not being enough capacity to serve the population that needs this kind of treatment. I think we could include it.

DR. DANIELS: Some of the aggressive behaviors are also a part of intervention work that is being done as well. So that angle of it might be relevant to this. But it also may be relevant to the safety working group that we will be doing in the future as well. We will take note of that.

Anything else? David?

DR. AMARAL: Susan, one thing that I think could be added is the dissemination piece of this. If we talk about this and come up with a consensus in the work group and then it does not go anywhere, I think we would not have accomplished our goal. I think we need to have some advice on how once a white paper is created how it is going to then be disseminated to the physician community.

DR. DANIELS: That is probably maybe for another slide. This is just topics that will be covered. Are there any other topics? Robin, did you have something?

MS. CRANE: Can I make a quick follow up on the safety issue? I wanted to note that also if we have certain topics that we are talking about in both health and wellness and the safety working group, if we make the call to include them in both then we would need to make sure that they are coordinating so that we do not have two working groups saying one thing about the same issue and another thing in the other working group and going across purposes.

DR. DANIELS: The safety working group is the last one that we will be convening because we put them in order last time. This working group may be finished with this work by then. We will know what the outcomes are hopefully and try not to duplicate effort or to at least build on what has been spoken about in this one.

MR. ROBISON: I just had someone message me online. Should we have death from drowning specifically up there? Drowning has been mentioned as a major mortality risk before and it is not here.

DR. DANIELS: Sure. Premature mortality, as you can see, there is an et cetera. It can be many other things. We just wanted to give a few examples, but drowning accidents, many of those other things would count.

MS. CRANE: We should say reproductive health too.

DR. BALL: I know it is an et cetera, but I also under the premature mortality rate really looking at the impact of long-term medication use with individuals.

DR. DANIELS: That topic actually was covered in the Autistica Conference on health and wellness as well.

MS. CRANE: I would also want to talk about medical decision making, which is not directly a health factor, but it is definitely something that could influence outcomes.

DR. DANIELS: This can be both medical related as well as service related.

DR. PELPHREY: Another online submission. Reproductive health care and maternal care for autistic women.

DR. DANIELS: Anything else from any IACC members here?

(No response)

DR. DANIELS: Let's move to activities. The activities that we have planned for the moment are phone meetings to discuss issues. I sent out a call to IACC members again to help us identify additional external experts who can serve on this working group. Once I get those names by next week, we will narrow those down to the people that can serve on this working group and we will invite them to join us and then schedule a meeting for February. We can have our first meeting.

The last time we met we talked about a written document being one of the products of this group, either a white paper, some kind of report of published article that outlines challenges and recommendations for health and wellness issues and/or recommendations for the provider community. That can develop as we have these discussions. And the same document can be used as a basis for the strategic plan update that will be required in the next year so that we can get additional use out of the work of this working group.

There also would be an opportunity, as our office plans these IACC meetings, at the upcoming April 2018 IACC meeting if the committee and the working group wishes to. We could set aside time to have a panel discussion that would cover some of these issues. As you saw, the list is fairly long. But if there were some issues that are high priority that you would like to discuss at that meeting, we could have the working group help us put together a discussion to happen at that meeting. The input from experts that might be invited to participate in that could help us gather information that would help contribute to our written document. Any comments about that?

DR. AMARAL: Susan, I think having a panel is actually a really good idea. I think though given the long list of topics, it might take the committee a couple of meetings just to prioritize what would go on the panel. I worry that April is pretty quick to try and get that done. I wonder whether we could not have the committee come up with priorities and then do the invitations for the July meeting.

DR. DANIELS: Yes, that would be a possibility. Alison?

MS. SINGER: I would say that these issues are of such great importance in the community that we should consider doing a panel in April and another one in July so that we would be able to really hone in on more than one issue. I would not want to wait.

DR. DANIELS: Great. Thank you. Larry?

DR. WEXLER: Thank you. Can we return back to the written document? Can that be discussed at this point?

DR. DANIELS: Yes, we can talk about the written document.

DR. WEXLER: Without denigrating the use or usefulness of the white paper report or published article, I would really hope that we would also consider a series of infographics to go out to the community that are actually – I wrote an email this morning in response to something that one of our researchers produced. And the question I asked is is there any human in the world that will understand how these data are represented. I think that it is really critical for us. Producing anything that is not used, not read is useless.

Thinking about the final products as the group is deliberating, I think is an important approach that we need to consider and not just for this group, for all of the different groups we are going to have. Thank you.

DR. DANIELS: That certainly is a suggestion that we could take up. We know, for example, Life Course Outcomes program at Drexel, has been really good with doing infographics with their information. There are some other agencies that also have gotten rid of some of their lengthy reports and replaced them with slide presentations with infographics. At NIH, we have an excellent medical arts program that can help us with designing things if we have concepts. Once we have content, certainly the presentation is something that we can work on and provide something nice. Thanks for the suggestion.

Other comments? John?

MR. ROBISON: With respect to improving health outcomes, it seems like all of our studies are focused on evaluating and remediating deficits. Would you see it as within the scope of NIH's responsibility to fund studies to identify strengths in a population such that that could be capitalized upon by employers as a way of NIH supporting positive intervention growing for autistic people?

DR. GORDON: Certainly, within the purview of NIH. Sure.

MR. ROBISON: Could we somehow ask that question then? Can that become an action that we at IACC ask for? We have initiatives starting around the country like Autism at Work, for example. Today, we have two people sitting here from Northrop Grumman, a leading defense contractor. They are here because they believe that there is an advantage to their company employing autistic people. That is very different from disability accommodation. We do not do anything in government to support that and yet that could be tremendously beneficial to our population.

DR. DANIELS: John, just to follow up on that. For the April meeting, we are planning a panel on employment. I would love to meet with the folks from Northrop Grumman to talk with them as well. We are going to be discussing that issue. It is very relevant. We appreciate you bringing that up.

MR. ROBISON: Susan, we should invite some people from the Autism at Work Initiative. They are part of it for Microsoft and all those folks.

DR. DANIELS: I have already.

MR. ROBISON: Excellent. Two of them are here now.

DR. DANIELS: Yes, but I have not spoken with Northrop Grumman. I would love to talk with them.

DR. AMARAL: I just want to comment because I had encouraged Susan, and I was really happy that Susan followed up on this. A couple of months ago, I heard a very inspirational presentation by folks at SAP, which is another big IP company. They made exactly your point. They developed a whole program to employ people on the autism spectrum, not because it was out of any kind of community spirit, but because they thought that they were going to get beneficial employees.

One of the things that they highlighted was that a person on the autism spectrum, once they are incorporated into a company and feel comfortable, there is stability there. We met some of the employees who said they – for 30 years whereas turnover seems to be the biggest problem in high-tech companies. I do think we will all feel very inspired by the presentations that Susan is going to have coming in April.

I think that this is a different topic and an important topic, but a different topic than the health outcomes work for us. I would hate us to get so diffuse in terms of what we are covering in the work group that we are talking about that we do not accomplish the kind of white paper and information transfer that we are hoping to do. Not to belittle the point that you are making, John. I think it is incredibly important. I would encourage the committee to take it on seriously in future meetings.

MR. ROBISON: I just think more employed autistic people equals better health outcomes. It is just a point that should be there.

DR. DANIELS: Yes, and so we will be talking about that in April and our colleagues at Department of Labor are very excited to be a part of that as well.

Other comments?

DR. AMARAL: Susan, I just encourage the fellows members of IACC, to get involved in this work. People have made really good comments. Hopefully, it will not be too burdensome, but we need to have everybody's expertise participating. I hope you will let Susan know that you want to participate as much as possible on this work group. I know that Julie and I are really excited to get everybody's advice and try and roll it into something that will be actionable as well.

DR. DANIELS: Would you find it helpful for me to send information about the work group to the entire committee whether or not you have signed up for it or would you prefer for me to just focus on specific people that have signed up? I am thinking if I send it out to the entire group, some of you can jump in for certain meetings. You will be able to do that and if you want to ignore the email, you can ignore it too.

MR. ROBISON: I would like to see it sent to everyone.

DR. DANIELS: Okay. I will send it to everyone so that you all have a chance. If you cannot make certain meetings, that is fine. But we hope to get as much participation as we can. Unlike a subcommittee, the working group does not have a limitation on the number of people that can be a part of it.

On my next slide – we just talked about topic suggestions. Next Wednesday is the deadline to get additional nominations for working group members and then we will narrow that down and get some people invited to join us. We will be looking for a date. Look for a Doodle Poll that will be coming your way to try to get a date in February for our first call. If needed, we can have another call in March before the April meeting. We can try to have some kind of a panel in April that will discuss part of this health and wellness issue, which is quite broad. A number of discussions likely will be needed to help you with your work.

That is what I have for the working group. Is there any other question out there regarding the working group before we move on?

MR. ROBISON: I have another issue that was just messaged to me and that is that we add maternal reproductive health care needs. Certainly, that is a big effect.

DR. DANIELS: Yes, and I have that on my list from the discussion.

DR. BIANCHI: I actually think that doing that would really complete the lifespan because as you know, we always say aging begins in the womb. Some of these later issues really have their onset prenatally and that could tie in some of these folate discussions as well.

MS. CRANE: I think we were also thinking of autistic mothers. The mothers of autistic people and reproductive health of people --

DR. BIANCHI: Yes. NICHD has a special interest in reproductive health for women with disabilities, both physical and intellectual disabilities.

DR. DANIELS: Diana, if your institute has any specific events coming up relating to that, please let us know so we can get that information out to the IACC.

Moving on from this, I wanted to just let you know that we are taking suggestions for topics for future IACC meetings. We may have several that are related to this working group, but we always keep a bank of ideas from the committee as we look for speakers and topics to cover. If you have any suggestions, feel free to just email them to me at any time as I know many of you do. We will keep that list running and use it to help plan future meetings.

We have just changed the IACC meeting for April to April 19. We came up with a conflict with the April 18 date that was set before that. We have moved it to the 19th, which is a Thursday. We hope that you all will be able to make it or most of you. I just wanted to mention that here and I did have a slide, but put that on your calendars. Of course, you will get more information about that coming up.

DR. BIANCHI: It reminded me to let everybody know that we have a crowd sourced site called PregSource, which is an opportunity for women to share and record their pregnancy experiences. We are very interested in hearing from women who are on the spectrum who are pregnant about their experiences with pregnancy. We can send the link out to everybody.

DR. DANIELS: Please do and we will put it on the IACC website as well. Related to that, you all received our OARC newsletter before this meeting. We have added a new section on community participation opportunities. We will add that to the next newsletter as well. But we tried to highlight some different community participation activities such as the Autism Science Foundation's Autism Sisters Project and some other activities. If anyone around the table here has an activity you want the community to participate in and you want it highlight, please let me know because we can put it on the IACC website and include it in an upcoming newsletter.

Now, lunch. We have boxed lunches that some of you ordered in advance. Those will be available nearby. We also have a restaurant in this hotel that you can go to for lunch. We will be reconvening at 1 o'clock for public comment. With that, enjoy lunch.

(Whereupon, the Committee recessed for lunch at 11:45 a.m. and reconvened at 1:00 p.m.)

DR. DANIELS: I want to get us going on the public session comment session of today's meeting of the IACC.

Today, we have three oral public comments that have been submitted. We will be hearing today from Dr. Lee Wachtel from Kennedy Krieger, from Lucina Clarke and Shari Chase has also signed up to give public comment, but has not arrived yet. We will hopefully hear from her as well.

As we listen, we can take note of any questions that we have and then we will have an opportunity to have questions and comments after each of these public comments.

I would like to call Lee Wachtel up to speak. If you would like to go to the podium.

DR. LEE WACHTEL: This is a little weird. I am used to doing presentations with a Power Point rather than reading from a paper. It is kind of like a throwback to high school. Bear with me.

My name is Lee Wachtel. I am a child psychiatrist at Kennedy Krieger Institute in Baltimore, Maryland. I run an inpatient unit, serving individuals, children, adolescents and young adults with autism and intellectual disabilities who are admitted to our inpatient unit for very severe challenging behaviors, usually behaviors including self-injury and aggression that have reached life-threatening and certainly life-limiting levels.

I have been in this position for nearly 15 years, and I would like to speak today on behalf of my patients, and on behalf of their families, many of whom have remained under our care at Kennedy Kreiger during the transition from childhood to adulthood.

The vast majority of our patients is significantly afflicted, and would be characterized in the DSM-5 as having autism requiring extensive supports and with intellectual disability. They do not come to Kennedy Krieger for autism or intellectual disability, however, but rather for the severe self-injurious, aggressive, and disruptive behaviors that they display, often within the context of further severe psychopathology that can run the gamut from anxiety, mood, and psychotic disorders, and more.

These kids are really suffering and so are their families. Their parents will move heaven and earth for their children. One of the hardest parts of the job is telling the moms and dads on our waitlist that we do not have a bed today for their bloody and battered and bruised child and hopefully we will have a bed sometime soon.

None of the parents that we work with are glad that their child has autism or see their son or daughter's autism and associated suffering as part of neurodiversity. In fact, most of the parents would sell their soul for their child not to have autism.

As one parent who spent 30 years campaigning for the best services for his son recently told me, "I would walk through perdition's flames for my son, but I do not buy into the autism fairytale."

These are not my words, but those of a parent who has walked the autism walk for three decades. And I hear many such comments. I know very well that this type of response and the mere existence of the types of severity afflicted autistic kids in our care flies in the face of the overriding current agenda for autism, where everything is very happy and diverse and some even suggest the removal of the autism as a psychiatric illness.

I would suggest that the DSM-5 characterization of autism does not accurately describe the condition and that there are likely many conditions currently all thrown together into the autism rubric, which only hinders science and our ability to make important advances to help everyone along this range of diagnoses.

But I am less for splitting hairs over diagnosis, and more for making sure that those who do not currently fall into the happy and hopeful side of the diagnosis, at least not happy and hopeful today, but with the potential for so much improvement and really reaching potential as one of the main kind of mottos or goals of Kennedy Krieger that these people still have a voice and do not become the black sheep of the autism community just because they are not blogging or reciting soliloquies at Lincoln Center.

Because that autistic kids with severe behavioral, psychiatric, and medical concerns, as well as significant cognitive disability, really do exist and so do their families, who are less than enamored with autism, and are frankly heartbroken and exhausted. These kids need our understanding and help just as much as the autistic child contemplating best strategies to succeed at college. These kids will continue to need the support of the autism community as they become adults, as they will not be able to live independently, will require extensive supports and substituted decision-making and cannot be pushed into models that just do not meet their unique needs.

I encourage the IACC and autism community in general to consider several things. First, the IACC needs to prioritize research on the treatment of severe self-injurious and aggressive behaviors. These behaviors are highly prevalent and is estimated in studies that about a third of individuals with autism will engage in self-injurious behavior and over half in aggressive behaviors, yet very little attention is paid to this devastating problem.

The IACC should host a panel focused on these dangerous behaviors. Not only are these behaviors dangerous to the children and families involved, but they often preclude participation in inclusive, community-based educational and vocational programs. These behaviors are often physiological in etiology, typically from a co-morbid psychiatric disorder, and do not represent communication from nonverbal individuals. It is often a medical problem that requires medical solutions.

Second, the IACC must promote a choice-based approach to service provision that ensures adults with aggressive and self-injurious behaviors have a place to go when their families can no longer safely take care of them. Some autistic adults have severe behaviors that simply cannot be managed in community settings. They may not exhibit them all the time, but they need to be somewhere with experienced caregivers who can manage dangerous behaviors when they do occur, with access to professionals who can treat them, as well as structured programs to maximize community access as well as providing meaningful and satisfying site-based programming.

This population needs to be surrounded with well-trained and well-paid aides because the health and happiness of these adults depends almost exclusively on that one variable. The IACC should ideally write a white paper focused specifically on the service needs of this population.

