

INTERAGENCY AUTISM COORDINATING
COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, July 24, 2019

The full Interagency Autism Coordinating Committee (IACC) convened in Rockville, Maryland, at Hilton Washington DC/Rockville Hotel & Executive Meeting Ctr., 1750 Rockville Pike, 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

MELINDA BALDWIN, Ph.D., LCSW, Administration
for Children and Families (ACF)

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

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

JUDITH COOPER, Ph.D., National Institute on
Deafness and Other Communication Disorders
(NIDCD)

PRESENT: (continued)

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

GERALDINE DAWSON, Ph.D., Duke University

ELAINE COHEN HUBAL, Ph.D., (representing Ruth Etzel, M.D., Ph.D.) Environmental Protection Agency (attended by phone)

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

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

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

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

EDLYN PEÑA, Ph.D., California Lutheran University

LAURA PINCOCK, Pharm.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ)

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

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

PRESENT (continued)

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

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

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation (ASF)

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

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

CHERYL WILLIAMS, Social Security Administration (SSA)

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

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PROCEEDINGS

DR. JOSHUA GORDON: Welcome, everyone, to the meeting of the Interagency Autism Coordinating Committee. Thank you, committee members, speakers, members of the public who are here, and members of the public who are listening into the web feed.

It is bittersweet to say that this is the last meeting of this iteration of the IACC under the Autism CARES Act of 2014. Sweet because I feel like we have gotten a lot done over the course of this iteration of the IACC. Bitter, because it is the last meeting. Also, as many of you may know, the Autism CARES Act - I don't even know what the date would be - 2019, I guess. It will be voted on today in the House, so we anticipate a successful renewal of this committee's mission.

However, when the committee is reconstituted under the new Act, it will be a new committee, with new members, and a new mission. So we mark the close of the IACC's meeting schedule with this particular meeting today. Not the work, we have some work to wrap-up before the end of September, when the committee officially closes down.

Given that, I want to take a few moments to recognize and thank all the members of the IACC present, on the phone, and from the past, for volunteering to serve on this committee. We know the only recompense that you receive is the joy of public service and the opportunity for me, the real recompense, is the opportunity to interact with you all and to hear about the wonderful work being done around the United States and to try to figure out ways we can bring the kinds of things that we hear about in this room, to

everyone all over the country, as well as to address the problems that we are not yet able to address.

It has been remarkable for me, at NIMH in particular, to see how some of the ideas raised, be it the focus on adults with autism, that has increased through the work of this committee over the last couple of years. Or more recently, the focus on comorbidities and aggression and anxiety, et cetera, in autism and how that changes - that really actually changes the focus of our research programs, and we hope that as well, it will bring changes to care, although that takes often a little bit longer.

Your service and your dedication for addressing these issues is what allows us to do our work. It allows us to make sure that all federal agencies here, from the

community, ensure that we do a better job tomorrow than we are doing today.

So, I really, really, thank you and hope that you continue to serve the autism community in a myriad of ways after the close of this committee.

Later on today, we are going to hear a summary of the accomplishments of this committee. So you will get a chance for a moment, to reflect on what we have done since 2014. But, thank you again, for sharing your time and expertise with us.

I also want to welcome and thank our speakers today. These include Representative Franklin Foil, from the Louisiana State Legislature, who is here with community advocates and professionals from Baton Rouge, Louisiana. Who will be sharing with us some of the work that they are doing to support -

to originate and support community-based autism services efforts.

We also have a panel of speakers from academia and advocacy organizations to talk with us about an issue that is becoming ever more important: the racial and ethnic disparities that are present in autism.

Also we will hear from Scott Robertson, from the U.S. Department of Labor, who is going to be sharing a new employment initiative with us. We have all been talking about the importance of supportive employment opportunities for those individuals on the spectrum.

With that introduction, I am going to turn things over to - sorry, one more announcement. We have had a request from our closed captioner because the layout of today's room, it is hard for the captioner to see who is speaking. So if you wouldn't mind,

especially the first few times you speak, if you could just say your name out loud at that time, as well as of course, during the roll call right now. That will help the captioner.

So with that, I will turn it over to Dr. Daniels, for the roll call, minutes, and a few other announcements.

DR. SUSAN DANIELS: Thank you. So in terms of announcements, I just want to say that we do have a live feedback link open on the webcast for anyone who wants to put in a last minute comment to the committee. That will be open until 11:30.

We also do have disability accommodations available, as per usual, the closed captioning on our videocast, the quiet room, that is available outside, and we do have CART for those who may need it.

I also just wanted to share a few comments about the committee. You have

accomplished an awful lot in the last few years and it has been a real pleasure to work with you all. I think that later on when go over reviewing those accomplishments, you are going to be amazed at how much work that you have been able to do to be able to improve what we have to offer the autism community.

There is a long way to go, but you have done important work in bringing these issues to bear. So we really appreciate your time and effort and we have enjoyed getting to know all of you on the committee. It is with sadness that we let some - some folks will be leaving the committee, but we will have new people to join us too. We do want more people from the community to be able to contribute.

So thank you so much for your contributions.

So now I will go through the roll call so we can see who is here. After I read all

this, we will also make sure that we have got everyone on the phone.

Joshua Gordon.

DR. GORDON: Here.

DR. DANIELS: Melinda Baldwin.

(no response)

DR. DANIELS: Diana Bianchi.

DR. DIANA BIANCHI: Here.

DR. DANIELS: Cindy Lawler for Linda Birnbaum.

DR. CINDY LAWLER: Here.

DR. DANIELS: Carrie Wolinetz for Francis Collins.

(No response)

DR. DANIELS: Judith Cooper.

DR. JUDITH COOPER: Here.

DR. DANIELS: Tiffany Farchione.

(No response)

DR. DANIELS: Melissa Harris.

(No response)

DR. DANIELS: Elaine Hubal.

(No response)

DR. DANIELS: Jennifer Johnson.

DR. JENNIFER JOHNSON: Here.

DR. DANIELS: Laura Kavanagh.

MS. LAURA KAVANAGH: Here.

DR. DANIELS: Nina Schor.

DR. NINA SCHOR: Here.

DR. DANIELS: Laura Pincock.

DR. LAURA PINCOCK: Here.

DR. DANIELS: Marcie Ronyak is not going
to be here.

DR. MARCIE RONYAK: Here.

DR. DANIELS: Oh, -

DR. RONYAK: Surprise.

DR. DANIELS: Sorry. Were you not going
to be here?

DR. RONYAK: I wasn't going to be here
yesterday. I am trying to cover -

DR. DANIELS: Okay. Great. Sorry about that. Great, glad you are here.

Stuart Shapira.

DR. STUART SHAPIRA: Here.

DR. DANIELS: Larry Wexler. Is here, someplace. Cheryl Williams.

MS. CHERYL WILLIAMS: Here.

DR. DANIELS: David Amaral.

(No response)

DR. DANIELS: Jim Ball.

DR. JIM BALL: Here.

DR. DANIELS: Samantha Crane.

(No response)

DR. DANIELS: Geri Dawson.

DR. GERALDINE DAWSON: Here.

DR. DANIELS: And David Mandell was not planning to be here. Kevin Pelphrey - also is not able to come.

Edlyn Peña.

DR. EDLYN PEÑA: Here.

DR. DANIELS: Louis Reichardt.

(No response)

DR. DANIELS: Rob Ring.

(No response)

DR. DANIELS: John Robison.

(No response)

DR. DANIELS: Alison Singer.

MS. ALISON SINGER: Here.

DR. DANIELS: Julie Taylor.

DR. JULIE TAYLOR: Here.

DR. DANIELS: Thank you. I know that some people had other conferences or scheduled leave for this summer. The summer meeting is always a challenging one to get to.

We will now go through the minutes. You all received a copy of the April 17, 2019 meeting minutes in your packets. You had it ahead of time to look at.

Does anyone have any comments on the minutes? Any changes or corrections that you

feel are needed? Hearing none, is there a motion on the floor to accept the minutes as written?

DR. AMARAL: So moved.

DR. DANIELS: A second.

DR. DAWSON: Second.

DR. DANIELS: All in favor.

(chorus of "aye".)

DR. DANIELS: Any opposed? Any abstaining? No one is on the phone as far as I know. So then the motion carries to accept the minutes as written. Those will be posted to the website. Thank you.

DR. GORDON: Now, next on the agenda would have been a report from HHS National Autism Coordinator, Dr. Ann Wagner. Unfortunately, Ann was called away for a personal family emergency. She is unable to join us this morning. So we will have to have

her send out an email to inform you all about the latest progress.

We will move right on then to the first panel of the meeting today. We are fortunate enough to have Representative Franklin Foil from the Louisiana State Legislature. I am going to ask him to introduce himself.

He will also introduce the panel speakers as they speak. These include Lauren Jumonville, the Director of Civic Leadership Initiatives to the Baton Rouge Area Foundation, Traci Olivier, a pediatric neuropsychologist at Our Lady of the Lake Physician Group, and Melissa Juneau, the former CEO of the Emerge Center for Communication, Behavior, and Development, and finally, Stephen Whitlow, the Executive Director of Transition Services at Merakey Gateway.

Thank you, Representative Foil.

REPRESENTATIVE FRANKLIN FOIL: Thank you Dr. Gordon and Dr. Daniels for inviting us here. We are both excited and honored to be here with you. I am really looking forward to presenting my Louisiana colleagues to tell you about the autism services we are providing in Baton Rouge.

Just to give you a little background about myself before we go into the panel discussion, I first ran for the Louisiana House in 2007. When I was deciding on what issues I wanted to make my priorities, to the top came advocating for parents with special needs children.

Now, for my background, I grew up with a sister with Down Syndrome. So I saw the struggles my parents went through in raising my sister and trying to get the necessary services to help her get through life and help my parents in raising her. Then my third

child we found out was diagnosed on the Autism Spectrum. So, I also, along with my wife, went through the struggles you have when you have a child with disabilities and you get to know other parents in the same position.

When I ran for office that was going to be one of my top priorities. I was fortunate enough to win in 2007. I was sworn in in 2008. I reached out to people in the community and said bring me some ideas. What can I bring forward as far as legislation?

Usually, the first request is we just need more money and more funding. Well, as a freshman legislator, that is probably the most difficult thing to obtain.

Fortunately, I met with a group who said - who came to me and said why don't we do legislation to require health insurance companies to provide medical services for

children with autism, specifically ABA therapy. I said what a great idea. Who would possibly be opposed to that? This would help everyone.

Little did I know insurance companies, big business interests, and others do not like to be told what they have to do as far as providing insurance coverage.

So, we started meeting and put a bill together - and meeting with the different stakeholders - and came up with a platform and introduced at that session. We had a lot of opposition as we started the process, but I had a much bigger weapon. I had parents of children with special needs who came down to the capital to advocate for the legislation.

It is one thing to send emails or to telephone your legislators. If you are actually there, in person, and they see you, it makes a huge impact.

So, we filled the committee rooms. We brought testimony from the different parents about the importance of this bill. More and more legislators came to me and said, you know, I actually have a cousin or a niece with autism. Back in 2007, it wasn't near as prevalent as you know as it is now, but more and more people realized they had a connection somewhere.

So, we were successful at the end of the day. We got the legislation passed. The governor signed it. That brought ABA therapy as a covered therapy for our kids in Louisiana. Before the legislation passed, we didn't have any ABA therapists in Louisiana. You had to go out of state to get those services. We started getting licensed ABA therapists to our state and the provider opportunities really grew for our children.

So, that was wonderful once we got that passed, but I realized that we still had another big issue: education. I know many parents are in the same boat as we are with our child, who are trying to find the perfect place for their child. In many cases, there are - there were not many options in Baton Rouge back in 2007 when we started this process. Most of the time, parents would put their children in schools, and schools would not want to work to mainstream the child or make the accommodations. They would want to push them to a self-contained classroom.

I looked at other states and big cities, such as Houston and Chicago, where they had autism-specialized schools. I thought wouldn't that be wonderful if we could attract that to Louisiana.

I was able to pass some legislation my second year in office to provide some tuition

assistance for parents with special needs children if there is a school that is able to provide those services. As you know, it is very expensive to educate these children.

You will hear more during our presentation from Melissa Juneau about the Emerge School, which is an autism school, which grew and has grown in Baton Rouge with the help of that as well as using the insurance money. With our children with special needs, it is a combination of health needs and education needs.

So, we moved on. As my child got older, we started wondering what are we going to do next about job training for our kids. There really wasn't anything in Baton Rouge either in that respect.

I worked with Baton Rouge Area Foundation and Baton Rouge Community College as well as my colleague, Stephen Whitlow, who

was starting a non-profit in Baton Rouge for life skills and job training. We went to our community college and said let's get a job training program. We modeled it after another program. Now, Baton Rouge Community College, I am proud to say, has a program where for one year, children with intellectual disabilities who perform at a high level will do one year of classroom training for job training.

What the school has done - it identifies partners in the community who will employ these kids as interns. The school provides job coaches that will go out to the different employers and provide the services to help that child to where they can work full-time.

All of us, as parents, our goal is for our children to be in a happy work environment. My son gets lonely when he is at home during the summer without anything to

do. Now that he is in this program - he loves music. He works at a radio station. It is a gospel radio station. He is actually on the air this morning doing his gospel show. So, it has just been a wonderful opportunity.

Steve Whitlow will also tell you about his program, which is also helping kids learn vocational training.

The final area we started looking at is housing. Once again, as your kids get older - when my child was - when I first got elected to office, he was seven. I wasn't thinking about housing. Now, my child is 19. What do we do for our children? We would like for them to be independent. We, as parents, are not going to be here forever. We want a nice, safe environment for our children to live.

We really at this point have no options in Baton Rouge. That is sort of a hot topic that we are working on today. We hope - we

are hopeful that we can get programs so we know when we are not here that our kids will be safe.

The panel here, today, is going to talk to you about all of those areas that we have been working on in Baton Rouge, healthcare, education, job training, and housing. We have come a long way. We have a long way to go still.

A year ago, after I had been working at the state level with these stakeholders next to me, I wanted to see what the federal government was doing. I really did not know what was going on at the federal level. I knew there was money for research and other things available.

I got on the internet and googled "autism federal level" and I found Dr. Daniels and her office. I called her office and they invited me to come up and visit with

them. I was overwhelmed with the amount of research that was going on up here. I said the problem is a lot of people in Louisiana don't know about this. How can we plug what you are doing in with what we are doing in Louisiana?

So, I invited them to come down to Baton Rouge. They came down a couple of months ago. We took them around and gave them a tour of what we are doing to show them what was going on.

We also have an autism stakeholder group that meets quarterly in Baton Rouge. They came and made a presentation to our group to let them know.

So, that is why we are here today. As a result of our collaboration with our federal partners, we have been invited to tell you what is going on in Louisiana. We need to use all of the resources that are available, both

at the federal and state level, to make this place a better place for our kids and adults with autism.

With that said, let me introduce the panel. Each member is going to tell you a little bit more about themselves and what they are doing with their organizations. Afterwards, we will have an open discussion time to answer any questions.

First on the agenda will be Lauren Jumonville. She is the Civic Leadership Initiative Director for the Baton Rouge Area Foundation. The Baton Rouge Area Foundation is a nonprofit, which raises money from donors and volunteers in Baton Rouge. The Baton Rouge Area Foundation uses those resources to do philanthropic projects in the Baton Rouge area. One of them is autism. Lauren will tell you more about what she has

been doing with the Baton Rouge Area Foundation about autism.

After Lauren's speech, you will hear from Dr. Traci Olivier. Dr. Olivier is a pediatric neuropsychologist at Our Lady of the Lake Physician Group in Baton Rouge. She also sees children with developmental disabilities as part of her practice, including children with autism.

After Dr. Olivier speaks, you will hear from Melissa Juneau. Melissa Juneau is a former CEO of the Emerge Center. She was appointed the CEO of the Emerge Center in 2018 after she oversaw the launch of the Emerge Enterprise, which is comprised of the Emerge Center, the Emerge Foundation, and the Emerge School for Autism, which is the first charter school in Louisiana for children with autism. She retired from that position in June of 2018.

Finally, you are going to hear from my friend next to me, Stephen Whitlow, who is the Executive Director of Transition Services for Merakey Gateway. Stephen is not only the Executive Director, but he is also the father of three children, including a young adult on the autism spectrum. He cofounded the Gateway Transition Center with his wife, Mrs. Sharon Whitlow, which provided support to - which provides support to autistic teenagers and young adults as they transition to adulthood.

At this time, I wanted to turn it over to Lauren Jumonville. I am going to let Lauren tell you a little bit about herself and what her organization is doing.

MS. LAUREN JUMONVILLE: Thank you and thank you for your leadership in this space.

As Representative Foil shared, my name is Lauren Crapanzano Jumonville. I work at the Baton Rouge Area Foundation.

If you don't mind, I am going to give you a brief overview of the Baton Rouge Area Foundation because I think we are a really unique organization in Baton Rouge and probably around the country. It helps explain why we are involved in this space.

As he indicated, we are a community foundation. At our core, what we do is philanthropy. We have donors who will open funds with us and use us as a vehicle for their philanthropy. We probably have several hundred donors with donor funds opened at the Baton Rouge Area Foundation right now. They, essentially, direct their philanthropic interest, but we help manage and grow that funding that they hold with us and help advise them on key issues in the community that may need that funding.