Finally, we need to invite more parents of severely affected autistic children to have seats on the IACC. These parents represent children who cannot represent themselves and they require a voice.

Thank you so much for your attention.

(Applause)

DR. DANIELS: Thank you, Dr. Wachtel. Does anyone on the committee have any comments or questions that you would like to ask?

MS. CRANE: I want to correct a misconception that I think people might think from hearing this comment that the people that are represented by the neurodiversity community are not Kennedy Krieger's clients. We have members of our community who absolutely have been clients at Kennedy Krieger.

On our worst day, we are very severely affected. We have self-injurious behaviors. We are suicidal. We have significant difficulty regulating our emotions and many people in our community have specifically been clients of Kennedy Krieger's. I just wanted to note that.

DR. DANIELS: Thank you. Alison?

MS. SINGER: Thank you, Samantha, for bringing that up. I think that is an important point.

I also think that Dr. Wachtel really identified a very high priority health and wellness area of focus. I would love to see us implement her suggestion and hold this panel at the April meeting. I know, David, you were saying you might not have a topic, but now this would be a great topic that she has brought before us.

I think it would also be a good complement to the employment panel that is planned for the April meeting because it would really speak to the breadth of the spectrum.

DR. DANIELS: Thank you. Did I see David Mandell?

DR. MANDELL: Yes. I think Samantha’s point I think goes very well with Dr. Wachtel's point – self-injury and aggression while perhaps varying by individual, are not isolated to one part of the spectrum and I think really highlight the need for this committee to address it head on.

I would also point to the need for a better understanding of more severely impaired individuals with autism and the issue of a lack of safe place. First, the lack of community services and the failure of those community services that often lead to the need for placements in patient settings is one critical issue.

The second is when those services are needed, there are so few places in this country where they are available regardless of where you lie on the spectrum.

We often think about evidence-based care within the context of community care. We need to be thinking about evidence-based care within the context of more restricted and segregated settings as well and what the standards should be and how we do research. I really am very excited by the network of inpatient settings that has been developed to begin to study these issues. We ought to be thinking about how to leverage that more and expand its capacity.

MS. CRANE: I just want to follow up because sometimes it is hard for me to get everything out at the same time. I have noted this in previous meetings. In the self-advocacy community, we have a saying that if you are seen as high functioning, you are seen as a person, but not as disabled. If you are seen as low functioning, you are seen as disabled, but not a person. Many of us have been seen as both at different times in our lives. Sometimes just different days, different hours within the same day we are seen as both.

The suggestion that anyone who is a self-advocate must be promoting a vision of autism that is unicorns and rainbows all the time. We never have a single problem. But if you do have problems then obviously you cannot self-advocate. We really need to move passed that. And we really need to actually start listening to each other and recognizing that no one who is a self-advocate -- if someone is a self-advocate on the autism spectrum, they do not think they are disabled. They are not going to be here. If I did not have any issues related to being autistic, I would not devote my entire life talking about autism advocacy because I would not need to.

We all have issues. Many of our members have been hospitalized often many times. We have real important things to say about that experience, about whether or not we even feel safe in a hospital, about what things can help us stay out of the hospital and we need to be able to be able to talk about it and be heard as well.

DR. DANIELS: Thank you. John?

MR. ROBISON: I think that this comment highlights the fact that there is a vast gulf in opportunity, attitude, and strategies for life that will work for people with higher and lower cognitive abilities in general. In the typical human population, we do not really presume that a bright, articulate person's approaches to succeeding in life will be the same as a person with very limited cognitive abilities. Somehow, we accept that. We try and suggest that the same should be true in autism and it simply is not.

I think that there are autistic people with significant cognitive disabilities who need different things from a person like me who does not have those particular disabilities, even though I am disabled by autism. Sam is disabled by autism. We are not disabled by those things. That does not make us frauds or imposters. It also does not make us parts of two different tribes. We somehow can recognize that people with cognitive limitations are humans just like us sitting here at the table. They are not some kind of different animal from us. Why can't we recognize that in the autism field? Why can't we just accept that yes there are very disparate needs for people in different places on the spectrum?

When you talk about walking the autism walk for 30 years, I walked the autism walk for 60 years and I am an actual autistic person. Isn't that worth something? What about Sam?

I am very strongly in favor of supporting people at all points on the spectrum. It is very discouraging to me to see commentary from people who are oblivious to that. I think it is particularly discouraging to me to get that kind of commentary from a medical professional. We should be able to do better. It is just bothersome to me.

Are we only commenting on that particular thing or can I offer thoughts on some of these other comments in the same vein at this moment?

DR. DANIELS: We will have time for the other comments. Let's finish with this one and then we will move on to the next.

DR. AMARAL: I just want to comment on what you said, John, but I also want to thank Dr. Wachtel for her comments. I do not think that those comments were intended to disparage anybody at any level of the spectrum. I think that they were trying to address the issue that many people who have family members who are plagued by some of these very serious medical problems feel like they may be underrepresented on the IACC. I think it is important.

I agree with everything you said. But I think it is important to remind ourselves that there are families that every day get up and deal with a child that has severe gastrointestinal problems or may be aggressive or self-injurious.

MR. ROBISON: Haven’t you heard me say that today, David? How can people forget? I said those very things.

DR. AMARAL: I am not saying that you do not say it. I am saying it is important for us to get testimony, broader testimony to reinforce the idea that we have to consider that subset of the population as well. That is all I am saying.

We have to go beyond fragmenting and pitting one area of the autism spectrum against the other. That is not very productive. I think we have to, as you said and I agree completely, address different issues with different individuals who have different forms of disability on the autism spectrum.

My only point is that I think we do have to hear every once in a while, from people who are going to highlight these medical and serious psychiatric problems that again are very deleterious to families. I am not saying that you have not highlighted that. But I am saying it is important for us to hear from others as well.

MR. ROBISON: I am not opposed to that, but I would point out with all due respect to those folks. Ten years ago, the only advocacy there was was parent advocacy. Now, there are autistic people speaking up for ourselves and you have just said that we need more parent advocacy. Parent advocacy was all there was and we still have it.

DR. WACHTEL: I just wanted to add in that I appreciate everybody's comments and I knew that what I had to say would be somewhat inflammatory. I often get involved in inflammatory topics. But I actually think everybody is on the same page and really reinforcing again the same idea that along the spectrum, there are so many different people with many different needs. We definitely in outpatient services, not in the inpatient unit, but in outpatient services at Kennedy Krieger --

MS. CRANE: I am talking about inpatient people who have been inpatient at Kennedy Krieger and who are in our membership.

DR. WACHTEL: The children that we have worked with on the inpatient floor at Kennedy Krieger on the neurobehavioral unit where I work are all people on the very severe end of the spectrum. Most of them functioning on maybe a toddler level of functioning at best. Maybe third or fourth grade level. I really represent the children with autism who are admitted in the inpatient unit, for example, who have detached a retina and now require retinal reattachment surgery and are going to spend a week in the MICU recovering from that type of surgery.

MS. CRANE: I am sorry. We have staff who had detached a retina and had retinal reattachment surgery in our organization. They then get called to high functioning to speak for the other people who detached a retina and needed retinal reattachment surgery. I want to make it really clear. We are talking about exactly the same people.

DR. WACHTEL: You may know people that I have not worked with on the inpatient unit.

Just speaking from my perspective and working with these children and with their families over the past 15 years, these families often feel like they do not have a voice. Their children cannot advocate for themselves. Many times their functioning levels preclude them from doing that. And the families are really at a loss. They do not know what to do, who to turn to. They feel like they are abandoned even within the autism community itself while their children are children and then when their children become adults, it becomes even more of a dire situation. I am just trying to speak to that part of the autism community that I hope that we can continue to provide appropriate attention for because the children cannot come and advocate for themselves and many times their families are so overwhelmed by the needs of taking care of those kids that they also do not feel like they have the opportunity to advocate or that they necessarily want to be heard because they represent something very difficult.

MS. CRANE: I absolutely respect that there are these – as autistic people, we have issues that can be very significant. We have medical issues. I just want to make it incredibly clear. People who are functioning, as you describe it, on a fourth and fifth grade level – I have people that have been described that way and who are in our membership. They are our members and I am here to talk about my members' issues. They do self-advocate. They do not self-advocate in the same way that you might be expecting them to. Once they reach adulthood and they have the support to make their wishes heard, they make those wishes heard. They often join ASAN. We have members who have spent decades in inpatient settings and who have exited the inpatient settings and then moved to self-advocate.

Often when people say that these are two different communities, they are really not two different communities. They are often the same community and that is what can sometimes feel frustrating for people to assume that just because I am here, I am not on the worst day of my life right now. This is a pretty good day of my life. If you saw me on the worst day of my life, you would think of me as a completely different person and it is true of many of our members.

DR. DANIELS: I would like to make one last comments before we need to move on to the next and Dr. Gordon is back. At the last couple of meetings, we have really appreciated some of the commentary about IACC membership that has been going on. I just wanted to clarify that IACC public membership is open to people that have more severe disabilities to a wide range of parents and self-advocates. We do have the ability to provide special accommodations, but we do have a nomination process. In the history of the IACC, we have never had someone with very severe disabilities put in a nomination. In the future when there are calls for nominations, please keep that in mind because we are open to having a wider variety of people on the spectrum or who have family members on the spectrum served. Thanks.

I will turn it over to Dr. Gordon to go to the next public comment.

DR. GORDON: Sorry I am late. Let's just say that I learned today why there are ridesharing services.

Shall we continue then? The next public commenter is Lucina Clarke. I am hoping I am getting that first name right, Ms. Clarke.

For timing purposes, let me ask if the third person is here, Ms. Shari Chase. No. If you are in the audience, please identify yourself. No. Okay.

MS. LUCINA CLARKE: Good afternoon everyone. My name is Lucina Clarke. Thank you for giving my husband and me the opportunity to be here. We came from Brooklyn, New York and it is really a pleasure being here and listening to the comments. As far as research is concerned, dealing with what I have to speak about today.

Our organization is called My Time Inc. When we created this ten years ago, it focused on the parents. It is all about educating the parent, empowering them and giving them the time for themselves knowing how to be involved in the "me time" activities, taking care of themselves.

And what I have learned within the 25 years of teaching as well as working with the families of children with autism is I felt that the lack of parental support and taking care of themselves was very important.

I look at research. Research is all wonderful as I say. But while research is happening, what is happening to the parents' life? What about the self-care? What about taking care of yourself in order to raise your child with a disability whether it is autism or any other disability?

Ten years ago, my husband and I created a program called My Time Inc. to educate, but also the piece about self-care and "me time". We are the only organization in New York City that really provides a "me time" or recreational program for parents. My concern is about what are we doing for the parents. How will they take care of themselves and the resources that are being provided? I know this morning on the first question was asked about whether black and white and racial disparity in autism of the parents being really supported.

I am from the Caribbean. When I heard the word autism, was the first time I came to New York to live. We have disabilities in the Caribbean, but it is not something that we talk about all the time. It is not a discussion to say we have – my child is autistic or my child has a disability.

When I came to this country, I learned more about the disorder. I studied autism and then I became a behavioral specialist and I learned that providing a very vital service, so this is important. But while I was there, I was seeing the lack of support for parents. What was the parent getting? What time was the parent taking for themselves? The percentage of divorce rates and families separating is very high now.

My husband and I created a "Me Time" program about three years ago. And what we saw was parents taking time and revitalizing themselves, becoming better. And then I heard you talking about emotional wellness. We have been implementing emotional health wellness program and to see the difference in how the parents walk in and how they leave. By learning how to do self-care versus taking time for yourself. Knowing that it is important that I am well in my mind, body and soul as well, to raise my child.

When you are doing the research and looking at what is out there and try to either fix or change the way a person with disability is, let's look at ways of how can we find the resources to help that parent through that journey. What are we doing whether we are sitting in a committee or not, to reach out to that parent who is raising that child with disability?

By having the recreational program for the parents to go out, to form new relationships, to build that self-esteem for themselves because yesterday I had a parent who came in. She said, Ms. Clarke, I did not come to get services for my child because I do advocacy as well. I came to get service for me. I felt so depressed. I felt all alone. I do not know where to turn. It does not make a difference if you are black, you are white, and you have all the money in the world. Autism does not pick and choose where it should live. It happens. And how as we as a community embracing these parents who are raising the children with disability.

Too many times there is so much ostracizing. You do not belong or you do not fit in here. What are we doing to bring – just as the Indian tribes, bringing that community together. Bringing that wholeness. That is what I am seeing what parents need.

I said to my husband, we need to do a survey. Do some more research and looking at when a parent walks into the organization and when they leave because the ability to receive a service like the recreational piece and the emotional piece, in helping them to change their lives, to change their children's lives because if a parent – I believe, if the parent is not well in mind, body, and soul, how can the child be well?

I want to thank you for this opportunity of being here because it is about really bringing us in this community more awareness, whether it is black, white or whatever you are, of how we embracing the individuals and embracing the parents who are raising these children.

Research needs to be done like when a parent goes out and we go bowling. The stress. You can actually see the stress release, just removing from the parents' face when they score a pin or they do a strike, And the laughter, when you hear the laughter of the parent at the moment when you know in the night the parents are crying because why is it me that had a child with disability or why aren't I getting the services my child may need.

Having recreational activities and having that emotional health and wellness in whatever you are doing is so important. That is why I came all the way from Brooklyn to come and share that because we need to embrace each other better. We need to embrace the parents and provide the resources of having a night out, having a weekend out.

One of the goals this years was we had a fund raiser, is to be able to take some of the parents on the retreat. Half of my parents have not had a date in a long time. When the child was born, they forget about dating. They forget about putting roses on a petal. They forget about going out. We are having a Valentine's – but I just got five couples to go out. They have not done that. We are losing the essence of your life. What is life about? What is our purpose? As providers or committee members, let's embrace these families. Let's find places, find programs that can give them that life again.

I want to thank you so much and I really appreciate being here. I will be back in April because I am very much interested in the emotional wellness and the job forces for our families of individuals. I hope that as you all continue looking and putting policies and doing changes, look at the families. Look at the parents, how are we really supporting them so they can go through this journey? I thank you very much.

(Applause)

DR. GORDON: Thank you, Ms. Clarke. Are there questions or comments from the committee?

MR. ROBISON: Ms. Clarke, I would just like to thank you for and really to commend you for coming here and embracing the potential power of community and how that transcends disability, race, economic opportunity, anything else. Community is the thing that can save us and I want to particularly contrast that with the divisiveness of the previous comment. We need to come together, not break apart. Thank you.

DR. MANDELL: Sounds like a wonderful program. Can you tell us how the children are cared for when the parents go out?

MS. CLARKE: As one of the providers from New York State, what we do is we try and connect the parents to other providers have respite. We connect them. We start, for example. We are going to go bowling within a month. There are some providers who provide respite. We set all parents up in a way that -- call this provider or even to get someone who you may know or trust with your child. There is reimbursement. So they can get reimbursement for that. We put them on a pace. This is your life. Let's see how we are going to get someone to take care of your child. It might be someone you know who your child is trusted with. Let's do that.

Also, we get some funding from the state, not much, but we do have fund raisers because I am quite out of the box. I do not take no from anyone. I believe no – I really believe there are so much possibilities and opportunities out there for families. I go there. I am like a bulldog sometimes for the parents because they need a life and they need to enjoy not because you have a child with disability. Your life is not doomed. Go out there and live life just as full as you can.

If we can provide outlets for these families to have a life again, let's do that. Thank you.

DR. GORDON: Thank you. Are there other comments?

We do have one additional public comment. Ms. Chase, is that correct? Ms. Shari Chase.

MS. SHARI CHASE: Good afternoon everybody. I apologize. I was giving a talk on radiation protection for the University of Maryland, trying to save the world.