One way we are a little unique is the department that I work in, our Civic

Leadership Initiatives area. In this space, what little unrestricted dollars we get from community members or others around the country who are interested in our work, we direct into hiring a staff, my team, who works on kind of quality of life initiatives in the south Louisiana area.

They tend to be multiyear, multimillion-dollar efforts that require significant partnerships with the public sector, nonprofits, the business community, and general stakeholders around the area.

If you hear me being a little vague about what they are it is because they tend to be things that arise as issues that we don't expect. We don't have a particular focus on any one area or topic.

As an example, right now, we have an effort looking at an urban lake system that is in decline and in need of repair. We have

another looking at an intercity passenger train between Baton Rouge and New Orleans, something we think is a key economic development driver in our area. What is more relevant to you today is this effort around autism that we have been working on with stakeholders.

I guess about five or six years ago, Melissa Juneau, the then-executive director of the Emerge Center, sat down with my supervisor, John Spain, with her board leadership and ours, and said that, essentially, what we have in Baton Rouge is a lot of spots of light, some organizations doing great things for individuals on the spectrum, but not a full continuum of care along the lifespan. Because of that a lot of gaps in coverage and services. Individuals struggle to navigate this complex system and

figure out what is and isn't available to them.

So she asked us, essentially, to do a gap analysis to look at what we have in Baton Rouge, what we are missing, best practices around the country, and how we can plug those ideas into our community. Being very naïve and not knowing very much about this space at the time, we said yes and that it would take us six months. I think around two or three years later we published a report with stakeholders from the community.

I brought it here, today. Certainly, if any of you are interested in thumbing through it, you are welcome. Mostly it is to show you how thick it ended up being and really demonstrated to us how naïve we were. That this is a complicated scenario for families to navigate.

Our very first meeting when we started working on this project we invited stakeholders from the community that we were aware of in this space to come together. We had faith leaders, parents, grandparents, individuals with autism, service providers, healthcare providers, public and private partners all around the table in a room just like we are sitting here today.

We asked everyone in the room to introduce themselves, introduce their organization, and share what services they provided in the community. When they finished, we were surprised because we heard of services and organizations we had never heard of before. We thought we were somewhat keyed in given our philanthropic role in the community.

So, we paused and we asked everyone in the room, raise your hand if you learned of a

new organization or service that you hadn't heard of before. Every single person raised their hand. That really stuck with us. If these organizations and these individuals in our community who are way more embedded in this space than we had ever been didn't know of everything that existed, how in the world is a family expected to navigate all of these services and opportunities for them?

So thus began our two-year journey. When we finished, we published this report really across the lifespan and all of the various points of intersect and decision-making that a family has to navigate.

We ended up with about 25 recommendations. Some of them very low-hanging fruit and relatively simple. For example, that original stakeholder group as well as all of the others that we learned about as we continued in this process should

continue to meet regularly. Even having people around the table was an important step in getting this continuum of care more coordinated.

We looked at early diagnosis. The average age of diagnosis is far too late. In Baton Rouge, sometimes later than it can be nationally. How do we ensure that people know the signs of autism? That our physicians are appropriately screening for this and doing everything that they need to do to get someone into early intervention as soon as possible?

Looking at our early intervention services, while wonderful, there were long waiting lists. Opportunities for families to get in were really limited. We needed to find a way to increase and enhance those opportunities for families.

Pre-K through 12 education, as Representative Foil indicated, there were a lot of really limited services. When they were provided, they were inconsistent. Not to suggest that has been fully rectified, but we do now have many more opportunities than we did before, certainly with the Emerge School and with others that have been growing over the last few years.

Then what I have here is adult transition. Really, it is probably more indicative of living as an adult with autism. Certainly, you will have a challenging transition out of the school system if that is where you have been, looking at employment and post-secondary educational opportunities and housing, all of the things that go along with that to live a fulfilling and as independent of a life as is reasonable and what you are looking for.

We started looking at this, our 25 recommendations, and who we are as the Baton Rouge Area Foundation, not an expert or someone who has lived and walked this autism space, and in talking with our stakeholders decided that what we really would like to do is create a network of key organizations in our community who would carry this mantle forward. Certainly, with our support, we would continue to stay involved, but to try to get people who are engaged in this space day in and day out, waking up and looking at this together.

You see here are three key organizations who kind of formed the leadership team, if you will, of what we have now dubbed our Capital Area Autism Network. The Emerge Center, who of course brought us to the table in the first place and has really innovated care delivery in this space. Our Lady of the

Lake Pediatric Development and Therapy Center, who is affiliated and a part of our - one of our major hospitals in the area, a real key medical provider looking at the medical needs of children in the space, and frankly, with a lot of resources that can help continue to enhance this space. And then Families Helping Families, who is a really critical advocacy and family engagement organization in this community for us. They have kind of led this next phase of the effort, working on implementing all of the recommendations in our rather large report.

We also embedded within this network different task forces. We divided out all of the recommendations into key areas that we could get different organizations to focus. Then we asked different organizations to lead up these task forces so that we are, again,

continuing to get more and more organizations involved and engaged in this space.

So, Services for Individuals and Families, that early intervention and continued therapy option.

Family and Public Awareness and Family Support. We heard a lot of need not only what I mentioned before of knowing the signs of autism, but also families who are looking for respite or opportunities for parents to get help and support as they are living in this space.

Transition and Workforce Development Opportunities, which - thank you - Steve Whitlow has led up for us and has really I think become a monster in this space because there are so many different issues embedded in that work.

Development of the Professional Workforce. By this, we don't necessarily mean

individuals with autism, but the individuals who are working with individuals with autism. We really had a gap and continue to see a gap in those providers in our community. So, how can we work with economic development agencies and with organizations who are looking to hire these individuals to grow that workforce?

And then the Advancement of Educational Opportunities for our individuals with autism.

One of the things - I will go back to that first meeting we held when all of the entities around the room didn't know of each other. We started really struggling with, how do we get information into parents' hands when they may not necessarily know where to go to get that information? We have now learned a lot about what is available in our community. How do we get that to families?

We found this organization, a non-profit based out of Boston, Massachusetts, who there have been working on a web platform that was accessible 24/7 - so, working parents could access it at night and kind of learn what existed in their community. We were really impressed by what they had been offering. So worked with them to develop an equivalent web platform in Louisiana.

They had found in their experience in Boston that the most often people were on the website was between 10 p.m. and 2 a.m. After they had put their children to bed and then they had a moment to breathe and start doing their own research. Clearly, not many service provider agencies are open at that time, and so having this web resource became really important.

What Exceptional Lives does is it essentially offers three different things for families.

The first are what they refer to as guides. These are the action steps necessary to accomplish something in this space. We have 11 guides across the lifespan - I will show you the list in a moment - that helps a family navigate through decisions they have to make.

An example would be in Louisiana we have a Medicaid waiver program where you can access additional resources by getting on that waiver waiting list, but it is a complicated scenario to figure out the right form to fill out, where you need to bring it, what information you should include, and then once you are on the waiting list, what can you do in the interim in order to start accessing other services and opportunities.

So, these guides are broken down into - we aim for a third grade reading level. More often than not it is probably closer to a sixth. Although, that is because a lot of the words in the disability community have a tendency to be at a higher literacy. We make it a point to explain those words because families need to know and understand them so that they can use them themselves.

Each of the guides are written in plain language with health literacy principles in mind.

The second piece is a resource directory. One of the things we heard, not just from families, but also from interviews with providers, is that they spend an inordinate amount of time trying to keep track of all of the organizations in our community who are providing services to these individuals. What we suspected would be

easier and better for the community as a whole is if we took that burden off of them and provided it to them as long as we ensured that it stayed up to date. So it was a resource they could access and use, but not something they were then responsible for themselves.

This resource directory is statewide. It looks at all of the traditional things you would think would be included, occupational therapists, physical therapists, ABA therapists, but even some more unusual things, dentists who have particular experience working with children with autism, hairdressers and barbers who have experience, so that we can help families to find and identify those opportunities for them.

The final piece of the website is if at any point in time when a family member or individual with autism is on the site and

they get stuck, there is a helpline, a chat feature, and an email that they can connect in.

Now, I mentioned that this organization is based out of Massachusetts, which is still true. What they have done is developed a network across Louisiana so that if it is a simple question or something maybe more technical, their team can answer it. But if it is something where a family needs that one on one individual attention to detail, then Exceptional Lives can make that warm handoff to an organization like the Families Helping Families on our leadership team so that they can help that family navigate the services.

These are the guides that we currently have in Louisiana across the lifespan, looking at these various pieces of the puzzle that a family may need to navigate. In looking at this list - so, it is interesting.

When we launched and when they launched in Massachusetts, SSI, that process is essentially the same no matter where you are in the country. So to date, that is the most popular guide on the website. People all over the country when they are googling - when individuals are googling, will end up there.

In Louisiana, our second most popular guide is the Autism Guide. This is a guide that you are getting that diagnosis and you are on the roller coaster of trying to figure out what this means. It kind of walks you through things you can expect, entities you can connect with.

Our third most popular guide is the Medicaid waivers, which, as I mentioned, can be a complicated process.

Then the resource directory. I mentioned that it is statewide. What I should highlight here is that it is tagged and searchable. You

can look for resources by age of your child, by services provided, by insurance accepted. We are also working - it is available in Spanish in Massachusetts. We will launch in Spanish in Louisiana in a couple of months.

It has been live in Louisiana since August of 2017. Since then you will see some of our key statistics. This is actually maybe a couple of months old. We have now had closer to 35,000 unique visitors to the website statewide and in our community. Which we are really proud of because when we have talked to other organizations, those numbers are really comparable if not beating some of the ones - other organizations in our community.

One of the things we found really helpful is we partnered with the library system statewide. They have fliers and pamphlets in every library in Louisiana

advertising this website. We have started trainings where we have worked with librarians so that they know how to use the website should anyone be there accessing it and in need of support.

Since we have launched, we ask everybody a little survey at the end of each guide or research directory search they have done. Of the individuals who answered, more than 90 percent say that it was helpful in what they needed. More than 95 percent say they would recommend it to a friend. So we have been really pleased with those numbers.

I will close with this. We interviewed I would say probably 300 families in the course of working on this report. You, as a family member who has a loved one with autism or someone with autism, really have to become an expert in what is available to you and what exists in your community. We really wanted to

try to take that burden away, to give you some opportunity to have a reprieve and access to information you could trust.

So when we hear things like this from individuals who have gone through the website that they are learning things they didn't know after 27 years of living with this, that, to us, says that we are starting to accomplish that goal. We are really providing a resource that people need.

REPRESENTATIVE FOIL: Thank you Lauren. Next, we are going to hear from Dr. Traci Olivier. Dr. Olivier is going to tell you about her work at Our Lady of the Lake Children's Hospital and touch on what she is doing with children with autism as well. Dr. Olivier.

DR. TRACI OLIVIER: Hi. My name is Dr. Traci Olivier. As Representative Foil said, I am a pediatric neuropsychologist out of Our

Lady of the Lake Children's Health. Today, I will be presenting to you on behalf of our Pediatric Development and Therapy Center and on behalf of our medical director, Dr. Stephen Felix.

I will give you a brief introduction of the talk, a little bit of background about myself and also about Our Lady of the lake Children's Health and our department there. Then I will go into talking about some of the programming that we are developing and have developed not only to complement our medical facility and expand the services there, but also to work in partnership with the community organizations around us.

I will speak briefly about the development of the Capital Area Autism Network, most of which Lauren has already very nicely outlined for you. And then I will talk about future directions for the Network

and some of the successes that we have had so far.

I completed my undergraduate training at LSU, but most of my graduate level training was completed across the country as far as internship and post doc. I always had an interest, though, in coming back home to Louisiana. It is a passion of mine.

I was seeing this theme that many of our individuals were having to go elsewhere for services. It wasn't just specific to children with autism, but it really kind of was across the spectrum of children and families and even adults who had complex medical or neurological issues. So, what would happen is they may get their acute care or initial diagnosis locally, but then either be sent home with nothing or be sent with less than stellar options or have to go elsewhere.

On internship and fellowship, I was in Baltimore and in Memphis. The number of Louisiana kiddos that would end up on my caseload was just unbelievable. Of course, I understand that those were special institutions and specialty hospitals and so there was a reason for that. But I had seen this theme not only in my own family with individuals who have special needs, but also more professionally as far as this caseload issue.

So, it is a personal passion of mine to be back in Louisiana to be able to help expand the services. So that is a little bit of personal background.

I am now at Our Lady of the Lake Children's Health. We are underneath a larger health system known as the Franciscan Missionaries of Our Lady or FMOL.

We are a faith-based, mission-driven organization. We are a non-profit. We are currently one of Louisiana's largest health systems. We have seven hospitals across Louisiana. More recently, we have expanded into Mississippi and we continue to expand.

In Baton Rouge, our flagship hospital is Our Lady of the Lake Regional Medical Center, which is where I operate out of. We are the largest private non-profit hospital in Louisiana. We are very excited that we will be opening the first freestanding children's hospital in the Baton Rouge area, here, in just a few weeks in the beginning of October.

Because of the Children's Hospital, the opening of that, it has really promoted a lot of growth within the health system as far as pediatric subspecialties are concerned. There has been a very large push to recruit more subspecialists that the system did not have

before. We currently have about 80 pediatric specialists who operate across 30 different subspecialties.

Within the health system is our department, the Pediatric Development and Therapy Center. We are an interdisciplinary team that focuses primarily on diagnosis and also treatment for children with a wide range of developmental concerns.

At present, on our team, we have some developmental-behavioral pediatricians who work along with the psychologists, both in neuropsychology and behavior psychology. Then we have a wonderful team of therapists and interventionists that span across physical, occupational, and speech therapy, and also a social work team, as well.

As I mentioned, we focus primarily on evaluation and therapy. One of the things that we have really worked hard to develop

over the years is this interdisciplinary approach to care so that we are not operating in silos as disciplines, but coming together to develop a coordinated approach to diagnosis and treatment.

We have specialty clinics within the PDTC. We also accept discipline-specific referrals.

One of our roles in this network that I will speak about a little further in the presentation is that one of our key responsibilities is to be able to provide for the medical needs of children with autism spectrum disorder and other developmental concerns. That is something that is somewhat unique about our institution.

A large majority of the children that we see have autism spectrum disorder. As I mentioned, we also see a number of other children that have either global

developmental delays that maybe have not been quite identified yet, or mental health concerns like behavioral difficulties or ADHD. We also have a number of children who have central nervous system disorders, whether that be cancer or cerebral palsy, Down Syndrome or spina bifida. We also work with our St. Jude affiliate at Our Lady of the Lake.

We have a growing number of children with learning and intellectual disabilities. As you all know, that is very highly comorbid with autism. So that is a very large majority of the children that we serve, as well. Also, children with very rare genetic syndromes.

One of the ways in which we are able to attack this in an interdisciplinary way is through our social engagement clinic. This is not the only entryway into our clinic, but it is one of the most popular.

We work with the interdisciplinary team that, at present, consists of developmental medicine, psychology, speech and language pathology, and occupational therapy. These visits are somewhat unique in that the goal is to have everyone in the same room at the same time and come together as a team to make a diagnosis looking at these different areas and then also come up with a coordinated treatment plan, most of which, if not all, can be carried out in our center. We also often refer to community-based organizations, too, which I will talk about in a minute.

Then we are able to provide ongoing follow-up, especially if other medical needs arise that we know are comorbid with autism such as seizure disorders, gastrointestinal difficulties, or feeding difficulties and other issues.

I will speak about our community partnerships and why this is so important to our hospital system. As I mentioned, we have a mission-driven purpose. That really boils down to serving those who are most in need. In Louisiana, we have a lot of need. Historically and still to the present, we have been a very low-resource but high-need area. Because of that, collaboration really is essential.

As Lauren mentioned, we were operating many times in silos across the state, not understanding what other groups were doing and what other resources were available. The more of an understanding we can get about who is doing what, the more we can work on the gaps there and utilize the resources that we have to serve the families more effectively.

I will just give you an example. Our Center, the PDTC, currently serves about 46

of the 64 parishes in Louisiana and in four surrounding states, being Mississippi, Arkansas, Alabama, and Texas.

So, this is not, again, unique to our system. I'm sure Emerge and other areas - other institutions in the area also have the same thing, where you are seeing children and families who are driving a very long way to get services because much of Louisiana is still very rural and there are not the resources in every area. Because of that it hits home that collaboration, again, is very essential to be able to connect the families with what they need.

One way we were able to do this - this is still in progress - is to help fill the gaps for some of the initiatives that are around the area. We have recently started to engage in telemedicine. This is very specific to our developmental pediatricians and moving

into psychology, as well, to where we can partner with other agencies such as Merakey and McMains and even St. Lillian's to provide a level of medical care that may not have been there before.

There are things, of course, that people will need to come into the clinic for. One of the ways this has been very helpful is for ongoing follow-up that doesn't require an in-person visit, particularly for those children who may be coming from far away. Our patients have responded very well to that.

In addition to the partnerships I've already mentioned, the referrals to local centers are just critical. We refer often to Emerge, Abilities and Launch, and several other agencies in the area, because, again, the need is just very overwhelming. Lauren had mentioned the long waitlists, especially for early childhood intervention services. As

a regional medical center, we very much struggle with long waitlists across the board. I know that other agencies in the area do as well, which is why it is critical to be able to expand the services that we have and the quality of the services.

I will shift briefly to talking about the Capital Area Autism Network. Lauren gave you an excellent background of how this network was developed. I will focus more on our role as the regional medical center.

This study in 2016 really highlighted a lot of the needs in the area. One of the needs that came out of that was the need to be able to address the medical concerns for these children, again, as many medical issues are comorbid with autism.

As far as our role in the Capital Area Autism Network, again, on behalf of Dr. Felix, we have participated in the

Implementation Committee. That consists of not only Dr. Felix, but representatives from the Catholic Diocese and from Families Helping Families.

This Implementation Committee has been integral in setting the purpose and direction for the five task forces that Lauren had mentioned, which I will briefly review as well. It is to set goals for the overall group and work with those task forces to implement those goals. And then continue that ongoing communication between the groups that, again, I think really started with the 2016 report and that we are working to continue now. Lastly, we work very hard to coordinate the efforts between the agencies and the disciplines.

This is a brief review of the task forces again. I will highlight some of the goals that may be of interest to you. The

document is much, much longer with all of the goals and initiatives.

Again, there are the five different task forces, one focused on services specifically for individuals and families with autism and then one focused on more of the family awareness, public awareness, and family support services. We have two that are focused on transition, one, again, focused for the transition of services for the actual individuals and families and then one geared more towards the professionals and being able to implement training and more opportunities there. Education is a very large part of this committee, as well, and the fifth task force.

Again, as our role as a regional medical center, if you look at the initiative for the first one, for the services for the individuals and families, there was a call to build a network of pediatric physician

specialists and psychologists in the Baton Rouge and surrounding areas. That is really where we have focused a lot of our efforts. Again, going back to the push and the initiative of the overall health system, with the opening of the new Children's Hospital, this has been very important.

We are also working on expanding those early childhood intervention services, as well.

Transition is something that has been talked about a lot at this meeting and amongst our group, as well. So that we are doing things to be able to promote that. Steve will talk much more about that from the transition and housing perspective. But it is a very important need in the area.

We have spent a lot of time focusing on the education aspect, as far as K-12 and even before kindergarten, the intervention there,

but these families, many of the parents are getting older and the children are getting older. It doesn't stop at 18. There is this critical point where we can work to educate parents about not only what to expect, but also the resources that are out there.

But we have much, much more work to do to be able to provide housing for these individuals that is supportive enough to meet their needs and to provide them with something to do during the day. As we all know, having a purpose and having something that is fulfilling is very important to overall quality of life and especially to mental health as well.

The Autism Stakeholders Group is a group that was really birthed out of the Capital Area Autism Network and these five task forces. As you can imagine, not everyone can serve on a task force. So this group was kind

of an outgrowth of that. Currently, there are about 65 individual participants who come together for semi-annual meetings to review the initiatives, further define and develop the goals, and then inform the community of what is going on.

One of the ways that they do that is through this Annual Town Hall meeting. This serves not only as a way to inform the community of the initiatives and the efforts and the services that are out there, but also to gain feedback about what is working and what is not working.

Lastly, I will talk about a few of the successes and then talk very briefly about future directions for our network.

I think if we boiled it down to one of the largest successes, I think everybody on the panel would agree, is that we are one step closer to decreasing this mindset of

working in silos and fostering collaboration among the teams. This has been a very critical component of our work not only to understand what other people bring to the table, but to be open to be able to work back and forth and then, again, figure out where things are missing and how we can come together.

We are not able to do it with just one institution or one agency or even one initiative or even one report, but that gives us a starting place. The more we work together, the more we are able to provide for the needs. Again, it is going back to what is very much at the heart of our mission at our hospital. That is serving those most in need.

Lauren talked about the Waiver Program in Louisiana. One of the successes, as far as our network, has been to actively work to decrease the wait times for those waivers.

The wait time was extremely long. There is still a lot of work to be done there, but we have had some good progress.

We have also been able to increase awareness and safety among the police force with increased training of signs and symptoms of autism and education as far as what to expect and how to interact appropriately with these individuals who might have different needs.

We have worked on getting Driver's License identification for individuals with autism. That can, again, help to promote not only awareness, but safety for these individuals.

One of the things we are very excited about is our partnership with one of our system universities, Franciscan University. They have established a Board Certified Assistant Behavior Analyst program, BCaBA.

This is the first one in the state. This is critical to being able to attract more individuals who can provide ABA. This offers another level of service delivery for those services.

We also have ongoing collaborations that are informal at this time and should soon be moving to more formal arrangements with McMains Children's Developmental Center and St. Lilian Academy, to be able to come together and meet more of the needs.

Going back to the Fran U program, we are very excited about this because we were able to leverage the 2016 report to be able to secure about \$800,000 in grant funding for expansion of primarily our behavioral services. So, we have ongoing renovations right now to be able to - again, for psychology, to expand there, but also

specifically to expand our early intervention and ABA services.

We are very excited that Dr. Eliana Pizarro, a BCBA, will be joining us in the summer of 2019 at the doctoral level. This is going to allow us not only to expand our services, but also to expand the training with LSU students and the Fran U bachelor's-level students.

With all of the successes, there is lots more work to do. As the initiatives change and as we make progress, some of the goals are going to have to change and be refined. That is one of the primary focuses of the network and continuing to work with those private partnerships to improve the services.

One of the hot button items right now is to continue to work on improving reimbursement for our clinic, in particular, and I am sure other clinics in the area.

Getting reimbursement for interdisciplinary services has been quite a challenge. When you have all of the providers in the same room together, that has been established as the standard of care for some of these disorders and interventions, but it is very hard to get that reimbursed from a billing and coding perspective. So we are actively working on that.

Then we hope to develop the Network into an independent, 501(c)(3) organization, which would allow us to further develop staff and be able to meet the needs and continue to do some of the work that is required between the meetings.

Thank you very much. I will turn it over now to Melissa Juneau.

REPRESENTATIVE FOIL: Thank you and Melissa Juneau will talk to you about her work with the Emerge Center.

MS. MELISSA JUNEAU: Good morning. I'm Melissa Juneau. My background is speech language pathology. I assumed the role as executive director in 2007 of the Baton Rouge Speech and Hearing Foundation, which has now been rebranded to the Emerge Center. I appreciate the opportunity today to talk to you about our work.

The Emerge Center empowers children with autism and individuals with communication challenges to achieve independence through innovative and family-centered therapies. We are an early intervention pediatric therapy center. Our vision, as I think everyone's vision, is to have a world where all individuals are able to maximize their potential.

It is important to know that we are a long-standing community organization in the Baton Rouge area. We were founded in 1960 as

the Baton Rouge Speech and Hearing Foundation by the Junior League of Baton Rouge to respond to children that were deaf and hard of hearing. So our work began there with just volunteers and then it moved and as we grew up and as the needs of the community changed, we evolved our services.

So, in the early 2000s, we began to see more and more children being diagnosed with autism. With that, we began our work to address those needs. We are an independent 501(c)(3). In 2014, we became the Emerge Center for Communication, Behavior, and Development.

It is important to know that in the early 2000s, there were really no center-based services in the greater Baton Rouge area for children with autism. As mentioned prior by the speakers, many people were flying in consultants. There was not broad

access for these services. As a local 501(c)(3), boots on the ground, our board was determined to be able to be that resource for children - all children in our community.

So, in 2004, we launched a pilot program with Louisiana State University, Psychology Department, and combined our group speech therapy program with applied behavior analysis for four children - center-based two-year-old children. The results were really phenomenal. Based on that, the board and leadership began to work in evolving the programs to what you will see we are today.

Here is the Emerge Center.

The Emerge Center is a therapeutic center, early intervention-focused, 26,000 square feet. We offer audiology, occupational therapy. We have a parent resource room. We have a large conference and training center, a café, outdoor dining, therapeutic

classrooms, kindergarten-level classrooms, occupation therapy gym, place for applied behavior analysis, and, of course, as a medical facility, we do all of the healthcare billing and we have a behavioral health department.

It is important to note that this Center was built on 100 percent donor dollars. We raised \$8 million from the Baton Rouge community. They really answered the call to provide these services to our children living in our area and within the state of Louisiana.

This is a snapshot of all of the services we provide, including establishing a therapeutic home for our young children. We offer all of the families support in addition to that.

Our team is 75 therapeutic professionals. At any given time, we have 30

university students studying speech language pathology, potential occupational therapists, psychologists that come and work with us and train with our professionals. We feel like we are launching, every year, new professionals in the field to be able to respond to the needs of the community and the state of Louisiana. As you can see, we have tons of fun.

What is the Emerge difference?

Certainly, you can see all of these services that many, many therapeutic centers provide. How we make a difference is we keep the child at the center. Every child that comes to us has an individual plan. We embrace that child and that family providing case management, making sure that each of those children have an individual plan so they can meet their maximum potential.

But we could not do this without our community partners. That would be the medical community, the educators, of course the family, and the greater community. That is how our children are going to really succeed is if we work together as a team.

Our families access our services through physician referral. What we provide is a time where we meet with our families over the phone to determine whether or not we are actually the right place for that child. Based on phone screen, we will either schedule evaluations or we will work with that family and other community partners to be able to make sure those families are not left on an island and they have to search. We help them find those services. We will refer them out. Ultimately, if they are a candidate for our services, they will be enrolled in our therapeutic programs.

These are snapshots of some of the children that we serve.

I think it is important to see the annual impact that this center makes on a given day - in a given year. On average, we receive about 3,500 physician referrals. We complete about 1,500 phone screens. We see on average 900 children in our Children's Development Center. We have provided 65,000 hours of therapy.

For our Speech Therapy Department, we see around 750 children with close to 30,000 hours of therapy. Our Occupational Therapy Department, around 200 children with 4,000 hours of therapy. In our ABA Department, 87 children, around 30,000 hours of therapy.

Around 400 children in our behavioral health services with around 80 children annually receiving ASD evaluations.

We have a school readiness program. It is our Bloom Program. It is a five day a week comprehensive program for children with autism. They receive all of our services coordinated. They are with us about eight hours a day, five days a week. We include case management. We prepare them for a school-based settings.

Then our audiology department, which is a lifespan practice, saw close to 900 patients.

What is unique about Emerge is that we know for our children with autism that - and our other children with communication challenges that are little, our families need to be able to participate in the activities that they normally would participate in in preschool in Baton Rouge. So, we set that environment, although we are a therapeutic center.

Our kids are with us half a day, five days a week, maybe two days a week. During that time, we plan these really awesome activities that we get to celebrate with our children. So, we have book fairs, sensory friendly movie days, holiday fest, grandparent's day, muffins with moms, donuts with dads. And it wouldn't be Louisiana without a Mardi Gras parade.

All of these experiential activities help our children be more successful when they go and experience this with their families. Our therapists make a therapeutic plan for each one of these activities, work with the children and the families, and then when they actually get to go to that Mardi Gras parade, they actually get to have fun and the families enjoy that time. We are really focused on the families so they can go out and be successful and enjoy that family

time with a therapeutic plan. They know they have a host of therapists behind them making sure that is going to happen.

So, as Lauren mentioned, in 2014, when we brought online the Emerge Center, we knew with this large expansion of space - we moved from 9,000 square feet to 26,000 square feet of space. We tripled our staff in a short amount of time. That meant we were tripling the early intervention services in this community. There would be more work to be done along the continuum of services for children and adults with autism.

So, we continue that work to be able to push towards advocacy. We serve on the Executive Board of the Louisiana Access for Autism Services Coalition. That is really focused on assuring that we have reasonable reimbursement rates for therapeutic services so we can provide those services.

We have appointed a Research Director at Emerge. We are currently - we currently have five research projects running at this time. In addition to that, we are collecting longitudinal data on our children that leave us that have participated in our comprehensive programs.

We work with the medical community. As a freestanding, non-profit, we can't do this work alone. So, we work with the medical community. We, last year, hosted 20 pediatric residents that rotate through our center. They spend a day with us and - a day in the life of our therapists, a day in the life of our children. That way they - when they go back and they see those patients in their offices, they are better prepared for that. Then they understand this therapeutic environment. They can learn about the referrals that need to be made.

We mentor. We mentor many university students as well as work with Fran U on that new program that was mentioned by Traci and work with our local universities on developing top notch Masters-level programs.

We continue to look at opportunities to expand. With that, we have launched the Emerge School for Autism.

The Emerge School for Autism's goal is to eventually serve, at its highest capacity, 140 children with autism. We started with 20 children.

It is the first charter school in Louisiana for children with autism. We are a Type I charter, so we work with the East Baton Rouge Parish school district.

It has a really unique position. We don't want the Emerge School to be a place for our children to stay forever. The goal of this school - it is a 100 percent special

education school - is to give the children the tools that they need so they can be successful in a general education environment. So, the 20 children that we enrolled last year, we have 7 children that will leave us and move to a general education environment. So our goal is to be able to have a therapeutically-infused educational environment where we work hand in hand with those educators and we prepare our children to leave us and to be successful in the general education environment.

Next year, we have 32 children that will be enrolled. In our debut year, we had 80 applications for only 20 spots. That speaks to the demand for this type of service in our community.

Now, as I mentioned, both the Emerge School and the Emerge Center are both 501(c)(3). This work would not be possible

without philanthropic investment. So to do this work, we have established the Emerge Foundation.

It is important because this foundation speaks to the community support. As a local non-profit, we cannot do this work without our community, through volunteer work, through philanthropic support, through leadership. So we have been really very fortunate to have this support.

Over two-thirds of our clients are on Medicaid or need some financial support. Invaluable time spent for care coordination is not reimbursed by insurance. That is what philanthropy does for us.

It should be noted that we receive 38 cents to the dollar from our reimbursement rates in Louisiana. So our Emerge Foundation works diligently because we are focused on

providing broad access to all children in our community.

Finally, it takes a village. I think you have heard that loud and clear from our group today. We can't do this work alone. This is what CAAN brings to the table for us. It allows us to know the work that is being done with the community, partner with other community organizations that are maybe doing similar work to us to broaden that network, to build that ecosystem, but also to maybe have unique collaboration with partners that we may not know. I will give you an example.

We, in Baton Rouge, last year, opened a new Children's Museum. They were really challenged with some of the children that were on the autism spectrum that were coming in and having meltdowns because their staff had never been trained. Emerge Center launched a collaboration with them where we

went in and we trained their employees and then they came and they shadowed our therapists.

Now, they have opened sensory-friendly nights. Their employees are so much more confident. That builds that network, that ecosystem gets stronger through these collaborations. CAAN is a perfect example and forum for that.

At this point, I will turn it over to Steve and he will talk about adult services.

REPRESENTATIVE FOIL: Let me also say Steve was recently appointed to a working group of the Interagency Council to study housing issues, as well. I will let Steve tell you about his work on that committee as well as what he is doing in Baton Rouge.

MR. STEPHEN WHITLOW: Good morning. You have almost made it. You are almost done. Congratulations. Sorry that you have to

listen to me last. We actually had a call to prepare for this meeting today. The only thing that was unanimous on the call is that I should go last so that everybody else would have time.

I will try to do my best to keep it brief, but we do have a lot of areas to cover. I would like to maybe shift the focus a little bit from some of the lessons that we have learned and maybe pulling the curtain back on some things that may inhibit other areas so you can overcome those obstacles. Although we have made accomplishments, there are always things in the way. There is always personal disagreements. There is always funding stream issues. There is a lot of different things that get in the way.

What I would like to do along the way is maybe point out some of those things so that if people are interested in trying to

replicate what we have done in Baton Rouge, then you might be enlightened by that. We are all here afterwards if anybody has any questions about what we have done. We would be happy to share that.

Let me tell you a little bit briefly about my personal journey so that you will understand that our journey sort of coincides with the journey of this project.

My son is currently 19. He is on the spectrum. I have a daughter who is 22, a son who is 13, and our middle son is on the spectrum. My wife and I are both attorneys. I practiced for 20 plus years. She went home when we got the diagnosis to make sure that things could be taken care of on the home front.

We were in a conference with the principal of our private school where our son was attending, which we were paying a lot of

money to. We asked what is next. He is in 9th grade. What are we going to do next? And there was sort of a shrug of the shoulders.

My wife and I, we have our qualities. One of them is that we are persistent. We would not say there is no solution. There has got to be a solution. So, on the way home, she told me - she said if there is not a transition program around, then we will start one. What she meant was you will start one.

Out of that decision, we decided that she would go back to work full-time as an attorney and I would start a part-time job as an attorney. I would look into this transition stuff. We would get it started. I would move on with my life. Right?

Well, maybe not.

One of the first official acts as we started gathering information that I did was I went to a meeting with the Baton Rouge Area

Foundation. It was also hosted by the Huey and Angelina Wilson Foundation. They brought us all together. We sat in a room like this. We had a lot of really smart people talking about ideas.

As a parent, I tell you that when Lauren said they raised their hands saying how many of you people didn't know of other people, most of the people raising their hand, if not all - it made me mad. As a parent, it made me mad because why the heck don't you people know each other and why aren't you working for me. That was an eye-opening experience for me. I didn't blame anybody, necessarily, but it was an eye-opening experience for me that as a community, in order to really assist the parents, we have to shift our focus.