This is near and dear to me. I guess I will just read from here.

My name is Shari Chase. I am a Maryland State health leader, a surgical consultant, and a television show host. My education was as a pharmacologist and an educator, and most of all I am a parent to a young 21-year-old young male with autism who, by the way, I love dearly. He has a 23-year-old brother who is a biomedical engineer who is trying very hard to make amazing devices for self-regulation for people with autism. I salute both my kids.

This is the most challenging and heartbreaking job. It is one where hopes and dreams have been robbed of my child and me. The cliff that we fell down is a bottomless pit with tangles and twists and no map to follow. Yes, there are plenty of days that are filled with roses, but more that are struggles.

The agencies are unequipped to guide and educate those with autism and the post high school education is surely not customizable for those with autism. This is a shame. Developmental Disabilities Administration unfortunately has no watchdogs out there. People are just festering in these places.

These intelligent sensory burdened individuals are pushed to the side, underestimated, and left to sweep, bag and fester where they have the drive to excel and become extraordinary contributory citizens. We must partner with agencies and retirees as guides.

There must be vocational programs, interventions as well, that can be taught and then replicated at home. Colleges need to create visual programs so that our citizens with autism can flourish.

Please, I understand trying to prevent autism, but these people are here and alive right now, and we need to help. Instead immediately demand that vocational, educational and interventional programs are required to be customized to those of us who think in pictures.

There are three points I would like to make. First of all, we have a wealth of knowledge and resources in our youth today, especially in our master's degree students. They are trying to find their purpose and make an impact in the world.

These students are motivated in several ways. They show their desire to continue to learn and make an impact. They are not funded and hence, they would be apt to respond well to grant offerings to dedicate their time to find interventions and devices to help with anxiety, self-regulation and advancements in autism areas for people on the spectrum.

This is a very competitive environment and often recognition is what is desired. Let us make national awards for the advancement of autism devices and interventions to inspire these students and other academia, to concentrate their efforts on improving the lives of those with autism.

Second, our retired workforce needs to make some money. Let's face it. It is not cheap to live here. Let's encourage through our tax credits and grants that these same people who have perfected their skills and encourage them to start mentor programs for those on the spectrum.

Third, we need vocational programs that teach people on the spectrum in the method that they can excel. Let us offer alternatives to the verbal response and offer alternative ways to deliver messages and knowledges.

Let us start incentive programs for businesses to start apprenticeships to allow those on the spectrum to change and give them the chance to learn and practice their new skills in real time environment.

Finally, let us lobby to ask for those who do employ those with special needs the ability to keep those very precious tax credits as long as they maintain a high standard of work environment and continuing education. With this, we will have a workforce that will continue to excel and then can eventually pay back as future mentors.

With this, I thank you so much.

Two areas that I just want to mention. I started to say my son. His company's name is

GIA and he is a master's student at Northwestern. I am very proud of him and about 15 other engineers and computer individuals who on their own dime, going to contests, taking every penny they have to develop devices to help people with autism regulate themselves, to empower those people on the spectrum. I really respect them for that.

Finally, a dear friend of mine is trying to create a model that can be spread across the nation. I am helping him with this. We are trying to start academies that would be similar to colleges where someone does – they could either use their Social Security money or other types of grants or pocket money, to go in and learn different types of skills in a rotating vocational schematic. There will be businesses that will be created and owned by the academy. To work at those businesses, you must be a graduate of the academy. It will be in the by-laws of each business that 25 percent of the work staff must be people who are on the spectrum.

They have already started one and Daltile said they will take all the products that are made out of it, which is huge, that is a huge business. But this is something that can be replicated and modeled across the country.

And the reason personally I feel it is important is my son Alec, who is 21, came out of high school. This is a child that was in GT engineering, but very low on the verbal area, but fabulous in the intellectual area. He went to college and because of his stimming, he jumped one time in his class and made a sound and then secondly, he was in class and all his classmates were leaving and went up to stand. The teacher came over and put his hand on my son's shoulder for 21 minutes would not allow my son to exit the room. Each time he said Alec leave. Eventually, my son, as you can imagine, grabbed his teacher's wrist and said, Alec leave and he was expelled from the school. That is unnecessary.

We need to just I guess, maybe enlighten people in colleges that we need to respect people in the autism spectrum even if they only can utter one word or write down a word. But we really need to fashion it so that the educational pieces are an area, one, they can understand, and two, to educate people and how to work with individual's autism.

I sped talked because I wanted to get it all in. I applaud everyone that takes their valuable time to come on this committee and others that travel around the country. This is a typical task to perfect everything we are all hoping to come to fruition. But if we can stay in the positive, we could highlight each individual's skill set, and work on those in this variety of suggestions I had here. Instead of worrying about what they cannot do, just keep worrying about what they can do. We can make each person rise to their very best ability and contribute to this nation.

There is nothing more than I think any parent would want for their child and any person on the spectrum would really wish to have happen. Thank you from the bottom of my heart.

(Applause)

DR. GORDON: Thank you. Any comments from the committee? I would mention real quick, that at NIMH we are very interested in helping both academicians and small businesses develop tools like the ones described by Ms. Chase that can take advantage of digital technologies and other approaches to improve care and treatment for individuals with autism.

John, I see you.

MR. ROBISON: I guess I would offer this comment in the event any of our lawmakers are listening to us or reading our transcript. Our last commenter suggested the importance of tax credits to employ people with disabilities. I just want to put that in perspective for all of you who do not know what that means.

Right now, Social Security will happily give a disabled person $25,000 to $30,000 a year in cash in housing supports to live disabled. Somehow, we are willing to give an employer $2300 to employ an autistic person. I guess I would ask you. What is wrong with that picture? We will plan 25 grand a year for a lifetime to support a person on disability and we will give $2500 as a credit to an employer who puts that person to work. With all due respect, it ought to be backwards. We need to look at a tax credit that is a serious enough amount of money that employers will do the research, figure out the techniques, and take the steps to employ people and keep them employed. $2500 or $2300 is talk, not real action.

DR. GORDON: Thank you, John. Kevin.

DR. PELPHREY: I wanted to thank the speaker for the comments. Very exciting. Particularly the description of the training program. I direct the Autism and Neurodevelopmental Disorders Institute at George Washington University. One of the things that we are focused on right now is trying to build a school or college within the college that focuses on the transition period from high school into college, taking kids in what would have been their final year of high school and helping them with that transition particularly with an intensive program where we are using different neuroscience techniques to try to understand what the kids would be best at learning and pair them up with that and then provide very carefully planned programs to help make college a success.

What we are seeing from the literature is that if our kids are not making that transition, if they end up back home and this is true autism or not, but if they end up back home and they have autism, they are particularly at risk for not leaving again. We are trying to have that opportunity, that kind of post-back program or post high school program where they can safely have failure experiences, but we are there to help provide that safety net and opportunity to succeed. We kind of talk about it like Hogwarts for autism.

We are particularly interested in partnering with different tech companies because where we are located in Ashburn, Virginia is in the heart of Amazon, Google data centers and different major cybersecurity firms. We would love to talk with you and have you out and talk more about potential collaborations because I think this is a real big need in the community and something that is very important to do.

DR. GORDON: We should move on. We now have Julianna Rava from the Office of Autism Research Coordination at NIMH, who is going to present a summary of the written public comments.

MS. JULIANNA RAVA: Hello. Since the October meeting, the IACC received written public comments from nine commenters. And for the purposes of this presentation, we have organized these under six broad topics. The committee has been provided the comments in full, but they will be summarized briefly here.

Topic one: the role of the IACC. Four comments were received on this topic. Dr. Debasis Kanijilal thanked the IACC for publicly posting online his written comments submitted in advance of the October IACC meeting. He also shared an email recommending the IACC to the Nobel Prize Committee.

Dr. Eileen Nicole Simon thanked IACC member Alison Singer for representing the perspectives of parents of minimally verbal children at the October IACC meeting. However, she asked that random public comments be discussed more thoroughly, not only summarized, and that more time be allotted for discussion by the IACC.

Ms. Michelle Guger shared insights from her experiences as an adult with ASD and offered to provide her perspective, which she thinks could be helpful to the IACC.

Ms. Vashti Johnson looks forward to receiving email updates through the IACC LISTSERV to help her better inform urban communities about the IACC's policies and vision.

Topic two is transition to adulthood and adult services. Three comments were received on this topic. Ms. Shannon Rosa shared her concerns about the availability of integrated housing options for her autistic adolescent son. She urged the IACC to help ensure integrated housing options are more readily available and to recognize segregating housing as isolating and dehumanizing.

Dr. Eileen Nicole Simon described the challenges of her autistic adult son's care, his issues with wandering and his difficulties participating in day programs.

The Autistic Self Advocacy Network thanked the IACC for its interest in the transition of autistic people to adulthood and praised the recommendations in their recent HHS report to Congress on transition age youth with ASD.

However, they cautioned against the notion that transition age autistic youth are a significantly different population from other youth with intellectual and developmental disabilities and therefore require autism-specific transition supports.

Topic three: concern about medical practices. Two comments were received on this topic. Dr. Debasis Kanijilal shared several emails he has sent to other committees to express his concerns about brain injury resulting from inadequate treatment of hypoxia in newborns.

Dr. Eileen Nicole Simon asked the IACC to discuss her comments describing potential links between autism and brain injuries resulting from umbilical cord clamping, asphyxia at birth, and prenatal exposures to drugs and infections.

Topic four: IACC strategic plan and autism research priorities. One comment was received on this topic. The Autistic Self Advocacy Network appreciates that the new IACC Strategic Plan is more inclusive of several issues that are important to autistic community, but urge the IACC to more strongly prioritize the need for federal funding on research topics of benefit across the autism community and the lifespan rather than continuing disproportionate funding for research on biology, causation and treatment of autism. They also urged the IACC to promote the involvement of autistic adults in their research process.

Topic five: resources and support. One comment was received on this topic. Mr. Wayne Clarke wanted to make the IACC aware of a parent summit hosted by My Time Inc. that brought health care providers together with the parents, grandparents, and caregivers of those with autism and developmental disabilities.

Topic six: vaccines and autism. One comment was received on this topic. Mr. John Best believes autism is caused by mercury in vaccines and expressed frustration with the IACC.

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

DR. GORDON: Thank you, Julianna. Are there comments or responses to any of the written comments?

MR. ROBISON: I would like to speak to a couple of them. Shannon Rosa commented that she hopes that we will be mindful about the issues surrounding housing. I know that in previous IACCs, Sam and I have appeared to disagree about exactly what we want out of housing. I think that that is because it is a really complicated subject.

And the thing that I want, and I think Sam wants to, is a world where if six William and Mary students from my university can get together and rent a house and live there and be college students, that is okay. Why can't six autistic people, who are receiving some kind of disability support, why can't they live in a home together?

I understand on the one hand we have a lot of debate about where people are subject to abuse, where we are protected, but I think there is also a fundamental issue of freedom of choice. I feel like in my queries to our housing department people when they have come to IACC, they have never been able to give me a straight answer about whether or not they support freedom of choice for autistic people and housing. That is a frustration to me. Shannon has echoed that. I want to repeat it here.

And the other thing that I speak to is we had two what you might call opposing comments. Jonathan Mitchell said I think the IACC should focus more on scientific research that finds a cure for autism and then Julia Bascom said that more needs to be done to redirect autism research away from the medicalized model of autism and research that benefits autistic people.

I would like to think that Julia and Jonathan both ultimately want the best quality of life for autistic people and they want us to live lives with the maximum of joy and the minimum of pain and suffering. And yet I recognize that they have different views.

And also, we heard from a parent advocate earlier and notwithstanding my disagreement with her attitude towards that, I believe that she makes a valid point that we could use more diversity on the IACC. I would say that I would support autistic people whose views are sharply different than my own joining our committee and I would support the return of parents although I will say that parents dominated the discussion for decades. I think it is time for diversity in voices.

DR. GORDON: I want to make one quick comment about housing just to remind everyone on the IACC, and those in the audience who may not know, that the work group process that we are starting out to approach the first being on the medical issues that was discussed this morning and one of the other two that we are – will stand up when we get the opportunity is one on housing. I think the committee recognizes the importance of trying to work through the complexities of housing and make some recommendations for what we might do federally and nationally. That is something that we are actively pursuing and will be doing with a work group.

Alison, I think you want to say something and then David.

MS. SINGER: I just wanted to comment on just the overall tenor of some of the comments that we have been hearing. In the comments today, the oral comments, the written comments, the comments in October – what we are hearing is that there are parents who have children and who are very severely affected who are members of this community who are feeling left behind. I think, John, what you said can very much relate to that. Ten years ago, advocacy was dominated by parents and individuals with autism felt lack of representation that their needs were not being taken into account. Now the pendulum has swung the other way. I think parents are feeling that the focus has been on areas that their children are not really able to access. It is very difficult to appreciate a panel on employment when you are focused on safety and preventing injury.

Samantha, to your point, I think we all can agree that your group represents individuals with autism at all levels, including severely affected people. But our organization also represents very high functioning self-advocates who are in favor of research and to causation. We do not really purport to represent the views of the neurodiversity community.

I think what all of this commentary and discussion over the last two meetings is really pointing to is the need for balance. Again, John, you said it when you made your comment that the needs are very different. I think that is why there is this frustration. But we just have to make sure that we are not over representing one group set of needs at the expense of another groups equally important set of needs.

MR. ROBISON: I absolutely agree. We also just have to be conscious that our absolute numbers are small. There is you, a parent. I am a parent. There is Sam who is an autistic person and not yet a parent. We do not have enough individuals. I agree with you though that we need more diversity and I support that.

I would also say that as much as some of these comments sound like they are really contentious and angry and sometimes I respond that way too. You know that you and I have been together doing this for many years and we have always gotten along. I like you and Len and the other parents that have been parts of the committee. When we get together, we are not each other's enemies and we do not fight, and we can move forward to do things. I just wish we could do that better here. I wish we could.

MS. CRANE: I have a couple of comments to make because I also found Shannon's comments really interesting and important. I will fully disclose that Shannon talked to me about her comments before she submitted them. I think of Shannon as a friend of mine.

Her son is someone with pretty high support needs. Her son is non-speaking and Shannon is also part of the neurodiversity advocacy community. I wanted to highlight just that fact, again, that we are diverse.

Her concerns really do come down to choice, as John pointed out. Sometimes when we talk about choice, we make assumptions about that. The choice is always going to be this or that. The choice that Shannon wants to make is for integration for her son. She is very concerned that her son will not be able to find an integrated community-based setting.

One of the reasons why many of us are concerned about choice is that ASAN has never really taken a position on. We do not have much of a – we do not really have many concerns about a situation where people just sort of decide we are all friends. We are going to rent a house together.

What we do see, and we tend to be a bit more concerned about, is when someone builds a house that can only be occupied by six autistic people and then they have to find those people to fill the house. When we have housing planning where you create a setting and then fill it, you are making people's choices before they have made it essentially. You are saying we know that people are definitely going to want this and we are going to fill this setting. That is not always true. When you have a situation where you have created – with six beds, you might be more likely to find six people who want it. When you create a setting with 50 beds or 100 beds, you are really making a gamble that you are going to find 100 people who truly that is their top choice. That is often not actually something that happened. And then you have to essentially fill beds with people for whom that would not be their top choice.

That is why we want to make sure that housing policy is as flexible as possible so that people can make the decision. People can say here is where I want to live and then bring their services in with them.

I also want to briefly address Jonathan Mitchell's comment because I was called out rather specifically in that comment. Mitchell, who is not a parent, has repeated requests that he made both outside this meeting and directly to Joshua Gordon that I disclosed my medical records as a condition of serving on the IACC.

I am going to repeat what I have already said because I want it completely clear on the public record. I am not here to represent myself. As my colleagues on IACC know, I have consistently advocating for greater research on communication supports, on seizures, on cross cultural and cross-racial differences and identification and delivering supports on a variety of medical co-occurring conditions that I do not necessarily have. I have been doing that not because of my own personal medical history, but because these are the issues that have been raised to me by my membership, by ASAN membership, not my personal membership, but my organization's membership.

I was not appointed based solely on my autism diagnosis. I was appointed based on my position at the Autistic Self Advocacy Network, which is a nationwide 501c3 just like Alison is not here just as a parent. Alison is here as a representative of the Autism Science Foundation. I am here based on my professional position as well. I take that very seriously and I take my responsibility to not speak for myself very seriously.

However, this is not an isolated incident. Very often, if we want to talk based on our professional credentials and we also disclose that we are autistic, we are asked to disclose personal information that others are not asked to disclose. It is a silencing technique and it is a double standard that we unfortunately have to face.

Professional experiences or qualifications are either ignored or they are actively used against us as we see in Jonathan Mitchell's comment.

I have never pretended that my autism does not affect me. I do have a professional diagnosis, which many adults on the spectrum do not have because they are very difficult to obtain, and they are expensive to obtain. But that diagnosis includes extremely personal details about my childhood, my later adulthood, my independent living skills, my psychiatric history, and I am choosing not to disclose them. I will continue to advocate for our membership to the best of my ability. Thank you.

(Applause)

DR. GORDON: Thank you, Samantha. We are running over but I think given the spirit of the discussion, I am going to allow us to continue to run over. We will get to you, John. There are a couple of people in front of you. First, Susan wanted to say something and then Alison and then John.

DR. DANIELS: I just wanted to make a clarification about membership because there was another comment regarding membership. We do have Alison Singer who is a parent on our committee. We have John and Samantha who are self-advocates. I also wanted to point out that Edlyn Peña is a parent, Kevin Pelphrey is a parent, and Marcy Ronyak is a parent. And then two members who have left, but were with us. Amy Goodman was a self-advocate and has since left the committee and Shannon Haworth was both a spouse and a parent. I wanted to make sure that people were acknowledged. There are a lot of people with different interests and experiences with the autism spectrum here on the committee and we respect them all.

MS. SINGER: I just wanted to respond to Samantha’s point about housing, which is not the experience. I think of the majority of parents who are looking for adult placement. The waiting lists are years long. We have our children who are moving out of pediatric residential placement. There are no places for them to go. Everyone is applying for these spots. Very few people get them. I do not know of any good residential centers for adults that do not have waiting lists miles long, years long. To say that they cannot be filled is just not the experience in the field.

MS. CRANE: I want to clarify. It is not that they cannot be filled. It is that there are multiple people who apply for these placements, not just because they need a place to go, but also because even if they would prefer community-based scattered site housing that absolutely does not exist. As between something that completely 100 percent does not exist and something with a waitlist, they are going to go for the thing with the waitlist. This is something that we hear from our membership quite often.

DR. GORDON: I think this is a great topic for us to consider in the housing work group. It is clear. There is a shortage of housing and what models might be best for the full spectrum of those suffering from autism is something that we need to work through.

MR. ROBISON: As Susan points out, we actually have more parent representation on IACC than I thought. I know that to be so. That still leaves the idea that there is an absence of representation from the autistic community members who hold sharply different views about their disability than perhaps Sam or I. She talked about Mr. Mitchell's commentary about her. And to be fair, he has also written the same things about me. He has written to Josh here suggesting that I and

Sam should be removed from IACC because of our views.

I went, and I met him in person this fall. When you see him in person, he is a kind of a whimsical, funny thoughtful guy who has had a hard life. He has something to offer that does not come through in snapping and biting at Sam and me. There are other autistic people who I see when I travel and speak, and they speak to me through assistive devices and other means. I realize those people potentially have a great deal to contribute to committees like ours. It is hard for me to imagine how they would participate in IACC as it is structured right now.

Just after lunch today, one of the folks sitting here in our audience commented to me about how hard it was to follow our proceedings up here because we do not have a closed captioning in the video stream. There is a time lag with the transcript, so you cannot read it. Whether you have an autistic impairment or just a hearing impairment, you cannot keep track of what we are saying. I think it merits some consideration. How could we accommodate those different views and how could we welcome them here?

Certainly, I do not want to encourage people to come and snap and bite at Sam and me or any of the rest of us, but at the same time, I do encourage different opinions. I think that there is people maybe that say and do things in a way that cause us to turn away from them and we do not hear a valuable message. I wish we could think more of that.

DR. GORDON: Thanks John. I was asking Susan just to clarify that although the live video proceedings are not closed caption and that is something that we can look into though. I suspect the cost will be quite high. The feed is closed captioned when it is archived. People who watch the proceedings later and I encourage anyone who is interested to do so can watch the proceedings with closed captioning. That is the way I understand when it is stored on the website.

PARTICIPANT: (Inaudible comment)

DR. GORDON: I appreciate the comment. Let me just repeat it because you were not at the microphone. I want to make sure everyone had the opportunity to hear it. An audience member noted that the request was to provide live captioning. I think we will look into it. We actually do not have a budget for this committee.

DR. DANIELS: I will add something. It actually is live captioned if you are watching it on the computer. It is just not on our screen in the room. We can look into whether you can – but then if you are watching it on the screen, you would be watching the video of us talking versus watching the slides themselves.

DR. GORDON: This is something that we can address. We can find a way to make sure that people who are here in the room have a way of accessing that. We will look into this. That is very helpful.

DR. DANIELS: We might be able, for example, run the actual video cast on a different screen from the slides or something else like that.

MR. ROBISON: She explained to me just so you know, that the live transcription is delayed. It would put a person in a position of looking at words that out of sync with what they hear in the room. That was the difficulty.

DR. DANIELS: I do not think that can be helped though because somebody has to be doing that and they cannot do it as it is happening.

DR. GORDON: We will look into possibilities for doing this at subsequent meetings. Whether we can set it up in time for April I do not know.

David, you also had a comment or question.

DR. MANDELL: Two thoughts. One is of course no one should have to share their medical records to be part of this committee. But I do think we should share our Spotify playlists.

The second thought was I wanted to point out something that was in the ASAN comment that I thought was really important when they were talking about transition and said it is not clear that people with autism need separate transition services from people with other disabilities, which I think is a great empirical question that we ought to be thinking about asking in a number of arenas, including housing, including primary care, including inpatient care.

There are probably other groups that have been working on this for longer than we have and have worked out some of the questions that we need to work out. I wonder in the context either focusing on specific aspects of health and wellness or on focusing on housing or other areas whether we could lift our heads up from the autism world and see what else is going on and see whether there are exact models or analogs that could really be appropriate for us to think about as we address this question in autism.

DR. DANIELS: David, just to reply to that comment. I did mention that we are in touch with the Federal Partners in Transition, which is a government-wide working group on transition in general. They are very interested in engaging with IACC. In the future, we may be able to have them come here and talk to us about those very issues.

DR. MANDELL: Sure. I hope we would do it not just for transition that we may have a lot to learn from intellectual disability community or the community that helps people with serious mental illness or other groups addressing these same kinds of issues.

MS. CRANE: I want to really echo that. Housing, for example, is a perfect example where people will say we cannot have people with significant behaviors housed in the community. It is something that the mental health community and the intellectual disability community have been addressing for a long time now through supportive housing models. Many people with psychosocial diagnoses or intellectual disabilities have challenging behaviors that can interfere with housing and have people result in people being expelled from housing. People have absolutely been working on this question. We need to be interacting with those fields.

DR. GORDON: That is a great point. I think a nice place to start that will be with the housing work group. We can try to ensure that we have representation that goes beyond the IACC and autism.

I think at this point, we should move on. We are running a little bit late, but we will be all right. We will make up the time a little bit later in the schedule. Next on the agenda is a panel presentation on autism screening. This is an issue that this group has dealt with in the past few years in terms of early identification and of individuals who are at risk or who go on to receive an autism diagnosis, how to do it and what to do once it has been done. It is an area of active research at NIMH and also of active concerns – sorry. Not just NIMH, NIH generally, and active concerns through the federal partners as well as many of you from the nonfederal representatives will recognize this as an important endeavor.

To start us off, we have four panelists and the first is Denise Pintello who is the chief of Child and Adolescent Research Program at NIMH and is going to start us off by introducing the networks that NIH has put together to study these issues.

DR. DENISE PINTELLO: Thank you, Josh. Good afternoon. It is always wonderful to be here I have to say. I enjoy learning and hearing all the feedback from the IACC.

My name is Denny Pintello. I work at the National Institute of Mental Health. I am here with some researchers who compose our ASD PEDS Network. And what I want to do in the next few minutes is to describe what the network is and tell you that it happens to be five separate studies that NIH has funded. It centers around the scientific work of some very dedicated and thoughtful scientists that are really devoted to finding new approaches to enhance early detection, engagement and referral to treatment for autism for very young kids.

Before I describe what the network actually is, I thought it would be helpful to give you an idea of how the network came about. And the answer to how the network came about is actually you, this body, the IACC as a result of the 2013 Strategic Plan. That plan identified the important need to address services for very young kids, transition age youth and adults. And trying to address services utilization as a direct result of the strategic plan, my colleague at NIMH, Denise Juliano-Bult and Beverly Pringle. They wrote a series of three different funding opportunities that was titled ASD, Autism Spectrum Disorder across the Lifespan. It focused on very young kids, transition age youth, and adults.

You also might recall that in that strategic plan the IACC prepared back in 2013, it was framed around a series of different questions. And the first question was when should I be concerned. And one of those FOAs that NIMH developed focused on this area and the importance of early identification so parents have some information so that they have a sense of what might they do and how to stay engage and work with being referred to treatment.

This FOA that we call Funding Opportunity Announcement – these were the general goals of that Funding Opportunity Announcement. But the most important thing that we really emphasized was its focus on underserved populations, toddlers, families and communities. That was the central tenant of that Funding Opportunity Announcement.

The wonderful thing is we received a number of fantastic applications. Unfortunately, we could only fund the top five. Let me give you a snapshot of what those applications look like that we selected and here are the locations geographically around the country. There were five of them. They spanned nine states and were proposed to be conducted in 16 different locations.

Let me just tell you quickly about the first application. Karen Pierce. She is at University of California San Diego. She is using that well baby checkup at 12 months. She is implementing a universal screen in San Diego and in Phoenix. From there, the universal screen would happen at 12 months, 18 months, and 24 months. It is a triple screen. Her goal is to detect early signs of autism and if needed, refer right away for ASD treatment.

Then the second study in Wendy Stone a little bit north up in Washington State. It is a rural study in four different rural settings. She is focusing on a similar, but very different screen referral treat model focusing on kids around the age of 18 months. If those kids are identified at being at risk, she is testing a specialized, evidence-based treatment to be delivered by 24 months.

The other three researchers that you are going to hear about later today – Emily Feinberg is conducting a comparative effectiveness trial comparing family navigator model to a routine care management model.

Alice Carter is looking at systemic interventions and many of you know EI, early intervention. She is looking at various approaches and then trying to enhance access to services especially among underserved toddlers.

And then Amy Wetherby and her colleagues are conducting a multi-site trial that is testing a number of different approaches especially an online, automated universal screening tool as well as an evidence-based treatment to enhance engagement.

Those were the five top applications that we wanted to fund. But before we actually funded them, one of the things that we always look at because there were five separate studies, we looked at – of course, they were similar, but we also looked at the differences. They had different research designs, different screening instruments, different approaches and strategies they were using to engage these families and of course different settings.

But when you looked at them as a set, we thought there is a lot of great potential here and that collectively of the five studies together, they were going to screen about 70,000 kids. If you use the CDC estimates, they would probably – we would find that about a thousand of those children would be diagnosed with autism. We really tried to come up with ways. How could we creatively harness the science in these five studies?

What we decided to do was invite these applicants who were now becoming our grantees to join and form a network. The wonderful thing is that they said yes. They agreed to also include four common measures in their screening protocols. As a result, this provides the opportunity to collectively pull data at various time points to see if we have more statistical power together to try to find some patterns and trends.

We funded them in 2014. Since they were awarded, they are doing a lot of different things. They are meeting routinely. They have developed a website to share instruments including translated instruments from different languages, treatment tracking matrices, different publications. They are training each other staff in various implementation procedures. And they are presenting at conferences.

The other thing that occurred since 2014 that was unexpected that many of you are aware of is the United States Preventive Service Task Force recommendation, which concluded that there was insufficient evidence to support routine screening when parents or providers did not indicate any concern.

In response to that finding, JAMA immediately released an editorial where they acknowledged that the ASD PEDS Network, which is what we call it by the way. I am sorry. I did not spell it out. The PEDS Network is Pediatric Early Detection Engagement and Services Network. That is why we refer to it as PEDS. That this network has the potential to address a number of research gaps, including some of the areas that were raised in the USPS Task Force recommendation.

Currently, we are now starting year four of the five-year projects. They are planning to be done next year. They are at the height now of their recruitment and data collection processes. They have just submitted – I believe a publication was just accepted. We are looking forward to that.

And the other thing is that we are convening monthly and in person meeting. We are addressing a number of different areas that hopefully will move the science forward.

Overall, these studies will be completed in the fall of 2019. These are some potential activities that are on our list to be addressed by or before then including – we would love to see if the IACC would like to have all five researchers come and present their findings once they are completed because we would love to hear your thoughts about your impressions as well.

And then the other thing that I do want to – in closing, what I would like to say is that it is our hope that these sets of studies, that this network can – if we find these models and strategies to be effective, we would hope that we can disseminate these and generate additional utilization across the country of what these researchers are doing so that we can make a difference in the lives of kids, families, and communities because that is why we are doing what we are doing.

It is my pleasure to introduce to you three of the five researchers from this study. First up will be Amy Wetherby, I believe, and she is from Florida State University. Her study is titled Mobilizing Community Systems to Engage Families in Early ASD Detection and Services.

Following Amy will be Alice Carter from University of Massachusetts at Boston. She is going to be talking about addressing systemic health disparities in early autism identification and treatment.

And then the last but not least is Emily Feinberg from Boston University. She is going to be talking about early identification and service linkage for urban children with autism.

It is our hope that we invite – after the presentations, we would love to hear your impressions, your questions, and any recommendations you have about how this network as well as other areas of future areas that we could work on for future research studies. Thank you.

(Applause)

DR. AMY WETHERBY: Good afternoon. I am very thrilled to be here and to lead off this panel. It is a bit of shift of topic from your earlier discussion, but yet very really intimately related because the hope is if we do better at early detection then that will translate into better developmental trajectories and better outcomes in adulthood. That is really what it is all about.

I wanted to frame it to begin with just the cost, but the cost is only a part of it because autism impacts families and individuals on the spectrum very much. It affects their whole life. But the cost is a big one just to think about the potential saving. It is one of the most expensive developmental disabilities. Lifetime societal cost for one child ranges from $1.4 to $2.4 million. Much of this cost does come in adulthood. If we can do better earlier, we can save a lot of money later.

Now, you are aware that the American Academy of Pediatrics recommends developmental surveillance for 9 to 30 months every well visit for developmental disabilities in general and for autism specifically between 18 and 24 months.

The problem is we are able to diagnose autism between 18 and 24 months, thus the logic of screening at that age. Yet the median age of diagnosis in our country to continues to hover between 4 and 5 years.

And furthermore, the children who are from minority, low income, and rural families, the diagnosis is a year or year and a half later. We can refer to that as a health disparity, which may prevent the opportunity to even get any early intervention.

And then was mentioned by Denny, this US Preventive Services Task Force report just made things a bit worse. We are already not doing so well with really good guidelines and recommendations and now they are saying in fact the conclusion is there is insufficient evidence to be doing this. And furthermore, we should wait for parents to be concerned.