We are so program-oriented that we lose sight of the families that we focus in on

because what we went through as a family - we were in the gap where we were having to hire people from out of state to do ABA services for our son just so he could behave enough to be in school - that we weren't made aware of a lot of opportunities that may have been out there just because there was no communication by and between.

So, one of the largest - the single largest outcome of our project is that we now know who to call if we have issues, we have collaborations if we have problems. We now know those people and they trust us. We can move forward together as opposed to working in silos. So, I think that is probably the biggest takeaway that I would have for all of this.

The Baton Rouge Area Foundation, the Wilson Foundation, published its report. They were nice enough to list all adult services

into one task force. They said, Steve, take care of this.

So, all we had to do as a task force was to handle transition services, housing, transportation, and employment. That is it. So, we handled that in the first three weeks and we are moving - no.

What we learned through our process - first of all, we have a committee of five people. One of my - the closest cohorts on my committee is Derrick Wesley. He works for the Baton Rouge Community College, the program that Franklin helped start for transition services. He and I have become not only good collaborators, but close friends because we have been able to talk through a lot of different issues understanding that we are competitors in the marketplace, but understanding that the supply side is big enough right now that we probably shouldn't

really worry about that. We should worry about putting our resources together to help a holistic approach for the families.

So, some people who may fit with Baton Rouge Community College's program better than mine, I will refer over to them and likewise. He will do the same thing. He understands what we are doing. We try to put the family on the right path.

The second part of that is as we were developing our programs - because we were really developing in parallel. We are both about four years old. Some of the things that they can do on a community college campus I will never be able to do as a non-profit. I will never be able to provide the type of instruction - vocational instruction they will on the community campus. But there is also flexibility that I have as a non-profit

that he doesn't have in an institutional environment.

Having those discussions about what our limitations are and where services may best fit helps to create square pegs and square holes instead of trying to put a square peg in a round hole. So, those collaborations have really been fun, challenging, and exciting. So for the transition services, we have worked together to coordinate with the school districts all the way up through adulthood.

Housing has just been something that we have started to tap into. I will explain my company's project that is on the horizon to you in just a minute. But housing we have learned is not an autism problem. It is a problem period, a special needs problem comma, an autism problem parentheses. So, we

are a much smaller part of a much larger problem.

So what we have done is we have partnered with other people, the Governor's office in the State of Louisiana has a housing project. We have coupled with them. We are reaching out to other non-profits that serve individuals that are beyond the autism spectrum to help to come up with a model that works in Louisiana. Because we may not have some of the funding streams that are available through governmental entities that are available in your states, but we do have some very generous donors that may be willing to put some resources together if we have a plan and if we are smart about it.

So we are working to expand the housing element into its own subcommittee and then create opportunities that way.

Transportation is another big issue for us. We were at the housing meeting yesterday. A lot of the transition programs said, well, they are located by public transportation. That just is not an option for us in Baton Rouge. There are very few places that are served in our area by public transportation. So we have to come up with more creative solutions.

Congressman Gary Graves' office with the Baton Rouge Area Foundation and Wilson Foundation with Franklin's leadership, we are now working on a rideshare-type grant plan. Maybe some of the dollars that are used in public transportation can be used for Uber, Lyft, and other things, where the state, federal, local government may share some of those expenses so that our guys and gals can get around a little better. So we are working on that.

Lastly, the employment piece, which everybody knows is probably the biggest nut to crack. A lot of these things that we are working on are contingent upon people having a job somewhere that is very viable for them and that fits them well.

We are working on - this has been one of the hardest struggles that I have had. Lauren can attest to this. One of the first things I said when we sat down at the table was we need an employment coalition where employers get together with non-profits. We work together. Isn't that smart? Well, apparently, it is harder to do than people would suggest.

What we have done with the employment area is that we have, again, reached out to the Governor's office, who has an Office of Disability Affairs, and tried to link with some of their efforts that we can piggyback on. What we hope to have in the long run is

another subcommittee that works just on those employment issues that we can coordinate through different needs to make sure that employment opportunities are available not only for our individuals on the spectrum, but also other special needs individuals. Also and just as importantly, that the employers are educated and know what they are getting.

One of the biggest - one of my strengths/weaknesses is I am frank. I lay it out on the table. So when we talk with employers, I will lay it on the table. I ask them what is the problem? Why aren't you hiring these people? Most of the time it is fear. They don't know what they are getting. They are afraid of being sued. They are afraid of being able to fire somebody. They are afraid of disruptions in their workplace. They are afraid of a lot of different things.

Those fears can in large part be overcome by education, but that takes time.

The other part of it is that there are some people that don't want to do this. If they don't want to do it, okay. Let's move on to the next target. But we don't know that until we have that frank conversation.

The partners that we have on our task force - the Baton Rouge Community College we have talked about, the Arc of Baton Rouge, Capital Area Transit Services, who is the public transportation, the Governor's Office for Disability Affairs, and a company called Moran Construction, who is in private construction. All of these people I had never met before we got involved in this project. All of these people now I could call on my cell phone and they would answer my call right away and help me solve a problem.

The partners that we have gained through this have been invaluable to us in developing our program. I would say that relationships in life, as we all know, are extraordinarily important. In our line of business, I think they are invaluable. I would encourage people that are willing to work with you that we take the time to foster those relationships. That is how we are going to move the mountain.

So, the lessons we learned as we moved through this process. So, the study - this little book that they have done, which is now out of date, by the way. I told Lauren on the way over here that she needs to update it because it is old. This study provided for us a common mission. A lot of times mission will overcome some obstacles. If we all understand that we are serving the same mission, then we can overcome obstacles.

From time to time, we will look back at the book and will say what are we supposed to be doing here? Are there things that we are not working on that we should be? Are these frictions that we are complaining about, are those just pebbles? Or are they really boulders? So, the common mission, understanding what we are working toward is essential in my mind. Otherwise, people are going to fracture into their own little world and stop moving together.

So, cooperation between agencies - again, I came from the legal world. I was not aware of the non-profit world before this. I really wasn't aware of the governmental world before this. Each of them are interesting and challenging and beautiful and ugly all at the same time. They all require cooperation between them because otherwise we lose sight

of the slide that was shown earlier, the family focus.

If we, as families, are left to figure out what the heck all of you all are doing and why you are doing it, then we are going to be lost in the process. That is in large part what was happening. Exceptional Lives website, the partnerships that we have created all help with that cooperation between the agencies, but it requires that we work on the same page.

I mentioned earlier that I am a bit of a frank person. I will tell you that frank discussion is required to understand the boundaries of how we can cooperate. There are certain things that we will not be able to cooperate on. Right? My now employer will not allow me to share a lot of our trade secrets with the other transition programs. I need to

talk with them about what we can share and what we can't share.

There are certain things that within our realms of existence that we are not going to be able to agree on. That is okay. We get that. In order to come to that understanding, we have to have a frank discussion about why we are here, what we are doing, and what are the boundaries of that cooperation.

If Lauren sits down with me and says I want you to work on this, but these are the restrictions, I can say yes or no. If I move forward, then I am saying yes to those restrictions. We will be able to cooperate in that regard. I will tell you that the communication by and between these groups has really been pretty good in that regard. Especially in our group, there will be times when it they say we just can't agree to that. There is going to be bigger obstacles to come

as we move forward, but understanding where we stand is a big part of that.

So, the other parts I have talked about other than the last one. The last one is sort of the biggest - my biggest pet peeve. We must be willing to challenge the status quo and seek a new something - I don't know. I guess I should have finished typing that. We need to seek a new normal.

What we are doing today - there is a reason why there is an Interagency Autism Coordinating Committee. It is because what we are doing today isn't as good as it can be. If we don't challenge that status quo, not only of ourselves, but of other people, then there is not going to be a new normal. We are going to continue to talk about these things. We will be left in the same place that we were when we got started.

As a family person, a person who has an individual on the autism spectrum, I will tell you that is not good enough. It is not good enough for us to stay where we are. There are families with resources. Franklin and I have gone through this path together. We are blessed with the resources to take care of our children. God blessed us with that opportunity. Neither one of us thinks that is good enough. The luck of the draw should not be good enough. We should be able to help all of the families that are in the same position that we are, which is why we are fighting for this. If we don't change the status quo, then it is not going to change for those families who can't necessarily help themselves.

Our little program started off as a transition program that provided what we call group skills training, which is a class-based

program that provided just general soft skills, some independent living skills, on a two-semester basis. It is all private pay, by the way. We didn't take any governmental dollars because we wanted to figure out what worked first.

We also do an independence program. We also have a t-shirt shop, which I will explain in a minute.

Our mission all the time - my staff gets tired of me saying this - is that we honor the inherent dignity of every individual that comes through our program. We may not be able to help every individual that comes to our program, but we honor their inherent dignity. We are not serving them. We are honoring them. That is something that is at the core of what we do. We are able to enrich their lives through the skills that we can provide to them, but it is all a part of

understanding who they are to us. They are our partners in this journey of life. We honor that.

We are never going to lose that core value. When we lose that core value, I am out the door. That is what it is all built upon. We want to take what we do and we want to create a community where families can benefit from all of the smart people that are around this table.

I want to point out one other thing, too. It makes me a little sad that there are not other people here at the table with us because there are so many people who have helped pull the sled along the way who work every bit as hard as us. I am sad that they are not here today, but understand that what we are is a snippet of the people that have been involved with this.

So, we started off a little non-profit. We helped these guys that you see in front of you there. That was our first class. We are so proud of them. One of them is actually still with us. He works in our shop from time to time. Love them to death. We are proud of their progress.

I mentioned earlier that what we try to do is we try to build pathways for families. We want this to be family oriented. Since I came to a big city with a subway, this is my attempt at a subway map. Everybody gets on at a different spot. What we would like to do is we would like to create different lines that go to different places. Maybe you get off one place and get on at another place.

So we have our group skills program that maybe somebody stays on for a while and then gets off at independence coaching. The one thing that goes all the way through, that

blue line, is called Gateway Ink. That is our t-shirt shop.

The idea of it is there is a path for everybody. Now, they are not going to end up at the same place. They are not going to start from the same place. The journey is going to be different for everybody. But there is a pathway for every family.

I will tell you in dealing with some of these families, they don't understand that. They don't know there is a pathway. It is up to us to help them to understand that there is a pathway for everyone.

I explained our group skills program earlier on. We - that is what we started with. Our group skills program is the basis for our transition services. The independence coaching is a one-on-one, more of a vocationally-based program. So once they have entered the soft skills training, we will

work with them one-on-one on where are you, where do you want to go, try to place them in different places that they may want to be working or volunteering. Not all of our guys and gals go to work. Maybe some of them just go have permanent volunteering gigs. That is perfectly fine.

One of the biggest assets that we can provide to our clients is the opportunity to be in the community. We heard a lot about that in the housing discussion yesterday. We bring them into different environments because often times environments are what define what jobs our guys and gals can take. We have them exposed to those environments in our programs.

Gateway Ink is a working t-shirt shop. As you are placing your t-shirt orders for your customized t-shirts, keep us in mind. We actually have a manual press. We design t-

shirts. We print t-shirts. We ship t-shirts. It is really cool because a lot of our clients have never really made anything in their life. To see them print a shirt for the first time is really a cool experience.

The idea for the t-shirt shop sprang from the idea that there are so many different levels of skillset that you can teach. You can teach computer graphics. You can teach the business side of it. You can teach folding shirts. There are different areas that you can teach.

The idea is not for them to stay in the shop and work there forever. The idea is for them to be in a real workplace environment so they can learn what it is like to be working around others and to understand what it means to take instructions from a supervisor and how to work in that regard.

The lessons that they are learning in their group skills program and their independence coaching are brought into the shop. So, if we have social anxiety issues, we will make sure they are coupled with somebody else maybe they don't know so they will work on those social anxiety issues. Whatever it is that they are learning in their individual classrooms, they will be bringing those into the shop as well.

The residential program that we are developing has led us to our new relationship with Merakey. Merakey is a national non-profit based out of Philadelphia. They do autism services, but they also do behavioral health. They do a lot of housing and behavioral health. They also do IDD work.

They were helpful to us as we grew. We needed training. They would provide us training for free. I don't know why, but they

did. If we had safety care training for a new employee, they would let us go through their training. So we developed a very good relationship with them.

In our community, we were approached by a family that had a large 10,000 square foot house that had been used for a home for unwed mothers. We had a flood in 2016. The house flooded. The other non-profit couldn't stay there. They fixed it up and they came to me and said heard what you are doing and can you use this project, this house. I was like yes. I don't know how, but we will do it. We will use it.

So I reached out to Merakey. What we developed is a transition house where the services that we provide on the ground now we will be providing in that house. There will be eight individuals that are able to live in the house, called the Cheatham House. They

will be able to live there with not 24/7, but some safety net help. Alongside of that, there will be actual training that will be going - planned for them on an individual action plan.

So that will all be part of it. We anticipate they will live there for one to two years and that we will find, hopefully, a place after that because our housing subcommittee by then will have solved all of the problems and we will have housing everywhere.

And that will be rolling out - we expect to have the first residents in September.

The Employment Coalition is what I discussed before. We have been banging around ideas for this for a while. What we have done as our program is to work with Derrick at the RCC, the Arc, and others, who do this work already, and try to create our own little

pool of employers. We are going to eventually try to create a database for available jobs and positions, create training plans for the employers, and then to identify a champion within the organization.

What a champion would be is just someone who knows our clients and would maybe know triggers and exit strategies and those sorts of things so that we don't have events that might lead to unfortunate outcomes.

These are just some of our t-shirt partners that have supported us in the very beginning. The middle guy is my son, Sam. Obviously, the most handsome guy in the picture.

I just want to close by saying that we have learned some lessons as we have moved along. We are not the same organization that I anticipated when we started Gateway Transition Center. That is because of these

guys. We have been able to identify what the marketplace looks like. We know we are not in Boston. We know we are not in New York. We don't have the same resources that everybody else has. But we do have our own assets.

We understand what is on the ground. We understand the marketplace. Through this cooperation, we have been able to invite some really smart people. Mr. Ball came down to the RCC to speak about employment issues. We have been able to utilize those different tools to understand who we should be for our community. Because of that I think we are a little bit better off than we were before.

It may appear as you get started in a collaboration like this that it is a threat to your entity because you might have to cooperate with other people. I will tell you that in the long run if you can take a few barbs along the way, your organization will

be better for it. You will be better informed. You will know your marketplace and your partners better. You will be in a better position to help your families, which is why we started this to begin with.

So, thank you all very much.

(Applause)

REPRESENTATIVE FOIL: So it says on the agenda now discussion. Dr. Gordon, how should we proceed?

DR. GORDON: Yes. We will take discussion from the members of the IACC. Any comments or questions for any of the panelists at this point?

Susan wanted to make a comment first.

DR. DANIELS: Sure. Thank you so much for sharing your work that you are doing in Baton Rouge. It was a real privilege to be able to come down to Baton Rouge and see firsthand what you are doing. I wish you could have

done a virtual tour so people could have the visual that I was able to see there.

The collaboration you have is amazing. We are glad that you can share it with our audience. Hopefully, there will be people who are listening that might reach out to you to talk about what they are doing in their communities. This can be the start of something for you to have a mutual sense of accomplishment and setting new goals.

So thank you so much.

DR. GORDON: Are there comments or questions from members of the committee?

DR. BIANCHI: I am Dr. Diana Bianchi. I am Director of the National Institute of Child Health and Human Development. I want to thank you for all of your comments and lessons learned.

I just wanted to let you know that this whole issue of transition to adulthood is a

gap area at the NIH. It is something that our institute is addressing, but all of the institutes and centers are addressing through the trans-NIH Pediatric Research Consortium. So, it is an issue for children who have congenital heart disease who now need adult care. It is an issue for people with intellectual disabilities of all kinds. So it is a big issue.

We appreciate your lived experiences because they will inform all of us as we work together. Even though we are the National Institute of Child Health, we don't fund all of child health research across the NIH. All of the institutes and centers and offices have some say in what is happening in terms of child health research.

I definitely hear your concerns. It is a big issue for all kinds of issues.

I think, being a pediatrician, myself, some of it comes from the fact that our focus has always been on survival or getting through the school years. There has been less of a focus. Now that people are doing better and living longer lives that transition is so apparent.

We certainly will be reaching out to you for further information as we try to address how we can move forward from a research perspective. What research can we do to address all kinds of issues for people with chronic conditions who are transitioning to adulthood?

Thank you very much.

DR. GORDON: Geri and then Nina.

DR. DAWSON: Thank you for a very inspiring set of talks. I think it is always so wonderful when you see so many different

kinds of people working together. As you say, that is absolutely what it takes.

I have a couple of questions. One is the issue of medical care. As you know and commented on, the prevalence of GI and seizures and other kinds of medical comorbidities that appear to impact quality of life, sometimes even more than autism. I wonder in terms of broader plans around things like medical school education, engaging the primary care providers, and just addressing that piece at a systemic level.

The other question has to do with - you know, I sense that - it is interesting being in the field so long how we are kind of following the large cohort through the lifespan. Now, we are at adulthood, transition to adulthood, and employment. One thing that really isn't talked a lot about is anticipating aging and the need for care

during the aging years that I think will be probably upon us sooner than we think.