What I would like to do today is begin by talking a little bit about the limitations of current screening measures, screening tools, screening strategies and then talk about what we are trying to do to change, really transform health care delivery for children with autism and then roll this out and potentially scale up.

The first point I want to make is the selection bias from screening tools. When you look at research studies that are published, often the sensitivity and specificity is very much inflated. And part of that is to look at the sample they have collected in the developmental level. If the developmental level is far below 75 then there is inflation. What that means is the sensitivity and specificity really are not accurate to represent the full spectrum. We now know at least 60 percent of individuals on the spectrum have an IQ within normal limits. If we are thinking about trying to screen for the full screen, if the developmental level is far below 75, we are not doing too good.

The top line shows the younger sib. The baby sibs study as a reference. This is Ozonoff et al. We see average developmental level on the four domains of the Mullen Scales at 75 or above.

If we look at one of the largest studies with the M-CHAT in primary care, we see a huge gap. In other words, what this is showing us is that this screening measure although the sensitivity and specificity look acceptable in this publication is missing many children who have higher developmental levels.

Just to contrast just to show you the feasibility of catching higher functioning children earlier, we have a new screening tool I am going to talk about, the ESAC. And from our ongoing research, we are finding developmental levels far closer to the baby sibs, which is our target.

The second point is that we need to think about how many children are possibly being missed in a primary care screening to really understand who are the false negatives. Who are we saying you passed, your children are not at risk for autism, but in fact they end up having autism? We know from the 1 in 68 children, the current prevalence estimates based on the CDC, which would translate to about 15 per 1000. If we take the screening tools that have been used in primary care in just a couple of articles that are published starting with way back with the CHAT, which taught us a lot, they were catching 2 per 1000. They acknowledged. We are missing far more than we are catching.

The M-CHAT is slightly improved. The recent study of screening 18,000 in primary care. The difference is they have actually gone a little older from the CHAT was 18 months. They have screened from 16 to 30 months with an average of 20 months. A little bit easier to catch children when they are a little bit older and yet they are catching 5 per 1000. That means they are missing 10 per 1000. That means they are missing more than they are catching. That is an important message. It is the most widely used screening tool, perhaps one of the best available screening tools, but it is not doing that well.

The M-CHAT in the study in Europe right at 18 months, 52,000 children without the follow-up phone interview, which is necessary to improve accuracy, 1 per 1000.

The ESAT, which is another tool in Europe conducted even earlier, less than 1 per 1000. Our tools are part of the problem. We have to acknowledge that.

I want to just report on – we reported a few years ago a study with the Infant Toddler Checklist, which Karen Pierce in our network is also using. This is a tool that I developed with Barry Prizant. It is a social communication screener. We were the first to use it and we found in our sample of 6000 children, we identified 90 children, which is right around 15 per 1000. I am confident we missed some.

This is a more promising approach to start. What we did is we started with screening for social communication and then we screened for autism. That two-step process maybe is a better approach.

And I want to also comment that this problem of under detection is not specific to autism. We are not doing well with other developmental disabilities. Based on figures of the US Department of Ed, we now serve an average of 11 percent at school age in special education. At preschool, we are getting about half. We are finding about half. That is not very good, the 5 divided by the 11.

If we go down to infants and toddlers, we are catching 2.5 percent. That means we are catching 20 percent. If you fourth that, it means we are missing 80 percent. I refer to this a lot.

If you are only screen in the early intervention system, you are still going to miss 80 percent of the children with autism even if you catch every single one that is referred into the EI system. And we need to do better for all disabilities.

Part of the problem is where we draw the line. Many states have their eligibility set at two standard deviations below the mean. That is equivalent to a standard score or IQ score of 70. That is the second percentile. The most widely used screening tool broad band is ages and stages. And most people are using their cutoff, which is at the second percentile. If your cutoff is at the second percentile, you are never going to get more than 2 percent. Part of our problem is the cutoff and it is also related to eligibility.

And the last point I want to make broadly is that part of the problem is the milestones that are out there. There is immense effort by the CDC, which I applaud, “Learn the Signs. Act Early.”. States have gotten behind this. But I really want to point out that the milestones that they are using may be part of the problem. These are sample milestones and they now have a new milestone tracker that is an app, which is fabulous, but these are the milestones they are using.

At nine months, may be afraid of strangers. It also happens to be at 18 months. I have triple checked this. It is not a typo. At nine months, may be afraid of strangers. May be clingy. You think about it. All kids with autism pass this at 9 months. At 12 months is shy or nervous with strangers. Cries when mom or dad leaves. Is that a good thing or a bad thing? Has favorite things. Most kids with autism they are going to have favorite things that they are overly fixated on. 18 months. Likes to hand things to others as play. I am passing around a document for at least the members. 16 gestures by 16 months. One of the earliest gestures to come in is the give gesture. This comes in at 9 months. These milestones are at the second percentile. Is that what we want to inform our families of? I think that is part of the problem. We are telling families milestones that are very low and families can be relieved. My child can do that.

Parent concern is very accurate because they do not know the developmental milestones. They do not know when to be concerned.

Retrospective studies and prospective studies of parents of children with autism show that about 75 percent of parents are concerned if their child ends up with autism.

By 18 months, about half. By 12 months, about 30 percent. If we rely on parent concern, we better not go younger.

Furthermore, very few report concerns that are specific to autism. They have more general concerns like their child is not talking. Their child has behavior problems. They do not know these are part of autism. The parents are not going to say I am concerned about autism.

The task force report is very problematic if we are going to rely on that. Parents are fairly accurate of telling you what their child can and cannot do.

This is from a study we reported in 2008, which shows our screeners, the purple bar, how accurate we are at catching children who end up with autism. The yellow bar is the parents say they are concerned or not about anything. The gap between the yellow and the purple is who you are going to miss if you are looking for any concern. If you are looking for autism, this is what percent, 18 to 20 months of these parents who had concerns in the yellow bar said, yes, I am concerned about autism. We are going to miss most of these kids. We cannot rely on parent concern if we are going to try to get under 24 months. If we want to keep waiting until 4 or 5, that is going to work, not under 24 months.

What I want to share with you is strategies that we have been testing, things that we have not worked. We have learned so much about things that do not work and those are important and then what we are trying that we think is going to work.

I started the First Words Project. It has been at least 15 years. We have had funding from the major federal agencies. I am very appreciative. Many of whom are around the table.

What I want to start with is the Smart ESAC, which is a new screening tool, Early Screening for Autism and Communication Disorders. What we did is we took the best questions from the infantile, their checklist. I am the author, so I can do that. Plus we tweaked them and we added questions that were not there and we whittled it down to the best ten to have a broadband screening for communication delay and then we added 20 more autism specific questions so that we could do this all at once.

We automated it working with Prometheus Research, built an online automated system so that parents get ten questions. They get scored immediately, positive screen. Then they get 20 more seamlessly. It is a little bit longer. And we screened for autism right then and there.

We have funding from NICHD now where we are validating down to 12 months with Smart ESAC. So far so good. It is promising for a universal screen. The biggest challenge is that it is electronic. It is not a paper version. You have to do it online. Working pretty good down to 12 to 36 months.

We have good sensitivity and specificity in the high 70s or upper 80s from 12 all the way up to 36 months. It seems to be cost effective.

Our questions are a little bit different than the M-CHAT in that we have more questions in both equally split across both domains of the DSM-5. We have a little bit more questions on repetitive restrictive behaviors. Most of the screening tools do not.

Now, I want to just turn to who should screen and how do we do this. How do we make this happen in your community? How do we make this happen across our country and possibly beyond to go global?

We see it as we have to have working together the early intervention system because they need to be ready. We need to agree that we are going to do no harm. I think we all agree in that concept. The EI system needs to be ready if we are going to be screening primary care. They need to be ready to know who these kids are when they come in. Primary care needs to be ready to be able to do this. And the family is at the helm. The family needs to be ready to have the support and ultimately the services.

What we are doing with our new funding from NIMH as part of the ASD PEDS Network is trying to roll out a whole set of online tools, courses, and resources that we have developed. We got some funding from the State of Florida to do the actual development of the online tools and courses. With this grant, we are rolling them out and studying them. We have a big team across four states.

What we are doing in this grant across our sites and the four states is to reach out to community providers and primary care medical home, publicly funded social service systems including publicly funded childcare, Early Head State, WIC, other programs like that. And we are also partnering with the National Black Church Initiative to try to reach out through faith-based organizations.

We started the project using an implementation science framework the first year, which I think dragged into two years in our planning phase. We wanted to identify challenges and barriers from families and from physicians and nurses and health care providers.

We conducted focus groups with professionals across three states. And what we found is that the professionals that they need training on autism. They do not know what it looks like at 18 to 24 months. They are very comfortable taking a wait and see approach. In fact, they prefer that. In fact, they are uncomfortable not taking a wait and see. It is a baby. They are not convinced that we can identify it that early. They do not want to needlessly worry parents.

They are very concerned about available validated screening tools that are feasible in primary care. And lastly, they do not want to screen unless intervention is available. And that means evidence base and that means available in their community.

Families had other messages that are important to think about. We did focus groups, worked very closely with the National Black Church. Seventy-five percent of our families were African American from inter-city New York, Atlanta, and Philadelphia. We had a large number of Hispanic families in Florida, and non-minority also participated.

What we found is there were three themes that emerged. One is the timing. Families really do not developmental milestones. Not surprising. They do not even know – many of them what a gesture is much less what autism is. They do not understand the spectrum of autism. They still think of a Rain Man version if you pardon my referring to that as autism. They do not understand the subtleties of the broader spectrum.

They feel this powerlessness. It is like structural violence from the wait and see because they start to see the signs. And then as they raise it to their physician and their physician is saying let's just wait and see. They feel powerless. And then they are not able to get the diagnosis for a year. You have to wait a year or two. And then resistance to diagnosis. Other families do not see it and their resistance. Why do we need to diagnose?

And lastly, they express very strongly the need for access to services for both diagnosis and intervention. If we are going to screen, we need to be able to offer services both diagnosis and intervention. We do not want to screen and put families on a two-year waitlist. That is going to do harm. That is going to lead to a lot of stress.

We have been rolling out a set of tools that I am going to share with you in the time that I have left in our study. I thought I would start with a summary of where we are at and then see how much time I have to tell what we are rolling out.

We have recruited CSPs, our community service providers, from these three different types of service systems. We are rolling it out. We started in year two and three in Florida, Georgia, and Pennsylvania at a smaller scale because we hit many roadblocks. Denny is intimately familiar with our roadblocks. We call it a work around. We have a backup plan and a work around.

Then we started full implementation really in year three. And actually, Miami just screened their first child in December. We brought Miami on in addition to New York.

Now, we are scaling up and it is very exciting. I think it was prudent to work through all the pitfalls that we encountered. We have recruited 396 CSPs to date in the four states. And 166 of them are actively screening. Some will be. Some have finished. We have screened a total of 5000 children, just over 5000 with 25,000 left to go. We are going to get there because we are now going at a much faster speed.

We have a nice diverse sample. We want it to be pretty much half male/female. That is looking good. Forty-three percent racial minority, 36 percent ethnic minority.

We are finding – once the children have a positive screen, we invite them in for an evaluation. We, at least, offer them an evaluation. They do not have to wait for community service.

I get up every day and I have to go – if this was easy, it would be done. It is hard. I feel a lot of pressure to pull this all out and make it work. I am not going to give up until we do. But it is hard and that is why it is not working. It really requires a transformation of a lot of things that we are doing.

I like to use a metaphor of a tricycle. We really need to provide professional development to early intervention systems so they know what they are doing. To primary care. We need to offer them a useful screening tool. And then the family. We need to support them. All three wheels.

With our funding from Florida, we have developed – we call it Autism Navigator. It is a collection of courses and tools and resources. We have 30-hour course for early intervention providers. This is completely scalable. We have seven states that are using it. It is rolling out. We have gotten good feedback except for the length, but there are a lot of nuances to it.

We developed then a primary care course second. We have two wheels on our tricycle. This is an eight-hour course. We launched it in the fall of 2015. With feedback from our advisory group, it ended up being eight hours. Then we hear that it is too long. It looks like this. Our motto is you never have enough purple. We like it to be soothing. We got a lot of side-by-side videos. We have over 24 toddlers with autism between 18 and 24 months. We show them older so you can be convinced they truly have autism when they are younger.

We have print documents for providers to learn more and to share with families, translated into Spanish. We are working on Portuguese and Creole because those are Florida languages and we will add more languages as well.

Then we built the course. You build it. How do you get them to come to it and finish it? That sounds good, but finishing it.

We had really marketing. I learned a lot about marketing. We have had to learn about marketing. In everything we do, we study. And we do not start more than one thing at a time. We are sort of week by week and month by month, adding another strategy. We added a weekly email. Once you register and get in the course for 12 weeks and then another 12 weeks. We are just repeating in case you did not open it. We had a really good response rate. It significantly improved the completion rate. We are very excited about that.

Secondly, we listened, and eight hours is too much. We built the Jump-Start unit, which is 90 minutes. We now have an abridged version. It is all in there. The hope is they go through the abridged version and then when they have a family in their office, they might go back and look at more. Someone in their office might complete the whole course.

We have built now a whole family ecosystem based on a lot of feedback. It has all sorts of bells and whistles in terms of electronic parent portal/provider portal. What I want to end with in a few minutes that I have left is to talk to you about our seamless path for families. We have the provider portal. The reports are completely generated. They just hit a button so they do not have to decide what to put in the report and they can release it, print it, save it to their electronic medical record.

The parent portal then depending on the screening result, negative screen, positive screen for communication delay only or positive screen for communication delay and autism, families then get links to different resources. I want to just quickly go through.

The first two are for all families because we want to get good information about milestones out to families. They clearly want it. It is needed. We have developed it. The first is our 16 by 16 series. You can get to this. It is free to the public on the First Words website. We also built the First Words website because families who might have a child with autism are not going to go to the Autism Navigator, Autism Speaks or Autism Science Foundation website as great as our websites are because they are not thinking autism. But we hope they will go to this website because they are thinking what does it take to learn to talk. This is just to get them there and to teach all parents good parenting information and then to find children with autism.

The 16 by 16. I am going to zip through this in 30 seconds. It is a picture show. You can go and get to this. We have a look book. Our first one is 16 Gestures by 16 Months. It takes you through the gestures that start at 9 months, 11, 12, clapping and then blow a kiss at 13 months. The shush as they can point at distance gesture at 14. Thumbs up. Symbolic gestures. Now, words should be unfolding. We can know if there is going to be a word gap or word delay by looking at gestures at 9, 10, and 11 months.

I am very excited. I worked hard on this during my holiday break. We are launching the 16 Actions with Objects, I hope, today. It looks like this. It should come out today if not tomorrow. It may be up today, but it may not be friendly on every platform. That takes a little while, all the different mobile platforms.

Sneak preview. You are the first audience to see this. We are very excited. Think about all the different actions with objects children should be doing. It shows us what they are thinking and what they know. Mouthing, banging, dropping at 9 months. Taking off and taking out at ten months. Pushing, turning at 11 months. And turning over. Patting, putting in at 12 months. Putting in means all these functional actions. Putting in your mouth and the bowl.

At 13 months, they start to pretend. We are starting to see symbolic action. They are pretending to feed. We start to see open and close. We start at 14 months back and forth and up and down like jiggling a pan. Drumming.

At 15 months, pouring is a really pivotal action. It shows you what they know. And washing and drying. At 16 months now, we have really the emergent literacy skills. Stacking, cutting out, scribbling, drawing.

All of this is about the best time to get ready for preschool is from 9 to 16 months. That is our message. I hope you will help us share it. This is free and available to the public. We will have a print document. The Look Book is about 50 pages. There are lots more. That was just a sample.

Secondly, the social communication growth chart. We have the picture. And then we now have the whole online milestones. You can get to these. You can see our milestones every two months. We have an explore and charting function with hundreds of video tapes. We have video clips. They are going to go down to 8 months in about a week or two. And then we have videos that go through. We have a charting function that looks like this that providers can pull up and we have a little friendlier version so that you can see milestones that parents are charting as they go along.

And then lastly, families with a positive autism screen. We have a beautiful package. First is about autism and toddlers. Free to the public. We launched it. It looks like this. We launched it in April 2018. We had our first 3000 users a year later. In this past October, we are up to 18,000. I suspect we are over 20,000. We are in 120 countries. With the Internet, it shows how we can go global.

Our old landing page looked like that. We have a brand-new landing page that we launched because they told us they were kind of scared to open it. Now, we have bite-sized questions. Lots of information looks like this inside. They can see before. I had hope to show this, but no time. And then change with intervention. But you can see that slide 16. It is available to you.

Video glossary. We launched this. We worked with Alison Singer way back in 2007. We have rebuilt it, brought it into the Autism Navigator and now it is actually a single sign on. You get to vote for free. This goes through the DSM-5 framework. Families go to About Autism in Toddlers and learn. I cannot tell you how many parents say I was in denial before. I did not know what it looked like. I did not think it could be autism. When I start to look at the videos, I get it. I need to get going.

And then lastly, I am so excited about this. We launched our How-To Guide for Families last year. It is a 12-hour course for families. We hope very friendly. You can get a description of it on

AutismNavigator.com. It is a whole online course.

We are also just starting, and we are going to be studying in our – we have a new ACE Network with other members of the ASD PEDS Network where we are going to be studying rolling this out and having family navigators be able to implement it, which is a very cost-efficient – let's get started right away to teach parents what they can do in their everyday life.

I just want to wrap up by showing you our new – the last new strategy that we have added is the – because the doctors do not really want to share this kind of a message with the families, which is maybe surprising, but understandable. We have added to the First Words website a new button called Screen My Child. Providers can now send their families to our website, click on that button. The families get to this page. If their child is between 9 and 18 months, we can screen them online. We will schedule a 30-minute meeting with them by phone or video conference. They can come in face-to-face, but most families prefer. We can give them a result over the phone if it is a positive screen. If it is negative, we release the result. Consent forms are online. They have to fill in this information and it works. We started this in November. It is exciting. It is taking off. We are using social media.

If families come in through the Screen My Child, they then get a free – so they can get a free subscription to the Social Communication Growth Chart. That is an incentive. We hope they will go to how do I join for free. Let's do it. Because families often do not think they need to have their child screened because they are not worried about their child's development. It all circles back. If we can teach them the milestones, then they are going to know to be worried.

I am going to go to my last slide, which is follow us on Facebook. Social media is going to be a really important way to reach everybody. I would like to thank you and hope that you will see this as a chance to do something really meaningful for children and families. Thank you.

(Applause)

DR. ALICE CARTER: While we are switching up the laptop, I just want to say how honored and really privileged I feel to be here with this committee today. I really want to thank Denny and Denise who is the other project officer for not only inviting us to be in the ASD PEDS Network, but also we are a really well-supported network in terms of our program officers who are fighting for us. I really appreciate that. And also helping us think through some difficult challenges that we have encountered.

(Pause)

DR. GORDON: While this is going on, we will have discussion time. We have reserved a half an hour for discussion at the end of the four-panel presentation.

DR. CARTER: I can go old school and share some information.

DR. GORDON: For those of you who might have panel presentations in the future, that is why we try to preload all these things.

Alison, you had a comment or a question. Why don't we go ahead and do that while we are working through the technical problems?

MS. SINGER: For Amy, we know from Baby Sibs research and from a study that was published earlier this year from Columbia that you are more likely to get an early diagnosis if you are not the firstborn child or if you have a lot of interaction with your grandparents. That really speaks to the value of parenting experience.

If we want to be more efficient in diagnosing kids, should we not be targeting this program at new parents perhaps through OB/GYN offices as opposed to just parents in general?

DR. WETHERBY: I think that is great, but I am not sure that during the OB stage – I think there are so many things that during pregnancy that you are worried about, which is the birth. I think shortly after birth, there are so many things, feeding, sleeping. Our guided tour that goes with our growth chart starts at six months. I think in terms of right now the observable signs of development, starting at six months I think is ideal. But of course, from birth to six months is about regulating all of the ability to sleep and eat. There may be some very early signs. Autism usually does not – observable signs do not evolve as you know until 9 to 18 months. We think starting at six months – and we have an online guided tour that is free to the public that parents can join online to learn about the milestones. I think that is really important.

Now, you could start in OB, but I think OB with pediatricians.

MS. SINGER: If not the OBs, is there some way to specifically target new parents?

DR. WETHERBY: That is what we are trying – I think every agency. We are working in Florida, Office of Early Learning, all of the different agencies that touch the general pediatric population, but of course primary care as well and faith-based organization. I think any agency – we have tried a lot of things. Going to Walmart or Toys R Us or the booth does not work. But I think reaching out -- childcare providers were very excited about the potential – there are all sorts of – there is actually 32 home visiting systems in Florida that the legislature thinks they are spending a lot of money on and they are. I think there are a lot of home visiting systems to reach out as well.

WIC would be ideal. It is tricky. They have a lot that they are supposed to do. But WIC reaches low-income families. I think we just need to work through all those agencies.

We are hoping the 16 by 16 will just be a catchy campaign that people – it will resonate. Doctors like it. Families like it. And that it can get them to the website to then know. I should screen my child. I should join the guided tour and learn. Parenting classes are essential. I just got a new puppy. There are puppy classes all over the place. You have a child. You do not even think about going to a parenting class, but yet it is expected if you get a puppy. We have to do better. I think you are raising a great point.

MS. CRANE: I wanted to raise something because I was just about this over lunch and normally it would not even occur to me to mention. In the autistic community, we see a particular pattern of adult diagnosis, where an adult is diagnosed for the first time after becoming the parent and having their child be diagnosed. In this pattern, what we often see and – Alison's point was sort of interesting in that light. We see parents who are completely unconcerned for longer than they might otherwise have been because their child is acting in a particular way and the grandparent is saying whatever. You acted like that too. The parent will say the kid is just like me. I am normal and so is my child. These kids – it is not just that the kids are being identified later, but also we are missing an opportunity to communicate with adults on the spectrum.

I think having concrete signs can help with that, but also just educating doctors that they are probably – it is a near certainly that at some point, they are going to – if they are interacting with the kid on the spectrum, some proportion of those kids on the spectrum – adults on the spectrum were never identified. And they need to be able to talk to those parents in a respectful way because if they talk about it in a stigmatizing way, they are going to alienate those parents.

DR. WETHERBY: I think you raise an incredibly important point. Just like we know that once you identify a child with autism, the sibling has a 25 percent chance of having autism as well. They should all be screened. Similarly, I think the parents – that is a really good point.

I also am the executive director of a state-funded autism center and we commonly see adults come in who were not diagnosed when they were younger. It is very common.

I do not know the percent of adults with autism who have children. I do not want to rely on them having to become parents to be identified. But I think we just need to do better. Absolutely. If you have a child with autism, the parent should be screened. That is a really good point.

DR. GORDON: Stuart, you had mentioned you had something to say.

DR. SHAPIRA: I wanted to thank Dr. Wetherby. That was a great presentation. I do make some points about “Learn the Signs. Act Early.”. As the committee members know because I have discussed it here and presented before on the “Learn the Signs. Act Early.”, it aims to engage and educate parents and caregivers on what developmental milestones are and how to celebrate and track their child's milestones in all domains of development including social/emotional, language communication, cognitive and movement and physical development.

“Learn the Signs. Act Early.” is broader with regard to development. It is not autism specific, but it looks for developmental delays or disabilities that could be indicative of many conditions that could benefit from developmental services. And “Learn the Signs. Act Early.” provides a suite of materials that illustrate milestones in these domains in different formats including the new photo and video library and a mobile phone app.

Now the milestones themselves, they do come from the American Academy of Pediatrics' Bright Futures and from Caring for your Baby and Young Child with some language adaptations to improve readability and parent comprehension.

As Dr. Wetherby, as you had mentioned in your presentation, the milestones in general, are typically reported as the average age that children should typically reach milestones. But “Learn the Signs. Act Early.” made a purposeful choice to report milestones as when most children are expected to reach them. When milestones are reported as the average age, it encourages health care providers and parents to take this wait and see approach. This was actually affirmed during some recent testing the materials. When parents interpreted as simply average as half will meet by now and half will not. They used that as a reason not to be concerned about their child not yet achieving particular milestones.

“Learn the Signs. Act Early.” will continue to make a conscious effort over the next year to more explicitly state that most children reach these milestones by this age. And feedback from parents suggest that children suggest making the milestones less variable and more concrete may make them more likely to take action when missing milestones.

A couple more points. “Learn the Signs. Act Early.” materials include a call to action and to act early, a message when parents notice that a child is not meeting milestones or has one or more red flags. This call to action includes bringing concerns to the health care provider, asking about the child's developmental screening results and providing information on how to contact early intervention services.

This act early message in the “Learn the Signs. Act Early.” materials were evaluated and have been evaluated in the past as recently as last year and tested with parents and health care providers for relevance and comprehension.

Just a couple more very brief points. “Learn the Signs. Act Early.” materials, as folks know here, are free. They are research based. They are audience tested. They are designed for parents. They are useful for all those working with young children, including child care providers. And they are written in plain language in English, Spanish, Chinese, Korean, and Vietnamese. They focus on milestones when to act early and what to do if concerned.

The program “Learn the Signs. Act Early.” is committed to continuous improvement and continued evaluation of the material is a priority. The program welcomes all ideas from the speakers here as well as from others on how best to do that.

DR. GORDON: Thank you, Stuart. I think now our technical problems are fixed. We will proceed on to the next panelist, Alice Carter.

DR. CARTER: Thank you very much and thank you for fixing the computers. I am going to talk about our multi-stage screening protocol that we are partnering with Part C Early Intervention agencies to implement. This is an implementation dissemination project with really an eye toward sustainability in the community. I am representing this work, but this is work that takes a village. I want to particularly highlight Chris Sheldrick, who is the dual PI on the project, and Abbey Eisenhower, who is in my department and very involved in day-to-day operations.

I mentioned our funding that we are very grateful for. I am going to briefly describe parts of our project and some of our preliminary findings. I am going to talk about some implications of understanding screening as a process rather than as an event with a particular instrument.

This picture actually comes from Emily Feinberg and it really is supposed to represent all of the ASD PEDS Network work. You can see I am working in the left most box in Part C, but several of our members are working in primary care. We also very much are thinking about the family and trying to make our screening family centered and recognizing the varying concerns, knowledge and cultural frameworks that parents will approach screening with as well as the different levels of knowledge and attitudes and beliefs that both EI providers and early intervention providers and pediatric staff will approach families with.

All of us share doing ASD screening with a variety of tools. Wendy Stone's project is facilitating engagement by having a rapid intervention that is available immediately. All of us are eventually doing diagnostic assessments and then we are also tracking engagement and services because if we are able to identify children early, but we are not able to change services patterns then we have just not been successful.

As Amy said, there are very long delays between when parents are first concerned when children receive a definitive diagnosis and when children from racial ethnic minority English language learning and low-income backgrounds receive an ASD diagnosis.

This is particularly unfortunate because Part C Early Intervention is a federal program that is free to families and has the potential to do a lot of good. I am living in Massachusetts where we are heavily resourced early intervention program. Our agency touches approximately 30 percent of the children in the state. That does not mean that each of those children get services, but a call is made or there is some contact, which I think also changes the calculus of how many children are missed. But still we are definitely missing kids.

Our project is all about shifting the age of initial diagnosis younger and particularly closing the gap to address health disparities in both age of detection, diagnosis, and receipt of appropriate services.

Just a little background on health disparities. There are multiple different definitions out there. But we are really coming at this from a social justice perspective. We see health disparities as a health difference or a chain of events that is signified by a difference in the environment, a difference in access, a difference in utilization of services or quality of services available to people, difference in health status or a particular health outcome that deserves further scrutiny. We are trying to scrutinize.

When we first proposed this project, we were aware that even when families from under-resourced backgrounds made it to Part C services and early intervention, still there were disparities in terms of when children received a diagnosis of autism. These families had already reached out. They had already agreed to participate in services. We felt like this was low hanging fruit in comparison to the work that Emily will talk about later in which trying to reach families who are not yet interested in services and are not concerned about their children's development.

To say a little more about health disparities, we can look at really a variety of contributing factors and the different contributing factors may have different solutions. It is really important to think about them and in how we organize health service systems and also how we train our workforce within those systems.

In terms of just family factors, language is certainly a big barrier, insurance status, transportation, immigration status. Whether you are in a family or center-based childcare setting can determine whether an early educator is going to talk to you about concerns about your child.

There are also internal level family factors. Do you expect that the diagnostic services you can access will be good for you and for your child and your family? Do you trust in providers? Are you afraid? We hear from many families that they do not want to get a diagnosis because they are concerned that that will mean that people think they are a bad parent, which they are at fault in some way and also just general knowledge and general beliefs about both child development and the services they might be eligible for.

In terms of clinic and provider-level factors with families working multiple jobs, we need to think about hours of operation, the cost of services. Is there anyone at the agency that looks like the family? How comfortable are they going to feel when they arrive?

We also have a big problem with – we are all using multiple screening tools that have been validated in some populations. But few of them have been formally validated in different languages or in diverse communities. It is quite possible that a family is not sure this screening tool is going to work for me. There is not so much evidence to support that it will although we certainly hope that it will.

And then there are – within clinic providers, we hear negative or mistaken perceptions, low efficacy expectations about a family following through. They will say this child is much too young at 14 months to have a diagnosis of autism. Let's wait and see. This family is chaotic. I do not expect them to follow through to services so why bother screening or referring them for a diagnosis. It is just too much time for this family at this time. There are also some paternalistic attitudes that really interfere with access to services.

Our broader project is also using a health beliefs framework. We know from work not in autism, but in social, emotional, and behavioral problems that parents will seek help under particular conditions.

First, in alcohol, you have to think you have a problem. If the parent does not appraise the child as having a developmental or behavioral or social problem, they are not going to think about seeking help.

Then they are thinking about seeking help. They are still not necessarily seeking help, but they are thinking about it. It turns out in our data that no one actually follows through and talks to a pediatrician or seeks help in another venue without first thinking about it.

And then once they have decided to seek help, they need an action plan and then they actually seek help. But then there are also decisions about maintaining that help-seeking behavior. And the determinants of these different steps may be different. What we know is that concern or worry is a strong motivator of seeking help. The kind of problem your child has. If it is an externalizing disruptive behavior that sort of is very visible in the community, you are more likely to seek help. If you are a boy, if you are older and if you are more severe, your parents are more likely to seek help for your condition.

That fits with missing children who may be functioning at cognitively higher levels or may have milder symptoms even though those children will definitely benefit from services.

The overarching goals of what we call locally are ABCD or at least screening project are really evaluating systems of care rather than evaluating individual measures. We are trying to see if by disseminating so by training three partners of early intervention programs to do a two-stage screening process, can we reduce health disparities in early detection and diagnosis of autism spectrum disorders, receipt of tailored or autism-specific intervention surfaces and ultimately improve developmental outcomes?

Our project is multi-faceted and a bit unwieldly, so I will not describe all the moving parts. But we are using mixed methods. We are talking with a lot of people in open-ended ways. Learning a lot of information. We are using health systems engineering methods to monitor the fidelity of our implementation.

We are doing cost analyses to figure out what screening costs and also developing some very cool statistical simulation models for testing hypotheses based on the existing knowledge we have.

We are really focusing on a screening process, which starts with when you hand the screener to the parent or even before you hand the screener to the parent. You are opening up a dialogue or conversation that has to continue through to receipt of services.