I know with a lot of the medical issues and the lack of providers that can then treat and really know how to work with a person in autism in a medical context - I see this as sort of the next crisis that the next IACC group will be talking about.

REPRESENTATIVE FOIL: I will open it up to anyone on the panel.

DR. OLIVIER: Sure. I will give you our perspective from our little clinic. I obviously welcome any other comments from the group.

The issue of the medical care and educating those in the community has been very challenging for us. One of the things that we do quite often is work with children in their IEP teams at school, their special ed teams.

What we see so many times is a lack of education and awareness on the part of the parent as to what is available to them for specialized services and also a lack of awareness on other professionals in the field, too. The challenges I think are very great. I am not quite sure how we are going to address them all.

One of the things that we have focused on in the clinic is the education and advocacy piece as much as possible, but it is very much a bottom-up type model at this point. We are hoping to be able to bring educational advocates - I think that across our agencies and fields that is one thing that parents really need is someone that can help to navigate the special education system and bring those medical issues to awareness.

A lot of times we see that kids are being improperly classified for purposes of

special ed. There is not really a good understanding. At places like Emerge School coming and other schools like St. Lillian's, there is maybe a greater understanding. Outside of that little ecosystem, it is very challenging.

I am not quite sure what the answer is. I know it is something that we see immediately as an issue. Again, it is a bottom-up approach at this point.

MS. JUMONVILLE: I will add on the medical piece, as well, and go back a little bit to the report, which is out of date but I still like to reference it.

One of the things when we were working on it was looking at those medical comorbidities. Dr. Stephen Felix at Our Lady of the Lake was really critical on that piece and encouraging us to think about it beyond just the traditional autism care.

He has a vision in partnership with Our Lady of the Lake and particularly as this freestanding Children's Hospital is opening, for a much more coordinated system of care among all specialties that could touch someone who has autism and all of the different physicians they may see.

His ultimate goal is that you would have the pediatric neurologist, pediatric cardiologist, the GI physician, all of those different physicians coming to one place where an individual with autism and their family can come and have one full day of appointments with each of those physicians and then almost a sort of conference on what is the plan of action for that individual and then a report out to the families.

We are a long way from there. I don't mean to imply it is something we have perfected. I do think it is something that

our community is really supporting him on and working toward.

Beyond that, to your point about education of up and coming physicians and the medical schools or even just general pediatricians who are seeing these disorders and these patients in their own clinics and their patients may not necessarily be connected to the right subspecialist or entities. He has been working really hard to try and integrate in some of these learnings and collaborations that we have had with them. Again, a long way to go, but steps in the right direction I hope.

DR. DAWSON: Just to make a quick comment, my big concern is that people on the spectrum are actually not getting treated in a medical context because people don't know how to really work with a person in the exam

room or in the emergency department or whatever the context is.

Just to give you a sense, at Duke University Medical System, where we work a lot with primary care clinics, we discovered that about 50 percent of the time the pediatrician really couldn't do an exam. Could not look in the ears. Could not really complete what is a basic medical evaluation because of issues around sensory or had difficulty identifying where pain was and things like this.

We have been engaged in a quality improvement project just in primary care to help people understand how you can work with things like sensory sensitivities or understand how to evaluate pain in a person who is nonverbal and things like that.

I feel like that is still another piece that we really need to tackle that is part of

this broader system that you are building. Without that medical care, quality of life - you are just not going to do well at employment or in school or in other contexts.

MS. JUNEAU: Thank you for your comments. Something that we have done at the Emerge Center is that partnership with the pediatric residents, but also with family medicine. So the resident comes in and, as I said, stays with us, an eight-hour day. Now, it is a day, but they follow a child on the spectrum. That might be through a speech language evaluation. That might be a group speech therapy. That might be eating lunch.

We felt that we developed - that has been about five years we have been doing that. The feedback that we get from these residents are really phenomenal. One, staying a day in the life of a child, they - in their mind, you come into an exam room. You see

that family. They are able to see that child in a naturalistic environment. I think that the way we are going to move the needle on that are more programs that way, where physicians can go outside of their space and spend time in other environments where children actually are.

Having family medicine reach out to us was huge. Because with family medicine, they are likely to follow that child through adulthood.

The other thing that we have been able to do is we have established a partnership with some local dentists. At this point, we have local dentists come in. It is not dental care, but they are in the environment that the children are in. It is more dental education for the child and the family.

As we have built that partnership with local dentists, with young children, again, you stay with your dentist a long time.

My background, I worked in Head Start in a variety of backgrounds. I feel like education is the key. As we educate other disciplines, then the fear goes away. Once you are successful - because you are right, 1 in 59 children will be 1 in 59 adults. So we have to move that needle on where people are comfortable, physicians, other professionals are comfortable. A place, a center like Emerge, offers that as an opportunity for partnership.

MR. WHITLOW: I will add quickly I think the telemedicine part of it is a big deal because when you have ABAs that are working with someone and they say - one thing I have learned in this process is that - I hadn't thought about it this way, but behavior is a

language. If the ABA - whoever is working with them on the ABA doesn't know what is going on, you can do a telemedicine with a doctor and say, oh, they just changed medicines, or their tummy has been bothering them or an earache. That can inform what is being done in the clinics.

It can also inform the doctor as to what medicines may - so that telemedicine part of what Lady of the Lake is doing is a big part. They have reached out to clinics at Merakey and Emerge to help that happen.

With the aging - let me comment quickly on the aging. I think there are two phases to aging. The first is the actual person, the actual client getting older and what to do with their pathway once they get older. It has its own challenges.

The other is caregiver aging. Once the caregiver gets older, which we all do, then the world changes as well.

So there are two sort of eggs in that basket. Both of them have to be addressed. More and more we see, as an organization, people coming to us and saying mom is 70. 46-year-old son has been there forever. What are we going to do? By that time, you are like, man, I wish you would have thought about this sooner because we have a lot of routine we have to undo here.

Those are both real key issues with aging. I think that will be cropping up in the not-too-distant future that we are going to have to address head on.

DR. OLIVIER: I would just add to that as well. The literature, as far as the psychological sciences with the caregiver burden and burnout is very robust. Yes, that

will be a huge issue and something that, again, we need to focus on not just for the individuals with autism or other developmental concerns, but caring for the caregivers as well.

There will need to be public initiatives and services to be able to provide respite and care for them, as well. If they burn out, then that would be a travesty.

DR. GORDON: Thanks. Nina, did you still have a question?

DR. SCHOR: Just in follow-up of this, I wonder, particularly for Dr. Olivier, having done similar things in Rochester, New York, with the building of a new children's hospital and the creation of new services for individuals really across the lifespan - I know exactly how hard that is. I salute you for what you have done.

I am wondering how you have dealt in the construction of the new hospital with creating a physical structure that serves the unique wayfinding needs and sensory needs and so forth of not only individuals on the spectrum, but their families who may have varying degrees of involvement with similar genetic disorders and so forth. Has there been special attention in this what I assume is a general children's hospital to the needs of this community?

DR. OLIVIER: That is a very good question. I will preface it by saying that I am about a year in at the Lake. Being that the hospital is opening this year, there were many, many years of planning that went into it.

I can say that there were special considerations in terms of special areas and

sensory areas, sensory playrooms and gyms, that are being factored in.

Concerning wayfinding, that was a big initiative in terms of how the hospital - the art and things developed and the decorations and all. It is very Louisiana-themed with every floor having a different theme that relates directly to Louisiana. For example, the first floor being the Mississippi River theme. There are wayfinding animals and guides that kind of orient you to where you are in the hospital and where you need to be.

I will say that something that has come up a lot and Lauren mentioned our vision and Dr. Felix's vision being to have this - really this freestanding neurodevelopmental center. The aesthetics of that center as we move forward have really been carefully considered. We developed a building committee to look at exactly that as far as how colors

might stimulate - overstimulate or calm an individual.

Yes, the hospital, as a larger entity, is more of a general hospital. So there are some very loud, very bright colors in the hospital. That has been a focus as far as us moving forward to a neurodevelopmental center to be able to keep in line with the aesthetics of the hospital, but maybe tone some things down and add a few more elements that might help children with sensory and other specific needs.

I will tell you when we first - Dr. Felix first created the Building Committee, we thought, oh how hard could this be? We are just picking out colors and this and that. I will tell you a tremendous amount of work has gone into that.

We are only really just - have our toe in the water at this point because we are

renovating one floor. As we move further to the vision that Dr. Felix has, it will certainly be very carefully considered.

DR. GORDON: Julie. Julie Taylor.

DR. TAYLOR: Thank you all so much for being here today. I have heard so many things in your presentations that I think are just really exciting.

I think the work that you guys are doing trying to pull people together, get the right people and all of the people at the same table to collaborate, is a model for, I think, what a lot of communities should be doing.

I wanted to tell you a little bit about a program that we have going on at Vanderbilt that is tackling collaboration in a little bit of a different way that I think, hopefully, will be helpful to your group and maybe a lot of others down the road.

We are thinking about collaboration in terms of adult services, we found over and over again - and we have talked about this here, in the room - that families have an incredibly difficult time navigating the adult service system. Whether it is SSI versus vocational rehabilitation versus Medicaid versus Medicaid Waiver, it is just so hard for families to kind of work their way through and try to figure out what they need to get for their son or daughter. If they get some of this, they get less of this. If they get too much of this, they have to get this to get this. It is just really hard.

We are working on trying to help families navigate their way through the system and have a project that is funded by the National Institute of Mental Health to adapt and develop a program that really walks families through the adult service system,

helps them understand kind of what their goals might be for their son or daughter, and then how to pursue the appropriate services and supports to help support those goals.

We developed the program in Tennessee. You know the adult service system is different in every state. So, we developed a program that works pretty well in Tennessee and probably not at all any place else.

Then got funding to make this more of a national program, where we are going to have kind of an intro for each session that says no matter where you are, this is SSI. This is a Medicaid Waiver. And then each site brings in their local person to kind of talk through how that actually works in their state with guidance from our manual in terms of here are the things that are the important things to cover.

We are adapting that right now and developing it. We will be doing a trial where we will be testing it in three different states. Just to see if getting families information about services in a digestible way is enough to actually budge the needle at least a little bit, hopefully a lot a bit, in terms of service access and improving outcomes for their son or daughter.

So, more on the way, but we are really thinking hard about how do we get this information together for families and for individuals and caregivers and siblings and whoever else, to really help walk them through negotiating this complex adult services stuff.

DR. GORDON: Thanks Julie.

REPRESENTATIVE FOIL: I would like to say one thing on that as well. As a practicing attorney, I routinely helped people try to

qualify for social security disability. It is very challenging. It takes a lot of time. The fees are capped for attorneys. You really have to do it almost as pro bono work. It really is very challenging for not just children with autism, but anyone trying to get those benefits. I hope that is something that Congress will address.

DR. GORDON: Last question or comment now, Stuart Shapira.

DR. SHAPIRA: Let me echo what everyone has said about thank you so much for coming and for some very enlightening presentations today.

Briefly, I am interested in just one question related to wait times and waitlists for receiving diagnostic evaluations and getting into intervention services.

I would like to know what impact there has been if you have information on the

projects and the activities that could have impacted the waitlist and wait times for diagnosis and for intervention services. Thank you.

MS. JUNEAU: Particularly at the Emerge Center, children are between three and six months waiting for an autism evaluation. That has actually gotten better, but there is still a three to six month wait from physician referral.

DR. OLIVIER: We have a very long waitlist, unfortunately, at Our Lady of the Lake. The wait times are terrible. It can be up to a year sometimes.

We are actively addressing it across all of our services. Providers - some of the ways in which we have started to do that is a triage process much like Melissa mentioned they do at Emerge, to ensure that this is the right fit. What we were noticing is we were

taking all of these patients and then, oh, this might not be the best fit for you and having to refer out. If we could do that in a more timely manner, it helps them get services quicker and it helps free up the waitlist a bit.

Another thing that we have done is to work very closely with our Foundation to advocate for more funding as a non-profit to show them the value of adding more providers. They have been very receptive to that. The more providers that we can add, in combination with being more efficient with the entire referral/triage process, are some of the current things that we are doing. But much more work that needs to be done.

MS. JUNEAU: I would say that one of the barriers is we have a large Medicaid population. The reimbursement rate for those services are low. Therefore, the number of

providers, clinical psychologists, physicians, that can do this diagnostic work often don't accept Medicaid patients.

When you are working with broad access to all, again, you are going to have those barriers. The largest barrier would be the reimbursement for those services.

MR. WHITLOW: I know from conversations with Dr. Felix if they accept - they have active patients from all 64 of our parishes in Louisiana. There aren't services in North Louisiana comparable to what they are providing at the Lake. It is compounded for Baton Rouge because of the unavailability for the rest of the state.

It is I think as you were point out probably a national problem, but it is also acute in our area, as well, just because of the nature of the state and the population that we have.

DR. GORDON: Real quick.

MS. JUMONVILLE: I will be fast. This is not exactly the question you asked, but I think it is a model for how this collective committee has looked at waiting lists for our community.

We mentioned the Medicaid Waiver program in Louisiana. The waiting list for getting a Medicaid Waiver was 12 years long when we first published this report, which is clearly significant. If you think about someone who gets on the Medicaid Waiver and then waits 12 years, their needs have significantly changed. Sometimes people pass away on the waiting list. They will move from Louisiana.

In partnership with all of our stakeholders and with the Louisiana Department of Health, they implemented a triage system much like Emerge and Our Lady of the Lake have been doing, as well. To

date, that waiver waiting list is really almost irrelevant. If there is anyone who has urgent or emergent needs, is getting services. Each year, they are reviewing those individuals who are waiting for services to see that their position has or hasn't changed. As well as working with those who don't have urgent or emergent needs to get them the appropriate services.

So, not exactly diagnostic, but I think a good model for tackling waiting lists in an innovative way.

DR. GORDON: I want to thank the panelists and the members of the IACC. I think, you know, it is wonderful to hear about these efforts at a community basis to provide services, a real breadth of services, to the community that needs it.

I think the last question and the answers to it illustrate the need to create

more - many more of these opportunities of these community-based programs even within locales that have already started it to deal with the need there. Obviously, to replicate this around the country would do great services for our families and individuals struggling with autism.

Thanks again for presenting. I hope those who are here and those who are listening on the web can take heart at the fact that we can design programs and we need to design more of them.

We are going to take a 15 minute break. We will return here at 11:30 sharp and resume with the program.

(Whereupon, the Committee took a brief break starting at 10:50 a.m., and reconvened at 11:15 a.m.)

DR. GORDON: All right, thank you very much. As everyone is taking their seats, we

are going to resume with the program. The next item on the agenda is committee business. I will turn it over again to Dr. Daniels.

DR. DANIELS: Thank you. I can't believe this is the last Committee Business presentation for this version of the IACC. We will take you through some of the recent work that the OARC has been doing and activities of the Committee.

Just to make sure that we acknowledge the OARC staff, thank you to the OARC staff for your work on this meeting, yesterday's workshop, and all of the meetings over the past four and a half, five years for this committee.

(Applause)

We really appreciate all of the work on the administrative background, making sure our website is up to date, our social media,

the many policy documents and reports that we put out. Thank you to the staff for all of the work that you have done.

So, the first item I want to be able to share with you is that we have mentioned that the OARC has been working on an International Portfolio Analysis Report. That report will be available to you soon. We will make a public announcement about it when it comes out in the next few weeks. We want to share an update about this with you here, at the meeting, so that you can hear about the work that has been done.

So, this is the first International Portfolio Analysis Report in which we collected ASD research funding from four countries: The United States, the UK, Canada, and Australia. Our collaborators included Autistica in the UK, who have been over to present here, at IACC, the Canadian

Institutes of Health Research in Canada, and Macquarie University in Australia.

We were able to, in collaboration with these different groups, do a comparison of the portfolios of research to reveal areas of emphasis, the similarities and differences between these portfolios, and gaps across the portfolios. This analysis did foster international collaboration and identified global trends in ASD research funding. We look forward to additional countries joining us in the future as we will undertake another one in the future to try to understand better what is going on across the globe in autism.

We used the 2016 dataset because that was the one that was most easily available to us. We have been working on this for a while. The data was collected by collaborators from 34 government and private funders across the U.S., UK, Canada, and Australia. I think each

of these collaborators feel that they may be able to get additional ones in the future, but for now, 34.

In 2016, there were over 1,500 ASD research projects, totaling - we did this in U.S. dollars - \$395 million. There is a breakdown in this chart, here, of the funding in each country and the number of projects.

We went ahead and aligned the ASD research projects with the seven research priority areas in the IACC's Strategic Plan because this is a convenient framework that existed, and it really does apply across research portfolios for any country. We used that since we already have done the coding for the U.S. Each of these countries did the coding for their country's portfolios in the same framework.

All of the countries had large investments in investigating the underlying

biology of ASD as well as investigating and developing ASD treatments and interventions. You can see the distribution across.

Though there were significant differences in the sizes of each country's portfolio, the proportion of each country's portfolio devoted to each of the seven research areas was compared. Details about various research initiatives that are going on in these countries are included in the report. So the report has more details about some of the projects that they have undertaken, some of the areas where they have surveyed people in their various countries to find out what priorities needed to be set for the research portfolio.