We currently offer our model in both English and Spanish. The EI agencies we are working with have actually owned the model. They talk about it as theirs, not ours anymore, which I think is a big success or a dissemination. And we are really doing targeted universal screening. We want to screen everyone that is in Early Intervention, but recognize that this is a population at much higher risk for autism than in a pediatric setting.

We are using standardized, evidence-based measures and we are building on existing family or Early Intervention provider relationships because these providers are in homes usually at least once a week. Sometimes a bit more than that. Sometimes every other week.

We are also using technology for training. We have a lot of web-based tools that our Early Intervention providers can access. We also are using this wonderful app that makes our lives much easier. When a child screens positive at the second stage of screening, they can use their phone to schedule an appointment with our research team. We also offer rapid diagnostic services, which is part of the motivation for our sites buying into the process.

In our Stage 1 screener, we are using an autism-specific screener. The Parent Observations of Social Interactions, which is very similar to the M-CHAT, but uses a different response format, which is not just true-false. It has multiple levels. And then the Brief Infant Toddler Social Emotional

Assessment, which actually is a more comprehensive social-emotional-behavioral problem assessment tool. That does include though 17 autism-specific items. We are using the autism-specific items on the BITSEA and the POSI.

But we also will move you forward in our screening process if either an early intervention provider or a parent is concerned about autism.

And then we do a second stage screener because we do not want to flood the system with all the children who might be positive at Stage 1. We are using Wendy Stone's observational assessment, the STAT. And then children will come to us for a diagnostic assessment that is very similar to what children get at the hospital. Although we probably talk more to parents when we diagnose a child with autism about family functioning and coping and that this is a very difficult thing to experience. Although many families are very happy about it because they have suspected something has been wrong for a long time.

We are targeting these three agencies because they work in the Circle of Promise, which is an area in Greater Boston that is basically characterized by a lot of under resourced families. This has various phases. I am going to talk about the first one, which I just showed you and then the second one, which is a series of follow-up interviews we do with families when they are still in early intervention after they get a diagnosis and then when they transition to preschool because we are calling them to find out what services are you getting and how happy are you with those services. What services would you want, but you are not currently getting?

One thing that has happened that has been very positive is we have really changed the awareness of the early intervention providers we are working with about autism. We have trained about 160 early intervention providers and are screening intervention and also just in the first stage of our screening intervention. I talked with them a lot about what autism looks like, how to talk to parents when you have a concern that a child might have autism. We have trained 32 early intervention programs and a day-long STAT Training. And then about 94 of our Early Intervention providers have come to diagnostic assessments. They are actually serving as navigators for the families between the screening and the bridge to diagnostic services, which they do with us at the research program for diagnosis, but also in the community, which has been great.

One of the first things we learned is that the Early Intervention providers really need a lot of support in having these difficult conversations. Someone mentioned this earlier. They are not well-trained in interacting with parents. They are used to talking with children and playing with children. They really felt very uncomfortable raising concerns with parents and at times, as Amy mentioned, they choose to delay suggesting further screening. We have developed a lot of resources to help them and that seems to be helpful for them in moving forward.

And then also important is knowing whether parents have any concern or not, not necessarily about autism, but just about development, behavioral and social development more broadly really helps the

Early Intervention providers know how to open this conversation.

They tell us that when they can see that parents checked red flag behaviors even though they are not reporting concern, they can wonder and reflect on those behaviors together as a point of starting this conversation when the families report concern and that is only in about half of the time. This is very consistent with what Amy said. Lots of families will tell you the behaviors. But they just are not concerned, not only about autism, but about their children's social development or behavior.

This is actually quite interesting because when we look at the non-autism behaviors on the BITSEA, which include disruptive, externalizing aggression kind of behaviors, internalizing anxiety behaviors and sleep and eating problems, the kids who later go on to receive a diagnosis of autism are elevated in all those areas in addition to the autism symptoms relative to children who do not go on to screen positive at all.

In terms of what we have accomplished, our partners have screened about 2800 children. And that represents 70 percent of the children in these agencies. We are able to track who is getting screened and who is not.

About 35 to 40 percent of children are screening positive at that stage. About 70 percent of those will move on to get a STAT when indicated. Seventy percent of those who go on to get a STAT when indicated are positive at that stage. Interestingly, our process – we lose kids from Stage 1 to Stage 2. Once kids are positive at Stage 2 around a little over 90 percent of them will go to the diagnostic evaluation. There is something about sitting and observing your child with a provider, watching and wondering. That seems to motivate access to care. And about 85 percent of the children we have evaluated have received a diagnosis of autism. That is almost 300 children.

Overall, in our agencies, our rate of diagnosis is just over 10 percent, which is much higher than you would expect in a pediatric community. The previous rate before when we compared kids who got a diagnosis through other means was two and a half percent. Clearly, we are addressing lots of unmet diagnostic need out there with this screening intervention.

The sample we are working with reflects very high rates of racial minority linguistic minority and low-income statuses. The children we diagnose have higher rates of English language learner status and low-income status. We feel like we are addressing health disparities. We will compare our sites to other sites in a quasi-experimental design, which will be stronger evidence of this. And then we have also demonstrated that the relatively high rates of screening 70 percent in overall compliance suggest that this is a feasible approach. But we can further improve our numbers by helping our early intervention providers feel more comfortable at the later stages of screening.

If we think about process for a minute, what we see is that non-Hispanic white families are coming in to screening a bit later, but not significantly so. But they are getting diagnosed significantly later.

If we look at income as a timing factor, we see that there are significant differences in when kids are coming in. In fact, the poor kids come in earlier, which may be because of pre-term status or it may be because of other risks. But that advantage is disappeared because they are taking longer to go through the screening system.

If we look at English as a concern, we see that they are coming in later and they are diagnosed later.

To facilitate time, I am going to say just one thing about service receipt. We continue despite earlier diagnoses – our gap in diagnosis is only about two months at most. We move from – David Mandell is 1.7 years or thereabouts to two months, which we think is pretty good. But in fact, it is still not enough in terms of addressing service needs.

If we look at each of three social indicators of health disparities, we see differences in race ethnicity. We see differences in language. We see differences in income. But the differences aggregate. And we know that in our communities, poverty travels with race ethnicity unfortunately because of years of systemic racism.

If you have no risk factors, 100 percent of those kids are going on to high-intensity services. This usually happens within two months. If you only have one risk factor, about 90 percent of kids get there. With two risk factors, still not much of a hit. But when we get to three of these risk factors, only 30 percent of kids are making it to high-intensity services. That is a combination of both system availability. Can my children get services in Spanish or in another language? And also, families being able to access those services and feeling efficacious about those services.

We are identifying children who make contact with the services system. We have very high penetration. What is happening in our state may not translate easily to other states. We have had major problems with workforce development and retention although now our sites are training internally for Stage 1. We still need to train for Stage 2, but there is huge turnover in Early Intervention systems.

We are also using these multi-method longitudinal qualitative interviews with Early Intervention providers, parents, and pediatricians. These have really informed our dissemination and implementation work.

I think I am going to end here with a quote from Atal Gawande. We yearn for frictionless, technological solutions. But people talking are still the way that norms and standards change. For early identification of autism spectrum disorders, we do not yet have biomarkers. This is also true for developmental delays and social and emotional and other behavioral problems and disorders. Screening efforts need to rely on parent and other caregiver, early educator and pediatric and Early Intervention provider reports and observations.

Open communication supported by trusting, respectful relationships and access to care is necessary for detection, diagnosis and connecting families to appropriate services.

(Applause)

DR. GORDON: Any questions from the committee?

DR. MANDELL: I love your way of talking about cumulative risk for these risk factors. Do you think the mechanism is the same for those risk factors? That is, do we need the same strategies to address each of those risk factors or is there something else going on?

DR. CARTER: I think some of the strategies are the same. I think we are going to see multi – we will see some things that are the same and then some things that are different.

There is definitely a major problem for linguistic competence in the Early Intervention system. Just as an example, each time I do a STAT training, I have to remind people that we need Spanish providers to come to the training like across three different programs. I have to say this list has providers who only speak English. I know you have some that speak Spanish. We need them. But those providers have heavier caseloads. They are busier. Their caseloads are more difficult. For specialty services also, there is much longer waits for Spanish-speaking providers.

We see lots of kids getting services in English and some parents will say English is my child's chosen language. But then the providers cannot really talk to the parents in a connected kind of way.

DR. GORDON: We have to move on. The next presenter is Emily Feinberg from University.

DR. EMILY FEINBERG: Thank you. I am really privileged to present our project to you today. It is nice to follow up on Amy and Alice. Just to put into context, our project really focuses on the folks that Alice identified with the multiple risks. As I go through, I think that will be more apparent.

I would like to just acknowledge our funders.

To put us back to the slide that Alice put up earlier to locate our project, while we are focusing on screening, our main efforts are really focusing on the continuum from screening to diagnostic assessment to engagement in services, and to ensure that the most vulnerable families successfully make those transitions through the process of care.

We call our project Project EARLY. I wanted to give a little bit of an overview about what we are doing. We are focusing on leveraging primary care systems. It is sort of urban, low-income families to support early identification and engagement in services. We come to our work from an explicit disparities lens. And the challenge that we are trying to address is really how to ensure that the treatment services and the advances in treatment services that are going on are shared equitably among all populations. We think that without an explicit strategy to ensure that the most vulnerable populations can access these advances that disparities can worsen.

We have been working with academic medical centers and federally qualified health centers to test an approach, which we call family navigation. It is tailored to the families who receive primary care in these settings and are most likely to experience disparities in care.

For those who are not familiar with navigation, it is adapted from something called patient navigation, which has its origins in cancer care. It aims to support families during discrete care transitions. In our case from the time of a positive autism screen until 100 days after diagnostic ascertainment.

Our work is grounded in the chronic care model. My training is really in health services research. We are really thinking about how to tweak those systems where kids are receiving care to work better for them.

The chronic care model characterizes the elements of the system that contribute to quality care for people with complex conditions. And the model emphasizes the interconnections between community and health systems and the alignment between diverse systems to foster informed activated families and prepared proactive care teams.

Our current ASD PEDS Network project grew out of our previous work and the input of families and stakeholders. It has an inter-generational focus and a recognition of the need to address social determinants of health and parental mental health as part of an overall strategy to improve outcomes for children with autism.

Although it was not intentional, our study design turned out to be very well aligned to address some of the questions raised by the task force. We use a similar analytic framework and the data we are collecting presents a number of opportunities to address key questions.

We are conducting a fairly standard, hybrid comparative effectiveness trial to assess the effectiveness of a primary care-based intervention versus traditional care management. Our goals are to shorten the time to diagnosis among children suspected to have autism, to shorten the deployment of autism services among those diagnosed and improve engagement of services.

We are conducting a concurrent implementation trial. I want to call out to one of our collaborators, Sarabeth Broder-Fingert, who is here in the audience, who is helping lead that work.

We are also conducting a time series analysis to examine screening rates over time and the effective and activated screening protocol, which actually is using CDC Act Early materials.

Our study takes place within three urban primary care networks that serve ethnically diverse, low-income children. Each is affiliated with an academic health center and is a member of the HRSA-funded Developmental and Behavioral Pediatrics Research Networks.

And the settings that are participating – they represent the diversity of clinical programs where many urban, low-income children receive their care.

Our study is looking at a number of outcomes. Primary are the diagnostic interval, which is number of days to a diagnostic resolution and time to engagement in ASD-recommended services.

We are also looking at a number of family-level intervention targets particularly the domains of social support, family stress and parental and family functioning. In addition, we are collecting some of the data that Denny mentioned that is shared across our ASD PEDS Network.

We have a fairly intensive follow-up schedule of families that are participating in this study, following them up with in-person assessments four times over our study period and including additional telephone follow up to get a sense of service received.

We are really excited that we have successfully recruited into a fairly rigorous clinical trial a population that represents those that receive care in these settings. These are the caregiver characteristics to start off. You can see that it is a largely minority and low-income population. What is interesting in the population is the differences among sites, which you cannot see here. In New Haven, most of the families are Latino families. In Boston, we have a very large proportion of immigrants. We have over 70 percent of parents who were born outside the US. In Philadelphia, it is mostly US-born black families.

Families in the study speak 24 different languages. We have no language exclusions for families who are participating.

And the child characteristics. Children are coming in at the age we expected, around 22 months. They come in after a confirmatory screen. They are disproportionately male.

Interestingly, about 44 percent are receiving Early Intervention services. And many of them since quite a young age, which we think represents both social risk and the effects of early adversity or other developmental delays.

In terms of functional assessment, they are not – looking at Amy's slide, they are not as low functioning as I think what Amy showed from previous studies of M-CHAT validation. On average, their functional assessment was about 1.5 standard deviations below the norm.

This is a complicated slide of our intervention model that I want to walk you through. We have four components in our model that look at screening, a decision rule for further intervention, and then an expedited diagnostic evaluation and referral to engagement and treatment.

We are using the available systems that exist within our communities and particularly within the developed academic medical centers. But we have worked with them to make them more accessible to families and to improve some of the really operational procedures within the clinical settings.

I want to focus first on the screening component and walk you through what is happening. The standard of care at the settings where we are working is that families are routinely screened with the M-CHAT at 18 and 24 months per the AAP recommendations.

All of the sites have fairly high rates of screening already. At most sites, it is over 80 percent. We are not dealing with the question of sites that are not screening, but the question of what is the quality of the screening and how is it working in this population.

The families are then – if they have a positive screen, they are referred to the study. We have created some screening enhancements that I would like to discuss. The main screening enhancement is a centralized referral for positive screens for confirmatory screening. At that time, we re-administer the M-CHAT and the follow-up interview if required. This is done over the phone in the family's primary language.

We found that that has been – we have learned a lot from that. We found that it has allowed us to address some of the literacy and language issues. In the discussions that the screeners have had with families, many of the screening questions have changed through those dialogues. A parent saying, I did not really understand what that meant. With the opportunity to clarify it, we have had not only screens change from screens that were positive previously become negative, but we have also had changes in the actual answers to specific questions as families understand more what the intent of the question was.

The results of the confirmatory screening are entered in the child's record at the referral site and communicated to the primary care provider by a standardized form. We use facts. We use the electronic medical record systems and we use secure email.

We also have loopback procedure, which has allowed us to get reports from the electronic medical records of all positive screens of children who have been screened in the primary care setting and loopback to the providers to see whether or not we can then approach families to do confirmatory screening and also invite them to our study.

The third part of our screening enhancement is an activated screen. We wanted to try in a site that has high levels of screening. We wanted to see if a fairly low-level intensity intervention might make a difference. And consistent with our chronic care model approach of trying to create more activated families, we sent out CDC Act Early materials to families prior to their 18 and 24-month visits.

What we will be looking at over time is whether the families who received the activated screens – whether there is any difference in screening rates and screening results.

These are the results of our primary care centralized screening and referral. I do not want to go through the numbers right here. You can see the flow. But I would like to highlight some of the key learnings of what we have learned from this.

We have learned that this approach to screening is acceptable and actually quite efficient. We were able to reach by phone 85 percent of the families who were referred to us and within eight days.

We found that it was an effective way to address literacy and linguistic barriers in this population. And in terms of efficiency, it identified children for whom further follow up was not indicated. Even though two of the sites, it was standard care to do the M-CHAT follow-up interview, which should have been one way to identify those children most at risk, we found that that was not done with any I would say quality standards. I think the sites would acknowledge that or with any consistency.

I think in the settings that we are working and with the populations we are working with, the feasibility of actually doing the follow-up interview during the primary care visit I think is really questionable.

While this was not the main part of our study, we are kind of excited about this because at least in Massachusetts under new Medicaid programs, all of our Medicaid population is moving into accountable care organizations. This is exactly the kind of structure that fits really well within an accountable care organization that can be deployed on a wide scale and do something that could actually increase efficiency, lessen the burden on the system in a way that is a really good fit for that population.

The other thing we learned was that confirmation of risk and a positive screen is not enough to support engagement. And that is where I will speak about the next part of our intervention, which is family navigation.

It also raised a number of new questions and hinted at next steps.

When we looked at our data, we were very surprised that the number of children screened out in our study by the M-CHAT follow—up interview was extremely different than what has been reported in the literature. It has been somewhere in the high 60-ish percent in published literature. We are only at 30 percent.

We do not know exactly why this is. It is something that we are looking into and whether it has to do with our population, whether it has to do with who is being referred, but these are all issues we will be looking at as we go forward.

Now, I would like to just a little bit change paths and talk about the family navigation study. As I said, this is a comparative effectiveness trial of family navigation compared to conventional care management.

A family navigation model – the navigators are trained in motivational interviewing and collaborative problem solving. And it is a manualized intervention, which helps guide their work.

How are they different than traditional care management? I would just like to say our conventional care management is what we considered a very high-quality medical home would offer to two families. It is greater than the standard of care in many places.

The family navigator does proactive outreach. They reach out to families. They work on engagement. They work both in the clinic as well as in the community and family's homes. The traditional care managers – everybody was assigned a care manager in the care manager arm. I can tell you. We probably only have about five families that have actively reached out to the care manager.

What they have done is help schedule the ASD evaluation. They made sure that referrals to birth to 3 services are done. They have resource guides and they are available for family-initiated telephone support.

Families that have confirmed risk are referred to the study. As I said, they are randomized if they fail the M-CHAT on the follow-up protocol. Then they are randomized to one of the arms.

The protocol begins at that time of positive screening and ends 100 days after diagnostic ascertainment when we think that children should be engaged in autism-specific services.

I want to introduce our navigators. We asked all of them to talk about what was most enjoyable and challenging about their work. I am not going to read off their quotes here for the sake of time. But what I do want to emphasize is that we have worked really hard to represent among the navigators the cultural, racial, and linguistic backgrounds of the families they serve. We actually learned something from not doing that.

We started off with one navigator who had great expertise working with families, but was not from the community, was not of similar race and cultural background. We had significant problems with engagement. She, for a variety of reasons, left her position and was replaced by someone that was a better fit with the community. And the difference in engagement and process measures was immediately apparent.

I wanted to just highlight – these are our Boston navigators. This is Jenny Acevedo, the navigator from Yale. And what she talks about in this slide really highlights the on the ground work that navigators do with families to ensure that really social determinants of health are addressed so that families have the bandwidth to really work around their child's development.

In this case, she assisted a homeless mother find shelter, access daycare services, connect with NEI services. And she commented and said at the three-month follow-up appointment, the mother reported significant progress in her child. Cases like this make being a family navigator extremely rewarding.

We are really excited to take this to the next step. In our work in the ACE, we will be training family navigators to be community interventionist. We will be helping to see if people at their educational level with the community ties can effectively provide evidence-based treatments to families in the community. I think that we are thrilled to be part of that work and to expand their role.

We are looking at a number of navigation measures. We think that is important because there is a lot of interest right now in navigation. But if you ask everybody who says they are interested in navigation and what that means, you are going to get – everyone will have an individual answer.

In terms of where we are going with the field, I think we are at a point where we need to be able to understand what the models are and to do rigorous evaluation. What components are important, what are necessary, what can we forego for broader reach and less expense?

We are looking at the number of contacts, the type and location of the contacts, the time spent by navigators working with families, and the issues addressed.

We are also looking at fidelity in two different ways. One is related to visit content and the other in the use of motivational interviewing in their work with families. We think that this work is going to be really helpful in moving the field forward.

We do have some process measures already. Our intervention has three core in-person visits. The navigators are meeting that target. The mean number of visits is actually in-person visits has been four. There have been on average 30 additional contacts with families. But most of these have been by phone, text, and some email. In terms of efficiency while it seems like a lot of contacts, they are generally brief, and they are able to use their time very efficiently in terms of using other modes of communication.

To end, I wanted to just talk a little bit about the overlap between our study design and the task force framework. This is something that is not only of interest to our study, but to all of the ASD PEDS Network and really thinking about what data do we have now. How does it align with the task force analytical framework and how can we best use our data to move the task force statement from an eye to a clear recommendation.

Because we follow the same process of screening in primary care diagnostic evaluation and following through engagement and services and because we are getting individual-level data at multiple points along this continuum, we hope that in particular we will have good data to address some of these contextual questions around the diagnostic and treatment resources currently adequate to provide services who screen positive and looking at some of the differences among racial and ethnic subgroups.

We have been fortunate to receive a supplement from NIMH, which we are going to use to convene an advisory group of former task force members to guide us in the analyses that we think will be most helpful in addressing the task force questions.

To close, I just would like to acknowledge our teams in our three states. They have been terrific to work with. We have learned a lot working together as a team. We look forward to working with the larger network and the ACE Network in our future work. Thank you.

(Applause)

DR. GORDON: Now we have some time for comments or questions from the committee to the panel.

DR. BALL: I just think it was outstanding research. Thank you. That is wonderful stuff. I greatly appreciate the fact that you brought it through to its finality where it is great that we can diagnose it at 18 months, but then what do these families do and the fact that you have engaged at least the systems. My question to you is are you using multiple different treatments because of where you are at. Is there a consistent set of strategies that you are using in each group? If so, are you thinking of long-term looking at some way of taking that information and seeing if you could do any outcome-based research based on that? So seeing the kid earlier, what do the outcomes look like?

DR. FEINBERG: None of the grants were designed to provide intervention. What we do have though are children who are in multiple service systems and receiving a variety of different community-based services. All of us are working very hard to be able to characterize those services, both the intensity, the type of service, family satisfaction with those services, and actual number of hours of services. While we are not providing any intervention within our studies, it was not within the scope of the RFA.

I think what you are raising is a really important issue. We are trying to gather that information and in the best way possible to be able to follow outcomes. Our hope is that we will be able to continue follow these children longitudinally and in a more observational way look at their trajectory of development.

DR. CARTER: The same for our project in terms of not administering any of the interventions that children are getting, but we are trying to document as carefully as possible.

We have partnered also thanks to a supplement. We have partnered with the Department of Public Health in Massachusetts. We potentially will be able to get children's exit scores from early intervention. We will be able to know what their Barthel scores are as they exit and we can look at that in relation to the density of services or lack thereof that they received.

DR. BALL: Do you encourage everybody to use the webinars that you have done on the website for providers, the one from the navigator?

DR. WETHERBY: Yes. When you say providers, there are lots of different types of providers. In terms of early intervention providers, our project is doing a little quasi-experimental treatment study where we are coaching them after – we are inviting them to the course and then coaching them. We are having them come to webinars and then we are also doing individual meetings with them to make them a little more engaged in the content and making sure they are understanding and using.

We are looking at a host of outcome measures in terms of standardized testing, but also utilization of everything. When everything is online, you know exactly who is in there, how long they are spending, what time of day they are in there and a lot more about them. It is amazing. We will be looking at the data about the providers as well as the families that they are serving for the families that come back and get evaluated.

I think that your question is a great one. The RFA for the ASD PEDS Network was extremely explicit of what we were allowed and encouraged to do in competing. The exciting part of where we are at as we wind down the five years of this cycle and the hope is that we may be able to compete to continue or whether it is within this network or in other ways so that we might be able to plan a treatment study as the next step. I think the first step was really looking at the screening process and utilization.

But now I think if we can study – and the work we do focuses on the families and the coaching. We are now working together with the new ACE Network with funding from NICHD. We are going to be studying parent implemented intervention and how we can enhance that. But the hope is with ASD PEDS Network that we can do other approaches to looking at the treatment as well.

DR. PINTELLO: It was our hope that now knowing what you know about the ASD PEDS Network, we wanted to invite you based on your knowledge and expertise to recommend some potential research directions for this network. I would love to hear your thoughts.

DR. WETHERBY: Is it possible for me to respond to the question about the Act Early that was raised right before Alice started? I appreciate your comment about the Act Early campaign. I think you raised many good points. I appreciate that.

The context of our meeting today in our presentation was about early detection autism. It is a much more narrow context. I think it was great that you clarified that your mission is much broader.

You clarified a number of things. I think it is really interesting the perspective of you want to have milestones that 98 percent or 100 percent of children are meeting and that that is important for parents. I can see that.

I would like to suggest that your milestones and I know they are not yours, but the milestones that are used and incorporated are broad-brush strokes. I think they are very broad-brush strokes of what children are expected to be doing.

What we have tried to do is come in and say there is also a need to understand better much more with a fine brush to come in and say these are the much more detailed skills that should be emerging. Maybe it is the average child, but I think if we can get in early, all children should be able to achieve that if they are in a good responsive parenting environment.

I think the vision is that our milestones are more detailed. They are every two months. They are across five domains just like yours, so they are broad, but they are about helping parents know what children should be learning month to month. If their child starts to fall behind, it gives them some direction, more of a curriculum to help to teach and strategies to teach their child.

I think that the two together and there are many other strategies as well and they would be very complementary. I have had the chance to speak with Camille Smith about this who is very active at the federal level in terms of the Act Early Campaign. I love your Birth to 5: Watch Me Thrive and the notion of celebrating the milestones.

I think it is just important to see that there is a need for both. I hope we both made that point together. Thank you.

DR. GORDON: Okay. Let's thank our panelists. We are going to go ahead and take a ten-minute break and return at 4:20. Thank you.

(Whereupon, the Committee members took a brief break, starting at 4:10 p.m. and reconvened at 4:25 p.m.)

DR. GORDON: For the final stage of the program, we are going to do a round robin. If anyone has anything they would like to report out to the committee. I believe we had one preregistered statement if you will.

DR. SHAPIRA: This is Stuart Shapira from the CDC. At the last IACC meeting in October, investigators from the Study to Explore Early Development or SEED gave brief presentations with very little background and rationale for the studies conducted because of time constraints. The presentations were on just a few of the many analyses that are in progress. CDC and the folks who presented really appreciate the helpful discussions about SEED and the presentations that occurred during the meeting as well as comments that were provided to CDC after the meeting.

The presentation shared at the IACC meeting were chosen based on them reflecting recent analyses and interests of the IACC, but they were only a snippet from the entire SEED study.

SEED investigators are continuing to conduct important analyses and publish results and since the last IACC meeting, there have been four papers published with many more expected in the next year.

DR. GORDON: Thank you, Stuart. I believe Geri, on the phone, you have something you want to contribute.

DR. DAWSON: I have several announcements just related to my role as past president of INSAR, International Society for Autism Research. One is that we are going to be publishing our first policy brief later this year. I think that the IACC will be very interested in it. It is about issues related to employment for adults with autism. There will be soon a call for proposals for the next regional meeting. To the extent that people may be interested in meetings in areas around the world where we typically do not have INSAR, you might want to get involved in that. There will be soon a call for also other proposals for policy briefs. That call is now already out, and it closes February 1.

There will also be a summer institute. This is going to be a series of webinars that will be held this summer and we will provide a little bit more detail about that later.

And then finally, the annual meeting is going to be May 9 through 12 and registration is open. That meeting will be in Rotterdam this year. Thank you.

DR. GORDON: Thank you. Alison?

MS. SINGER: Thanks. I just wanted to point out a couple of things. One is we just released an RFA for undergraduate summer research fellowships. We encourage everyone to apply. In the past, this has been a really great opportunity for siblings of people with autism and individuals with autism to get involved in research. You can find that information on our website.

We also put out an additional RFA. We do this several times a year for our Accelerator

Grants. These are grants that are designed to supplement existing grants in case there is an unexpected discovery to speed up the research process or improve dissemination or take advantage of an unexpected finding. I encourage people to apply for those grants.

DR. GORDON: Thank you. Are there others around the table who have something to contribute?

DR. WEXLER: It is Larry Wexler from the Office of Special Education Program. Five and a half years ago, we funded a research center that asked the basic question. What is happening to kids with disabilities who are engaged in online instruction? The answer was nothing. Essentially, there was no specialized instruction. There was nothing to meet the individual needs of kids with disabilities in digital and online instruction. Obviously, we were pretty concerned. There was a huge number of kids with disabilities who are in full-time online instruction.

This September we funded a $5 million research center. Their task is to develop software designed to adapt and customize digital materials for kids with disabilities. We are not talking about accessibility. We are talking about content adaptations.

The software will enable teachers to differentiate instruction to meet the diverse needs of kids with disabilities. It will enable educators, children with disabilities and their parents to select settings and preferences that provide access and customized instructional materials to meet their individual needs in digital or online instruction and that the software will allow the material to self-adjust so it is presented at appropriate instructional levels based upon an individual child's input.

We are encouraging that the software can be embedded in the development of commercial materials. It will be an open ed resource. It will be available for free to any publisher that wants to use it. An example we gave in the priority was that it could provide user preferences and controls that automatically adapt instructional material to use an equivalent or alternative resource such as text passages at different Lexile levels or mathematical equations with whole numbers between one and ten instead of fractions or decimals.

I have no idea what we are going to get for $5 million. That is the fun part of it in all honesty. It is a venture capital, but we put the money in the hands of some incredibly smart people. We think it will change digital instruction for all kids, not just kids with disabilities. That is our hope. Thanks.

DR. GORDON: Thank you. Anyone else around the table first?

DR. LAURA MAMOUNAS: Yes. The NINDS and the NIH held a workshop in December, December 7 through 9. It focused on developing physiological and functional or discussing physiological and functional biomarkers in neurodevelopmental disorders, particularly those associated with autism, intellectual disability, and epilepsies. It was a two-and-a-half-day workshop. We had over 130 people attend. Quite a bit of people from industry. We had the FDA. We had the NIH. We had academics, clinicians.

Right now, we are starting to put together all the notes and we are going to write a white paper. There are quite a few recommendations that came out of it that we are happy to share with everybody at some point.

DR. CATHERINE SPONG: I would like to first echo Dr. Gordon's earlier statement about Autism Early screening as one of the priorities here at NIH. As you recall Dr. Amy Wetherby mentioned that she has funded one of the new autism centers of excellence, working in the areas of early screening.

I would like to reiterate that there are two other autism centers of excellence, which is also working in the areas of early screening. One is the Duke's Autism Centers of Excellence and the PIs. There are two PIs: Dr. Geraldine Dawson and Dr. Scott Kollins. They are working on the comorbid ADHDs in the diagnosis of autism. Also, Dr. Diana Robins at Drexel University, which is working on randomized clinical trials of autism screening.

At NIH, we are very excited about nine new autism centers of excellence. Dr. Kevin Pelphrey is also the principal investigator and one at ACEs. I am sure in years to come, we will get to know their science and hear their presentations.

DR. GORDON: Thank you. Anyone on the phone? I am not hearing anything so either there is nothing coming --

DR. REICHARDT: It is Louis Reichardt. I have been listening in, but I do not think I have anything super important. Thank you for asking.

DR. SPONG: Also, Dr. Amaral was one of our principal investigators.

DR. GORDON: Anyone else on the phone have an announcement they would like to make? Otherwise, we will wrap it up. Our next meeting will be on April 19. It is a switch from the 18th. It is a Thursday, which is a little unusual. We realized we were conflicting with an important autism biomarkers consortium meeting that had been previously scheduled on the same day. We thought that was not wise. We look forward to seeing you all back here at that point. We do not know where it will be yet, but we will let you know.

DR. DANIELS: We are looking for a location and we will let you know. We also will keep you informed of the Annual Autism Awareness Month event that is held by the NIMH. I will send that information when it is ready. We look forward to Autism Awareness Month in April. Thanks for being here.

DR. GORDON: I want to thank Susan and her entire staff for putting on another great meeting. Thank you.

(Applause)

(Whereupon, at 4:38 p.m. the meeting adjourned.)