That information will be in the written report, but here is a graphical comparison. You can kind of see how the U.S. compares to

some of the other countries in terms of where the areas of emphasis are in the portfolios.

We also will be putting all of this information into the IACC/OARC Autism Research Database, the ARD, which is available from the IACC website. We are going to have an entire new tab that will be international data. We hope to continue growing that in the future.

When the report comes out, this will also be available there. People can access it to find out more. If they want to perform their own analyses, they would be welcome to do that.

Anyway, this has been a great project and a good start to trying to understand beyond our borders what is happening in ASD research. Are there any questions about this report? Geri?

DR. DAWSON: Are the funding levels direct cost for that fiscal year?

DR. DANIELS: They are total cost, I believe.

DR. DAWSON: For that fiscal year?

DR. DANIELS: For however they define their years. It is just the way we do for the portfolio analysis. Some people use a fiscal year. Some use a calendar. We just ask them to be consistent and always do the same. We just don't want to make it administratively hard for anyone and make them change their scheme for doing it.

Yes, all of the detailed information will be on the website.

Unless there are any other questions, I will move on to just give you an update on the IACC Strategic Plan 2018-2019 Update, which I updated you on last time.

So, OARC is continuing to work on this. What we were waiting for as of the last meeting was to add summaries from the recent workshops. We had a workshop on mental health issues in May. We had a workshop yesterday on housing. So summaries of those workshops will be included here.

We did get some feedback from members of the Committee about a few additional things to add to this report. Those have been added already. We are just putting it together.

Our plan will be to distribute this draft to you by email to look at again. You have seen one draft. We did receive some feedback. And hope that we can just approve it via email.

So it will contain a summary of the Health Outcomes working group and workshops, a summary of the Housing working group and workshop, a summary of the 2016 IACC

Portfolio Analysis Report, and summary of the Autism CARES Act Report to Congress, and a summary of some of the activities you all have been doing here in the Committee. You can look forward to hearing more about that via email. OARC will take care of getting it published once the Committee has approved it.

Next, we have a few minutes to talk about the working groups. We would like to give an update on each of the working groups. We will give a little time to the chairs of our two working groups to share about their recent activities.

Just as background, on the IACC Health Outcomes Working Group, this has been a very busy working group over the last year. The IACC convened this working group on health and wellness issues for individuals with ASD. The co-chairs have been Dr. David Amaral and Dr. Julie Taylor. The scope has been health

and general wellness for people with ASD, co-occurring physical and mental health conditions, premature mortality, patient/provider interactions, practitioner training, and parental and family mental health.

Just listing some of the activities, we have had a couple of conference calls. We had two important workshops, one on physical health on September 27th of last year and one just recently, on May 21st, on mental health issues.

Meeting summaries for each workshop have been prepared. The mental health one I don't think is on the web yet but will be fairly soon. And the Working Group is working on a written document to provide an update on these issues. That is still pending. The next iteration of the IACC, if they would like to

pick up this issue again, will have a nice blueprint provided by this working group.

I would like to give a few minutes to David and Julie to share updates on the workshop and the work of the working group.

DR. TAYLOR: We had a really nice meeting in May. You may remember that we - in our first workshop, we really focused in a lot on physical health issues that were addressed and then got a lot of feedback from a lot of people on the committee that we needed to have a comparable meeting really just focused on mental health issues. So we scheduled a second meeting to really focus in on that and talked about a whole lot of issues.

We talked about depression, suicidality. We talked about anxiety, self-injurious behavior. We had a really nice section where we heard from the perspectives of autistic adults who had different mental health issues

that they had been kind of working through and parents. Then talked a bit about accessing mental health services and some of the challenges there, as well.

I think we were able to gather a lot of information, have a lot of nice discussion. Now, are beginning to work on the document to put together - are we thinking it is going to take the format of more of a policy brief? Is that what we decided? And we will have something to share by the end of September.

DR. DAVID AMARAL: Yes, just to add to that, I think in both of the sessions we heard that people on the autism spectrum are facing a number of medical challenges and mental health challenges. The end result of that is that their lifespan is actually being shortened. The data are really consistent whether it is in the United States or in Great Britain or the Scandinavian countries

or Australia that the lifespan of people on the autism spectrum is not what it would be expected to be if they didn't have autism.

I think there is a number of challenges. The foremost one is to make people more aware of some of these issues. I think - my hope for the document is that it can promulgate the notion that we have to start attending to these issues.

There are some fixes that are actually pretty straightforward. One of the causes of death in autism is drowning. Some of the papers that have been published on drowning in autism say we should be ensuring that people - young people with autism get swimming lessons. That seems something that is straightforward and pretty reasonable.

Others, I think, are going to be surprising to the general population. Suicide is a major cause of death in autism,

particularly in higher functioning people with autism and particularly in girls. To get the word out that if a person on the spectrum has suicidal ideation, suicidal thoughts, it shouldn't be pawned off to that is just because they have autism. It should be taken very seriously.

I found both days very informative. I really hope that we are going to be able to translate this to a broader audience and that we are going to be able to improve the quality of life for people on the autism spectrum.

DR. TAYLOR: Can I just say one more thing building on what David was saying? The other thing that really came through really clearly to me in those two days is that there are a lot of people who are doing really important and I think really effective work

in basically all of these areas that we are looking at.

We are getting really good ideas of what to do, what therapies work, what different programs might be effective, how do you treat these conditions. But we are really getting a block or a log jam in terms of getting that information into the hands of providers, into the hands of the people who can actually do something with it outside of people who are in sort of specific university settings or the specific researchers developing the programs.

So that is another hope that I have for the document is to really kind of pass on information or at least present it in some sort of way that we can get some of this information into the hands of the people who can actually use it more widely.

DR. AMARAL: Just to say thank you to OARC for being able to get this organized. I think they were really effective meetings and had lots of participants. The discussions were really lively. OARC kept everything under control and productive. So we really appreciate that.

DR. DANIELS: Thank you. It was a pleasure for our team to help out with these meetings. These meetings are available on archived webcasts on our website. Anyone who missed them, you can get them. You can also look at the slides from these meetings. I would definitely recommend it if you are interested in these topics.

We felt that these were very productive meetings and look forward to finishing up the document. So this is another item that we will be sharing with you via email to try to get approval of the general content. If we

get toward the September deadline, we will just make sure that it is left off at a place that OARC can finish the work and get it to publication for you even after the Committee might have sunset.

Thank you to you both for your leadership and to all of the members of the Working Group and the Committee that have weighed in on this and been participants in these activities so far. These are issues that are really important to our community. We are glad we were able to make a little bit of progress in this area.

Next, we would like to give you an update on the IACC Housing Working Group. This working group, in 2019, convened to work on housing issues for individuals with ASD. The scope has been research and best practices on housing, implementation of current federal regulations, and housing

issues faced by autistic individuals with more severe disabilities. Our chair has been Alison Singer, who is also a member of the IACC, our longest member of the IACC.

The Housing Working Group activities have included a conference call on June 20th. Really just hot off the presses, we just had a workshop yesterday all day here in this very room to talk about housing needs of people on the autism spectrum. We had a really diverse group from across the country. Very well, including even the middle of the country, which is sometimes not as included as we would like to see in the future. So I was really pleased that we were able to get some people here from many different corners of the country to share their best practices and ideas for housing and the wonderful work they are implementing that meets the needs of people across the entire spectrum.

Today, we are having a full committee discussion. We will be hearing from Alison in a minute. Our plan is for OARC to put out a workshop summary. That will come out soon.

Future work and activities may be planned by the next IACC if they would like to pick up the housing issue again, which is definitely an area that is very important to people and will not be going away anytime soon. So we look forward to having this working group provide a nice blueprint for the committee on that.

I will give Alison a few minutes to talk about the activities of the Working Group.

MS. SINGER: Thanks, Susan. I want to thank everyone who participated in yesterday's Housing workshop. I think we all found the day incredibly informative and productive. I particularly want to thank

Susan Daniels, the outstanding team at OARC, for organizing such an important event.

I think we heard yesterday very clearly that adults with autism want autonomy. They want the opportunities to make their own choices about their housing. But we also heard that we need more options for people who cannot function in places that might offer that level of autonomy.

We saw several examples at different care levels of best practices. I think we saw some very vibrant models of care. But I think we also struggled with how to scale these models to meet the growing capacity needs. We also struggled with how to pay for these residences to be built.

I think most importantly we acknowledged the fact that we don't have good data on outcomes or the drivers of good outcomes. Our discussion, as an IACC member who is not

here, David Mandell, likes to say, is based on values and not on data. So, for example, we have no data indicating that living in a home in a community is actually the best outcome. It is just a value that many people have.

So we started to create what I think is a very good list of next steps. Some of these steps are focused on research and data collection and are actually within the purview of the IACC. I am just going to summarize briefly some of the key ideas that came out of the Committee.

First, we recognize that we need a diverse set of options for our diverse population. We saw a lot of great models. We need to keep in mind that the spectrum is very broad and includes people with very severe debilitating behavioral symptoms who need a high degree of supervision and also

includes adults who may need some support, but who can otherwise function independently and who may, in fact, be harmed by overly intrusive support.

We learned that most people with autism still live in their family home and that many of their caregivers are over age 60. We need to look specifically at this population and what happens when their parents die. They are at risk of homelessness, but are currently not counted among those who are risk for homelessness.

We learned that the cost of housing, by which we mean the brick and mortar cost of housing, are relatively constant across the different models. Cost differences are based predominantly on the services and supports that are provided in the residences.

We learned that repurposing or retrofitting existing housing like low-income

housing doesn't work well for our adults because they have specific types of structural, lighting, and technology needs in order to thrive. They also benefit from a calm, destressed environment that includes quiet spaces and calming colors. These also are drivers of cost.

We learned that until someone has actually developed and operated a property, they don't really appreciate all that is required in terms of scaffolding the financing, the community policymaking, the operations issues, the legal issues, and the cost of making sure that the residence can be sustained. But we saw many good models. The feeling was that now we need to expand and replicate the successful models in other areas and start to seek funding for replication projects.

That said, we recognize that there are many differences in state laws that will make it very challenging to replicate the successful models. We need to have a better understanding of the state-by-state differences.

We spoke about challenges of housing service delivery, including the fact that direct service providers are undervalued and underpaid. Also, we discussed issues around the fact that program service providers often bundle their services forcing individuals to use their limited resources to pay for services that they don't want or need in order to get services that they do want or need.

We spoke about the fact that current regulations seem overly burdensome. Compliance with these regulations siphons

time and resources away from activities that provide actual benefit.

Finally, the recommendation that I think the IACC can respond to directly, we recognized the need to focus on outcomes and not settings. We thanked CMS for recognizing that need and changing the HCBS regulations.

But we recognized that we have no research on what is a good outcome or what are the drivers of a good outcome. Having this very fundamental data would make it much easier to affect the type of public policy changes and support new housing initiatives, including funds to build new sites and support attendance at these residences, as well as ways to increase capacity.

So the Workgroup is recommending to the IACC that research on housing outcomes and the drivers of successful outcomes be

considered for inclusion in the next iteration of the Strategic Plan.

Again, I just want to thank everyone who participated in the workshop, particularly the IACC members who participated. Geri, thank you. Samantha, thank you for your participation. I think it was a really important first step in our efforts to confront the growing housing crisis.

DR. DANIELS: Thank you. Samantha, do you have a comment?

MS. SAMANTHA CRANE: I have a couple of additions and notes to this. One thing that I - respectfully, I would disagree with some of the things that you said we learned. For example, you said that we learned that retrofitting existing housing doesn't work. We heard people who were doing - who were using existing housing and we heard people who were not using existing housing. As you

said, there is no research on this question. So I don't think we can say that we learned that. We learned that some people felt that way. We learned that other people felt differently.

Second, and I think - you know, it is true that a lot of this discussion is based on values and not research. But there is a - I don't remember - David Hume or some philosopher that I can't remember from my undergrad days said that you can't get an ought out of an is.

What I mean by that is that finding out - research can tell you what is, but research can't tell you what to value. When we talk about what we research on good housing outcomes that presumes that we know what good means. When we design research we have to decide which variables to measure. Values tell us which variables to measure.

Values can tell us that autonomy is good. We can measure which housing options increase people's autonomy. We can also measure which housing options increase safety. We can also measure which housing options are most stable. Some of these measurements are not going to be meaningful without other measurements. A really good stable housing option was Willowbrook because people never left. That is not something that we want. We don't want another Willowbrook.

So, we have to be talking about values at the same time that we talk about directions for new research. Otherwise we aren't going to know what a meaningful measurement is.

DR. DANIELS: Thank you. In follow up to the work of this working group and the take-home messages that we received in the interim between committees, we also do have federal

agencies that were present at the table yesterday and they have ongoing work that will be happening in the interim time and certainly heard what was said and will be able to consider some of the discussions that happened. Work can continue in the meantime. Then hopefully, the IACC can pick this topic back up.

MS. CRANE: Ivanova Smith was one of the self-advocates - had to leave before the end of the meeting in order to catch a plane - sent me some final thoughts that I sent along to Susan. I was wondering if we can somehow put that into the record of the meeting or consider them to be public comments or something along those lines.

DR. DANIELS: I can look into a way to do that. I don't think I can add something to the meeting that didn't happen in the

meeting. Maybe we can make it into a public comment.

MS. CRANE: Yes. Maybe turn it into a public comment. They are very long. I can't read them aloud right now.

DR. DANIELS: Thank you. Any final comments on this before we move on?

Thank you so much for a great meeting yesterday.

So, I wanted to give you a brief update on the reauthorization of the IACC. As you know, the IACC is authorized by the Autism CARES Act of 2014, currently. This Act is going to expire on September 30th, 2019. Our current IACC members will serve through that date. Your terms are set to expire on September 30th.

The next steps that we have coming up are when reauthorizing legislation is passed by Congress and signed by the President, the

Secretary of HHS will issue a call for nominations for new committee members. This will come out through the OARC. We will issue that call for nominations through our office.

This call for nominations will be posted in the Federal Register and on the IACC website. We will use email and social media, et cetera, to make sure that it goes out to individuals that are interested in this. So if you are interested in making sure you receive that call for nominations and you are not on our mailing list now, go to our website. There is a place where you can sign up to get on the mailing list and get yourself on the mailing list.

The current draft legislation limits individuals, the public members, to two terms of the committee, which is something that would be new. We know that anyone who served two terms already will not be eligible if

that legislation in its current form goes through.

Nominations will be considered and approved by the HHS Secretary and a new committee will be convened.

So, giving you an update on legislations. The Health Subcommittee of the House Energy and Commerce Committee held a hearing to discuss the reauthorization of the Autism CARES Act on June 25th. You can get to the video of that hearing through the IACC website. It is currently on our carousel. We provided the weblink here.

There have also been a couple of markup sessions. The Health Subcommittee of the House Energy and Commerce Committee voted to send the bill to the full Energy and Commerce Committee. Then on July 17th, the full committee passed the bill with some amendments.

As of today, this afternoon, we are expecting the full House is going to consider the bill. There will be some activity on the House floor. Some of you that have your phones - unfortunately, we don't really have time to livestream that into the meeting because we have a lot of things scheduled. Maybe you will be watching on your phones. I think it is supposed to be around 2:30. Maybe we can make sure that staff are also watching. We can know what happens with that.

We will put links to the video on the website, as well. We have links to everything through the website to keep you up to date on this.

Are there any questions about any of that? Everything is going very smoothly. We hope that we will see that the committee is reauthorized and will be able to enter a new cycle in the future.

I wanted to also share with you some of the accomplishments of the IACC. I notice that it is noon, so I am not going to take up a lot of time, but wanted to commend you all for the amazing work that you have done in the past five years.

I know the committee really started meeting in 2015, so four years, but it has been a lot that you have accomplished in terms of getting the very comprehensive update of the Strategic Plan published in 2017. We are working on the next update that will be published soon covering a couple of years. We have done four Portfolio Analysis Reports, covering six years of funding data, one International Portfolio Analysis Report that is going to be coming out, and five Summary of Advances reports detailing advances in science and services research.

In terms of your activities, we have held 15 full committee meetings, 9 IACC working groups with 24 working group phone calls and 3 full-day workshops. So, this is really a lot. You have had a lot of dedication to be present for all of these things.

Just a listing of some of the topics that we have addressed in the past several years. We have done screening and diagnosis, biomarkers, physical and mental health conditions, women and girls with ASD, self-injurious behaviors and aggression, genetic and environmental risk factors, treatments and interventions, patient-provider interactions, youth and adult services, transition-age youth and young adults, employment, wandering, housing, adult treatments, premature mortality, suicide, ASD surveillance, data banks, federal program

updates, advocacy updates, and we have had updates on various areas of legislation, including financial planning and Kevin and Avonte's Law.

We have covered a lot. There have been some wonderful new activities that have spawned from some of this internally. Although it is sometimes hard to feel like you have discussions and you don't always see those outcomes, the outcomes do come. It takes a little while to take all of the information in and see programs realign and new ideas form, but these things do happen. We have seen them happen over the past decade and plan to continue fostering that type of work.

Thank you for your many suggestions, your participation, recommendation of speakers, and to the community for contributing through public comment and other

means. So to the IACC members, thank you so much for your service.

With that - and this is just a listing of everybody. We will be breaking for lunch. For lunch, we have the Olive's restaurant that is here in the building. That is probably your easiest bet, but there is a Safeway grocery store directly across the street and a few places you can walk to, but crossing Rockville Pike is a little bit iffy. So, be careful. We don't want any adverse events happening with this meeting.

You can go out to lunch and then reconvene at one o'clock. We will be doing public comment.

Any final comments, Josh?

DR. GORDON: See you all at one o'clock.

(Whereupon, the Committee recessed for lunch at 12:05 p.m. and reconvened at 1:00 p.m.)

DR. GORDON: Good afternoon. Thank you everyone for coming back promptly from lunch. I hope you all had a nutritious one. We have an exciting afternoon. As usual we are going to start with the public comment. We had two individuals sign up for oral comments. We have as usual, a number of written comments and we will also be synthesizing and presenting comments that were received through the internet for the live feedback comments that happen along the way.

All of the written comments are in the materials that you received prior to the meeting and are in your folders. They are there but they will be summarized by Dr. Oni Celestin later in the process.

So with no - oh, and has been our practice, we will hear all the comments, the oral ones, the summary of the written comments and the summary of the live feedback

comments, then we will have a discussion amongst the Committee so that we can process and respond to any of the comments that were mentioned at that point.

So with no further ado, I would like to ask our first oral commenter to come to the podium. James Williams. Again, as our practice, we have a timer. You will be given five minutes, at which point I am afraid I am going to have to ask you to come to a close if you go beyond that.

MR. JAMES WILLIAMS: Thank you very much. I would like to thank IACC for giving me this opportunity. I also want to let IACC know that the written comment I submitted was intentionally longer, and that was meant to be a separation from my oral and written comments so that things I cannot say within the time limit can be shared within that comment.

I am here to talk today about an issue that is not the same in every state or area, but is an issue that affects many adults with autism, and that is common misconceptions about the relationship that many people with autism have related to disability benefits.

Lots of adults with autism in many parts of America rely on disability benefits as their main source of income. And a lot of people sometimes wonder why that is and then sometimes wonder why an adult would choose that over employment.

Today I am going to talk about some observations that I have - have had as a traveling autism advocate, about some of the reasons why people with autism may choose that path and the importance of understanding those reasons.

It is also important to understand that states have difference services and treat

their residents with autism differently. In some states having disability benefits is a prerequisite for getting other essential services.

I have many adult friends with autism who rely on certain therapies; medical treatments, and access to health care. In those states they are told, if you want this treatment you must be on SSI or SSDI or we are not even going to let you have a foot in the door.

I know people who have sacrificed employment in order to get those benefits to get those services. In addition, the cost of living is not the same in every part of America. Some places are more expensive than others.

Anecdotal evidence has shown that in many cases we call it underemployment - jobs that tend to employ people with autism and

retain them, tend to be relatively low paying. In some places a person with autism can't support themselves on a full-time job and have to go on disability benefits to be eligible for low-income or HUD housing and other things, to make sure they can afford to support themselves.

In some high-cost parts of the country I have gone to, full-time employed adults have to live at home, in their family home, while their peers, other adults with disability on disability benefits, are living independently. In some cases, the cost of living can be twice for a person not on disability benefits versus a person on benefits.

Here is a case in point from a state that I will not say or name I will not name for privacy reasons. An adult with autism worked full-time for 10 years. She earned

\$1,000 a month after taxes before she was on benefits. Her rent was \$500 a month. She also paid for utilities, car insurance, in the most dangerous part of her city, she feared for her safety. Her house was very poorly maintained. She got fired when the company she worked for went under new management. She then fought to get disability benefits. When it turned out that the only reason she had that job for 10 years was due to accommodations that no other employer was willing to give her. Not even a local autism agency.

She is on benefits now. She is now in HUD housing. Her rent is \$333 a month, that includes utilities. She is in the safest part of her neighborhood and her community. She no longer fears for her safety. She has people assisting her and maintaining the cleanliness

of her living space and the part of the duplex she is renting.

In short, her standard of living is higher not working on disability than working. This is a reality many adults with autism face. Before we start calling adults with autism system gamers or lazy because they are on benefits, lets pay attention, IACC, to the actual realities they are facing in their communities. It may be one of the few ways they had to survive living independently was being on disability benefits.

Thank you very much for this consideration and have an amazing rest of your meeting.

(Applause)

DR. GORDON: Thank you Mr. Williams. We appreciate the comments. There will be an

opportunity to discuss them later in the public comment session.

Next we have Dr. Eileen Nicole Simon.

DR. EILEEN NICOLE SIMON: MIT students recently requested suggestions for things to put into a time capsule to be opened in 200 years. I suggested an umbilical cord clamp be placed in this time capsule.

In 200 years hopefully no one would use a clamp to stop blood-flow from the placenta before a newborn baby has begun breathing.

Clamps came into use after anesthesia made surgery possible. The first midwifery clamp was described in 1899, with instructions to wait for pulsations of the umbilical cord to stop. However, by the 1930s umbilical cord blood was collected for transfusions.

In the 1970s fear of jaundice led to clamping the umbilical cord as soon as

possible after birth. But it had already been demonstrated that bilirubin only crosses the blood-brain barrier following a period of oxygen insufficiency.

By the mid-1980s, immediate clamping of the cord was mandated, and taught in textbooks. The autism epidemic soon followed.

Oxygen insufficiency at birth is often recorded in medical records of autistic children. The brainstem auditory pathway was damaged in monkeys subjected to asphyxia at birth. Could this lead to language learning difficulties in human children?

Blood-flow from the placenta should be allowed to continue until the baby begins breathing. Placental blood-flow stops after the lungs take on the function of respiration. This knowledge is now available on the internet to everyone.

More and more parents are requesting that no clamp be used following birth of their child. Pulsations of the cord stop after the lungs take on the function of respiration. The cord then becomes white and can easily be cut with no loss of blood.

DR. GORDON: Thank you Dr. Simon.

(Applause)

DR. GORDON: We have no other preregistered public oral comments and so we will now hear a summary of the written comments from Dr. Celestin.

DR. ONI CELESTIN: Good afternoon. Since the April full committee meeting the IACC has received written public comments from six commenters. The committee has been provided the comments in full, but they will be summarized briefly here.

Mr. Yuval Levental urges the committee to research the use of probiotics as a treatment for high functioning autism.

Ms. Donna Young expressed concern about the practice of maternity active management during labor and early umbilical cord clamping. She believes that this practice puts babies at risk and may be a cause of autism.

Dr. Eileen Nicole Simon wrote about the experience of her adult autistic son and urged the committee to provide employment services for those with high functioning autism.

She also wrote about the possible roles of metabolic disorders, brain injuries at birth, language disorders, and hearing disorders in ASD. She requests that the committee discuss her comments.

Finally, Dr. Simon submitted a summary of a grant proposal she has written and asks for advice on getting it funded.

Mr. John Mitchell expressed concern about previous comments at an IACC meeting regarding wandering behavior in autistic people.

Ms. Jane McCready believes that, given the heterogeneity of ASD, autistic people can only speak for themselves and their own experiences. She requests that the committee continue to include parents of autistic individuals who are unable to advocate for themselves, as well as self-advocates. She believes that this will be vital in order to increase the representation of more severely impacted individuals in autism research.

Ms. Colby Blakesley wrote about her experience with autistic son. She expressed that he needs more structured activities and

one on one activities, as well as a sensory diet.

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

DR. GORDON: Susan, do we have any live feedback comments?

DR. DANIELS: No, we did not receive any live feedback comments for this session.

DR. GORDON: I don't know if it is about the summer meeting but many, many fewer public comments than we have had in the past. Usually it is a book sized document. It must be that people are away enjoying the heat, I suppose.

Nonetheless, I think this will give us an opportunity to comment and discuss on the comments that were presented.

If anyone from the committee would like to start us off.

MS. CRANE: I just wanted to just acknowledge what James Williams was saying at public comment today because I think it is a very important point and it is something that came up in the Housing workshop as well. Which is that without access to benefits, autistic people have a much harder time accessing housing and affording housing and accessing the supports that we need in order to stay in the community.

We were hearing in the Housing workshop about how many people are waiting for years on waiver waiting lists or aren't eligible for waivers at all because they exclude a large segment of the autistic community in the criteria for applying for a waiver.

I think we really just - all of our conversations about what services are useful and what housing options are useful, are not going to be very productive unless we make

sure that people actually have access to the benefits that make these supports available.

I think we also need to really think about the disincentives that our benefit structure creates for people who want to be employed and want to have meaningful work but because states have not set up buy-in programs or waivers that accommodate people of different incomes, people feel the need to go on SSI and limit their work activity in order to get access to these important supports.

DR. GORDON: Geri.

DR. DAWSON: I want to follow up on James' comments as well. We have heard this again and again and again and again, that there is this catch-22. I see it every day at our people in our clinic and so forth. And we know how important work is. So Julie's work has shown that work is one of the ways that

people, of course, feel productive and engaged in the community, have social relationships. All those things that are so important for quality of life.

I don't know whether the next IACC, since this may be my last statement I will try and have a little forward impact here, but you know whether the next impact could actually - I know this is more of a state level issue, but somehow this seems like low-hanging fruit that we not put people in a situation where they are unable to work in order to get very basic benefits.

That has to be solvable.

DR. GORDON: Often these things are solved by appealing to the nature of those who might impose it. So individuals, politicians, policy makers, who might oppose changing it, would be concerned about the cost of expanding access to disability-

associated benefits. But one might imagine, that actually there would be considerable costs savings if people were allowed to work and receive reduced benefits then you would get people off the disability rolls.

I just wonder if there are any comparative data from states - it sounds like there is variance from state to state. I wonder if there are comparative data that we may be able to compile and emphasize that would allow policymakers to understand the implications of changing policy.

Anyone have any answers to that? I see - yeah.

DR. JOHNSON: At the Administration for Community Living we have been doing quite a bit of work in the area of employment of people with disabilities, including people with intellectual and developmental disabilities. A lot of the barriers are

around policy issues. So we have various efforts going on to address those policy issues. Some of it focused on efforts at the state level.

We have what are called, Partnerships For Employment Systems Change Grants. We have had these grants in 14 states, that are designed to bring different state entities together to address some of the policy barriers that are in the way.

Also, the reauthorization of the Workforce in Innovation and Opportunity Act in 2014, helped to facilitate some changes that could be made at the federal level to get around some of these issues. We work with different federal partners on some of those issues. I see that Scott is here in the audience from the Office of Disability Employment Policy in the Department of Labor. They have been doing a lot of work in this

area as well, working with states to address some of those policy issues.

But sort some of it also rests in CMS, and again, they have been working on it as well. Our current leadership at ACL has formed an interagency or cross-agency employment task force, to continue to work on this issue in this administration. So, it is a very complicated issue but a lot of it is around some of the policy barriers that exist with the state and the federal level.

DR. GORDON: So we are asking -

DR. JOHNSON: One other thing that I would add is that we do have different investments that are collecting data and analyzing employment rates for people with disabilities. My particular office funds a longitudinal study looking at employment rates. We haven't seen a lot of changes in those employment rates but some of the data

is starting to go up, and we are thinking it is because of the changes in WIOA.

DR. GORDON: It would be interesting to look at that state by state, depending upon state policies with regard to maintenance of benefits.

DR. JOHNSON: And that is what our research does - it looks state by state.

DR. GORDON: Very good. Scott is from the Department of Labor. He is going to be talking later about a Department of Labor initiative, but I am wondering if you have any comments that are germane to this discussion.

DR. ROBERTSON: Sure. I would have mentioned during my presentation, but I can share now is that we would be happy to share any resource information that would be helpful for the committee. We have a lot of data obviously on the employment sphere, and

that is something that we have lots of concerns about folks as far as being able to maintain benefits and have work incentives to support that. So we do a lot of active collaborations with the Social Security Administration, our federal partners over at ACL, and other agencies in this space.

We also for instance, for folks being able to return to work and stay at work, have lots of initiatives that are going on in that area, too.

Did you --

DR. GORDON: No, I was going to say it sounds like there are efforts at the federal level to try to broaden eligibility. I recognize that I can't request of my fellow federal employees that they lobby legislatures at the state or national level, but I am wondering if you can provide any guidance to advocates, self-advocates,

individuals, about how to try to convince states to use these methods that you are all working on that they can work on in the local or state level, to try to maximize utilization of the kinds of things that you are doing?

DR. ROBERTSON: Yes, and the other thing I can also say about the state and local level is that ODEP supports something called the State Exchange on Employment and Disability. We have shared this information also with our federal partners before, which collaborates through intermediate organizations like the National Governor's Association, the Council of State Governors - sorry, the Council of State Governments, and the NCSL, the National Council of State Legislatures. We don't mandate. We provide a sort of more technical assistance collaboration on policy change.

For instance, they put out a report a couple of years ago called, Work Matters. Then have been helping some of the efforts in the states, for instance, Kentucky, and some others have been very active in forming task force for this effort.

I could share more information with the committee, maybe if that would be helpful, and any other resources in this area around work incentives, and I know that - I think the Congress - that legislation, I think, proposes I think, to add us potentially as potentially you know, a member on maybe the committee in the future. So maybe there would be more employment engagement in the future for instance, if Labor were ever to join on IACC.

DR. GORDON: I think ACL was a recent addition, as well, to the IACC now.

DR. JOHNSON: We have always - my office, Administration on Intellectual and Developmental Disabilities, has always been a member of the IACC. We were under the Administration for Children and Families. So we were representing ACF when ACL was created.

Just to add to your point about resources in the states, we do fund a number of grant programs in the states. One of which are State Councils on Developmental Disabilities. They are required to have as members of the council, individuals with lived experiences. That can include people with autism spectrum disorder.

A lot of what they do is around educating policymakers and building the self-advocacy skills of people with lived experiences. A lot of them work on the issue of employment and are working towards to

changing policies in this state. For example, establishing employment first policies in the states. That is a resource that is available out in each state and territory.

We also fund what is called, Self Advocacy Resource and Technical Assistance Center. They recently published employment toolkit for self-advocates. So that is another resource for folks to have.

DR. GORDON: This is really helpful to hear about and really appreciate, Mr. Williams, you bringing this issue up before the IACC. I think we will certainly look at as we anticipate a next IACC meeting, further discussion and perhaps some resource development on our end.

Hopefully those of you who are working for advocacy organizations on a local basis will be hearing this and thinking about ways

that you might take advantage of these resources to try to encourage policy change.

Are there other comments or questions regarding Mr. Williams' public comment or other public comments?

I will just for a moment, respond to Dr. Simon's comments. There are really two aspects that she commented on. One was for the housing, which was interesting. It was a suggestion to work with a hotel chain to develop a combined employment/housing initiative. I think that was a really fascinating suggestion.

I think the one today, dealt with a specific hypothesis about a potential contributor to autism risk which involves the potential for asphyxia at birth, which is a risk factor for a number of CNS disturbances, including autism, to cause damage to the brain stem systems that are important for

proper hearing and expression of language. And it is an interesting hypothesis, one that Dr. Simon has raised in past comments as well.

In direct response to the question that Dr. Simon has asked, which is how might we get funding for this? The response is relatively straightforward, we have many, many more hypotheses, as I have said to this group, then we can possibly explore scientifically. What we do to try to figure out which ones to pursue is to have rigorous grant applications be submitted to the NIMH, typically done by individuals with experience designing experiments and running them. Those are vetted first by an external peer review panel. Then those applications are considered by NIMH staff, recommended to me, and on advice of a similar FACA group like this, a

council that I have, we decide which ones to fund.

I am not personally aware of the evidence that would be in support of the hypothesis that Dr. Simon has brought together, although she did provide a compendium of it in the written comments. I think a lot of the evidence that she cites is unfortunately, like most hypotheses that haven't yet been explored, circumstantial. I am not sure that I am qualified to decide whether it is worthy of further review.

But we would certainly encourage applications with regard to exploring this and other hypotheses to be put through the normal peer review system.

Are there any other comments on either the written comments that were submitted or the oral comments?

In reading one of the written comments, by Mr. John Mitchell, that was directed at one of our members, I just want to say - I won't mention the details of it, but to my mind this particular comment, which objects to some comments that Samantha Crane made at the IACC is misguided and incorrect in representing Ms. Crane's experience, experiences, I should say, and also her opinions. So I would just want it entered into the record that I disagree with this comment and I think that Ms. Crane has been an exemplary representative of the perspective of individuals with autism across the spectrum of severity and that she has discussed the issue of wandering, which was specifically mentioned in this comment, as well as many other issues with a unique perspective and an important perspective. It

has been valuable to hear from for this committee.

Louis Reichardt.

DR. REICHARDT: I completely support the gist of your statement.

DR. GORDON: Well, we are ahead of schedule. We will take a few minutes to set up but if the panel is ready. I think everyone is here from the panel and ready. I suggest that we start it early so that we can give it plenty of time for discussion.

So our afternoon panel presentation is on Racial and Ethnic Disparities in Autism. We have heard already today about geographical disparities. Now we are going to be focusing on racial and ethnic disparities.

This panel is a distinguished panel of academicians and advocates and community members from really around the country. I am very pleased to be able to introduce it. I

will mention in advance each of the members and then introduce each in turn as they talk. Each one will have approximately 15 minutes to give their presentation and then we have reserved approximately a half-an-hour at the conclusion for a common discussion.

The panel members are Dr. Sandy - and I mispronounce any of your names - Magaña. Professor in Autism and Neurodevelopmental Disabilities at the Steve Hicks School of Social Work. Coming to us from the University of Texas at Austin. She will be discussing Detecting, Understanding, and Addressing Racial and Ethnic Disparities Among Children with ASD.

Dr. Magaña, please, come to the podium.

DR. DANIELS: Yes, the panel can go ahead and have a seat at the table up front. You are welcome to present either from the podium

or from the table. Whichever you feel more comfortable with.

DR. GORDON: Okay, then I will introduce each of them as they take their seats.

The next after Dr. Magaña will be Dr. Temple Lovelace, Associate Professor of Special Education at Duquesne University. Dr. Sarah Dababnah, Assistant Professor at the University of Maryland, Baltimore. Camille Proctor, founder of The Color of Autism Foundation and founding member of the National African American Autism Community Network. Matiana Ovalle from Grupo Salto in Chicago, Illinois. And José Luis Ovalle, regional coordinator for the Salto group, and then finally Yetta Myrick, who has been an invited public comment. President and Founder, DC Autism Parents.

So with that panel again, Dr. Magaña will be the first to present on Detecting,

Understanding, and Addressing Racial and Ethnic Disparities Among Children with ASD.

DR. SANDY MAGAÑA: Great. Can you hear me okay or should I move this closer?

DR. GORDON: A little closer would be good.

DR. MAGAÑA: Okay, that is probably better. So thank you so much for having us come up and having this topic as part of the committee. I do hope that this topic comes up a lot more. We have already been discussing together how we really need to have this even a focus of this, of this committee.

I am going to be present more of the research, mainly focusing on a lot of the research I have done, but some overview of other research as well. First, I want to give a little definition about what is health disparities and health equity. What do we mean by those things? Then why is it - then I

would like to talk about the actual disparities in the research in terms of diagnosis and services among children with autism spectrum disorder and then get a little bit into the reasons for disparities. Although the rest of the panel is really going to get into that much more in depth. I think that really requires some in depth thinking. And they will talk about an intervention that I have been working on to focus on reducing disparities and some other ideas for that in future research from my perspective.

So what are health disparities, and we have been talking about disparities in terms of geographic areas, right. Health People 2020 defines it as being a health difference that is closely linked with economic, social, or environmental - that should be disadvantage. I think that is really

important because we are not just talking about a difference, right, so this person has a different health than that person or this group has different health outcomes than that group. But it really has to do with group that are already disadvantaged in terms of being systematically discriminated against or social and economic obstacles you know, could be based on any of these types of identity issues. So that is really the key. The idea that it is historically linked to discrimination or exclusion. I think that is an important thing to keep in mind.

We talk about health equity. A lot of times people sort of equate those two terms, health disparity/health equity. Health equity is really about reducing and eliminating disparities, right, so we want to make sure that everybody is getting equal health treatment. So we are really striving for the

highest standard of health for everyone and giving special attention to the needs that are especially are vulnerable or who are especially, experiencing disparities because of the socioeconomic and other kinds of disadvantages. Really putting special attention there.

And then those two terms are really linked, right, because health disparities are where you are really documenting the problem and sort of the metric of the issue. And then equity is where you are really fighting for social justice or trying to make those changes.

I am going to move on into why are disparities important in autism. We do know that first of all, autism - I mean disability is a disparity category, right. So if you compare people with disabilities to people who don't have disabilities there are

differences based on the experiences that people with disabilities face.

Now when we are talking about autism diagnosis treatment and services, we had such a great panel this morning that talked about how hard it is for families to access diagnosis and treatment across the lifespan and how we are not even there yet in terms of really providing those services in every community. So that is true.

But then you also have to consider that if you look by race and ethnicity, and that is what we are focusing on today, many families from different racial and ethnic groups cannot even access the basic services that were discussed today or may not be eligible, may not have the insurance to pay for it. And so it is even more severe for people from different racial and ethnic

backgrounds and socioeconomic backgrounds, as well.

It is really important, you know, this field is new. We are discovering new things. We are showing evidence of certain treatments that are effective for children and adults with autism. We need to make sure that everybody can get those. That is what we are talking about in terms of why it is important for autism.

So I just want to give a framework in terms of how - sort of guides my research when I am thinking about research on disparities. This comes from Kilbourne, you know, in the general health disparities field.

So you have the category of detecting. I am going to be sharing some research on detecting so you are really defining who are the vulnerable populations. You are measuring

those differences in the populations. You get to understanding and that is where you are really identifying what are the reasons for those disparities that we just discovered.

So what are the social determinants of health? What are the barriers? Understanding each individual community, too, in more depth. I think we will get a lot of that from this panel is going to be - is really a key part of understanding.

Also just looking at individual provider and community and macro levels as well, for understanding. And the same thing for reducing when we are talking about addressing disparities or trying to reduce disparities. We can look at the parent and the family and individual level, but we also need to look at community level and policy. We have heard some discussion about policy today. So I will talk a little about that.

So now I am going to move into some of the research that is out there about disparities. So people here are very familiar with the ADDM Network CDC Study. This is just data from the latest round. We are looking at what is called prevalence, but I would not call it prevalence because it is really about documenting in health and education records whether the person/child has autism or symptoms of autism. So we can see that there are disparities in that documentation.

If we had a chart over time, you would see that African American and Latino kids had big differences in terms of detecting autism at the beginning, and then that continued where the current one shows African Americans being a little closer, that gap being narrowed, in the overall data. But we do know that these data are based on different states and so some states do show disparities

between African American and white children on detection and others don't.

Latinos tend to be consistently undercounted in terms of autism. If you looked at that time chart that I don't have, you would see that, that it consistently is.

Asian Americans, too, I think some of the states did show disparities for them versus others. That tends to be a very small population. We are going to talk a little more probably about Asian Americans and how they are left out this disparity story sometimes just because of numbers and large data sets.

There have been several studies, too, with CDC data showing different things like that African American/Latino children tend to be diagnosed with something first, then autism, it creates a later diagnosis. Having that later diagnosis is an issue. That has

been found in other research by David Mandell and others.

Also the fact that Latino and African American children have a higher proportion in kids that are in the ADDMs study that have intellectual disability. That does not mean that African American and Latino children are more likely to have intellectual disability than white children with autism, but it means that the ones that are captured in this data do. So they are probably more likely to get diagnosed if they have an intellectual disability. Could be one theory of what is going on there.

So there is a lot of research based on the ADDM study that we can look at.

I am going to move on to some of the research that I have done with my colleagues, Susan Parish and others. We looked at the National Survey of Children with Special

Healthcare Needs. This particular study we compared white to Latino children on access and utilization of health care. So we are talking about general healthcare. I know there was a discussion about that - how health care providers don't know how to treat children with autism. When you break it down by race and ethnicity, it is even worse for children from minority backgrounds.

So we see here, this is 2006 pre-ACA, but that children were less likely to have access to insurance if they were Latino and they were less likely to have a usual source of care. And we know how important that is for health care.

They also were more likely to have difficulty using services and had problems getting referrals. There have been other studies show that, even by pediatricians themselves saying that they were less likely

to refer Latino children for diagnosis. A study by Katie Zuckerman showed that.

This is another study where we looked at - we looked at the 2006 and the 2010 data from that survey and we were looking at quality. Quality questions were things like does a provider listen to the parent. Is the provider sensitive to family values, and so on. In the 2006 data we found significant disparities between white and black and white and Latino children. Then we looked again in 2010 and thought, hey, there has been a lot of policies out there. A lot of statements saying we need to reduce disparities. Did that make any difference? So looking at the 2010 data we found no, actually the same disparities are there. So you can see that the white children, the parents were more likely to report better quality versus the African American Latino children.

That is the health care. Then when you get down to specialty services - so we are talking about evidence-based treatments. A lot of folks in this room are doing or helping to fund research that shows evidence in terms of outcomes for kids. ABA is a big one that is very well established. So we know that Latino and black children are less likely to access ABA or other evidence-based treatments. There is some research showing that. We do need more research in this category I would say.

A study that we did showed that you know you would think that if you have a greater need for services, if a child has a greater need, they would be getting more services. We looked at the Pathways data and that showed that in general that was true. But when you looked at Latino children compared to white, Latino were not getting more services if the

needs were more severe. So you have those issues and then fewer therapy hours and more unmet therapy needs, there are some other studies that have been found. Again, I do think in this whole category we need a lot more research.

I am just going to talk briefly about understanding - because I know my panel is going to focus a little bit on this - but these are just the buckets that I came up with. Other people may categorize them differently. Certainly, cultural competence training and using tools that are culturally adapted is an important area.

I have the category of limited social capital of low income and racial and ethnic groups. We can also think about cultural issues, which a lot of it does base on their social capital as well. I think we will hear a lot from studies today about that.

And policy barriers, I mean we did hear earlier talk about Medicaid being low reimbursable for services. Some states Medicaid does not pay for ABA. That is a huge struggle. Once states do start paying for ABA, there is the reimbursement issue. So those are policy issues that create and contribute to disparities.

So I am going to talk real briefly about this study that I worked on, looking at the autism diagnostic interview schedule. So we know that there are a couple of instruments have been sort of established as school standard. ADOS, of course, is very key. It is ideal if you can use the ADI-R and the ADOS. Although many clinics don't use the ADI-R just because of how long it takes to do it, but they might use some version of the questions.

The ADI-R has been translated into 17 languages but never validated for that different culture. It is just direct translation.

These are just some studies that were done in different countries so you can see there is some variability in terms of the sensitivity and specificity of the ADI-R.

The top row is the initial validation study that was done in the United States. Japan seems to work really well there. Some variation with Greece and Finland. So those are the only studies that I have found so far. There might be some others out there.

So we were really interested in looking at Spanish-speaking families in the United States. So we did a study with Spanish-speaking Latino families. We used the Spanish version of the instrument that is available through the service that sells the

instrument. And so we had 40 - excuse me, 29 parents who had a child with autism - yeah, that had a child with autism, and then 21 had a child with other developmental disabilities. So we kind of modeled it after the original validation study that Cathy Lord did.

We can see with the demographics here that the average age of parents was around 40. These parents were majority foreign-born, over 95 percent foreign-born. Their English language was limited. The children in the study were average age about nine. You can see the levels of intellectual disability. An interesting thing to point out is that the majority of them were born in the United States. So they are US citizens - we are having this whole conversation about this whole immigration thing right now in the country.

So these are the results and this is based on DSM-IV categorization. I will talk a little bit about DSM-V. What we can see is that there was significant differences in some of these domains between the autism and the DD group, especially social reciprocity and restrictive repetitive behaviors, but not in the communication domains. I am going to talk a little more about that, why that is.

We see the sensitivity and specificity, if you compare, at the bottom you see the original study, 96 and 92. Ours was 69 and 76. So much lower sensitivity and specificity. Of course, we want to know why - talked a little more about that.

We did look at the DSM-V. So there are the two general categories there, the social communication and restrictive repetitive behaviors, and it did distinguish in those two groups a little bit. Strongly,

significantly. We found that the sensitivity was higher with the DSM-V. Specificity was a little lower. So meaning that children that have autism were more likely to be included in the diagnosis using the DSM-V than they were for the DSM-IV, which may contradict some of the research that is out there about that.

So just thinking about why, why some of these differences - I mean, we needed a lot more research on this topic, actually. I do have a student who was funded by INSAR to come work with me this summer and she is doing a lot. She is taking some of our data, some of our videos, and trying to figure out which questions are really not working well with these Spanish-speaking families. She is going to be doing some cognitive interviews. And so we will get into more of the why.

The language issue is a big one because especially with the DSM-IV, a lot of times the Spanish-speaking parents, if the child spoke more English than Spanish, the Spanish-speaking parents did not know the level of the language of their child. And so I think that is an interesting take-home for clinicians to think about you know if you are asking a parent report about the language capabilities of the child, they may not know accurately that information.

So I am going to move on. I am moving quickly through this so we can have time for everyone. But talking about addressing disparities. I mean there are different levels, right, that you could do. One is culturally-tailored interventions that help to reduce disparities, right. That could either be like taking existing evidence-based interventions and culturally adapting them or

creating new interventions specifically for a particular cultural groups.

Then interventions that provide training to providers to reduce disparities. This is something that we definitely need a lot more research on. You know, training providers to be culturally competent and to really understand some of the issues that are creating barriers for families. And then policy level - we talked about Medicaid. That is a really good example of a policy level intervention that could help reduce disparities.

I am going to talk real briefly about an intervention we developed specifically for Latino families called Parents Taking Action. We formed an advisory committee with stakeholders, including Latino immigrant parents and providers that serve that population. We used a specific framework

dealing with cultural issues and then we used Promotoras de Salud. When we are talking about there is community health workers, the Spanish word for that, so I will talk a little more about that.

Our curriculum included sort of three broad categories. One is general psycho-education. We are finding that these families, once they get a diagnosis, nobody tells them what is autism in the language - you know, in their language. A lot of times they will go several years without really understanding what autism is. So that is a really important issue, just psycho-education about autism and evidence-based strategies, what are they.

Advocacy and parent support. Obviously big issues. And then actually teaching them about evidence-based strategies. Things that they could actually do at home while they are

on a waiting list for getting ABA or other kinds of services.

These are our promotoras in Chicago. We work with Grupo SALTO, which Matie is going to - and José, are going to talk about, the great work that Grupo SALTO does. These promotoras are parents of kids with autism and they were already leaders in Grupo SALTO. So that is why we selected them because they are already emerging as leaders. We trained them in a curriculum so that they could deliver the material and intervention.

We also did the study in California. These are our California promotoras. Then our training was pretty intense. We did 32 hours of training with the promotoras going through the whole curriculum, doing role playing, doing a lot of education. So that was a big endeavor of itself, doing that training.

So for our study we did do a randomized trial across two sites. There were 42 who received the intervention and 54 who were in the control group wait list, so they got the intervention later. The parents were average around 37. The children around five years old. We included children from two to eight, because we know there is a late diagnosis issue for this population. So there were some kids up to that age.

These are our findings. Our main focus was on parents getting them to use evidence-based strategies because we were not intervening directly with the child. We were not providing intervention with the child themselves. So we did find that parents felt confident in using the strategies we were teaching them, and that was significant for the intervention group. We also found that they were reported - this is parent report -

reported using the strategies more frequently at post than they did at pre. So those were significant findings for the overall group.

We also, this surprised us, we found a reduction in using the social communication questionnaire in social communication impairments for the intervention group. We actually did not expect this because we are not working with the child. But something we want to explore a little bit more as to why that is but we did teach them some strategies they could do with their children. So hopefully, maybe, they were using those strategies.

And then we also found a difference in evidence-based services. So parents in intervention group were more likely to be receiving at the end of the intervention, evidence-based services. So that was the disparities issue, right, trying to reduce

disparities in getting evidence-based services. So we had some pretty good outcomes there.

There were differences by sites, which I can talk to people about later. You know, they were very interesting, we are publishing on.

But in general, parents felt more empowered. They began using the strategies that we were teaching them, and children were accessing more evidence-based services and reducing - some reductions in social communication problems.

I am just going to go through this slide and then I am going to pass it on to my colleagues, but in my opinion, future research we need future research in all of these areas, right, so detecting - we need more research examining disparities in evidence-based services and supports. I will

say there are more up-and-coming scholars doing this research and so I think we are getting a lot of new investigators and graduate students who are really interested in this disparities issue. We all need to help mentor and promote that research. So there are people doing that.

Understanding - we need more research understanding the barriers and understanding the needs of different populations. So a lot of that is qualitative work and I think we need to support that qualitative work. There is also quantitative work that can be done in that area as well.

Then addressing - we need to, we need more funding to go towards culturally-tailored interventions; Also looking at system-wide efforts to reduce disparities.

So that is what I have and I think my last slide is just acknowledgements.

DR. GORDON: Thank you Dr. Magaña. Next we have Dr. Temple Lovelace, Associate Professor of Special Education, Department of Counseling, Psychology, and Special Education at Duquesne University. She is going to talk to us about Disparity Personalized: Centering the African American Voices of the Autism Community in a Research Framework.

Dr. Lovelace.

DR. LOVELACE: Thank you. Good afternoon everybody. One thing I am going to do is actually give you that qualitative view of what disparity looks in the African American community.

Some other objectives in my presentation are to look at something called the Autism Disparity Causal Loop. This takes a systematic or systemic look at what the impacts of disparity are and how our parents

and other providers are viewing that disparity when it comes to autism.

I am going to give you a really deep look at the perspectives of caregivers and then just a sneak peek at some national perspectives and then my own recommendations for future research.

So we looked at the importance of multiple methods of inquiry, one thing we find is that there is a different way of looking at the social world that actively invites us to participate in dialogue and that there are multiple ways of seeing and hearing.

So up to this point a large majority of the autism research has been quantitative and looking at that multiple way of seeing and hearing, I want to start to elevate more qualitative research that we understand

particularly with what is going on with our families and individuals with autism.

So if you look at the current NIH priorities in health disparities, the first two speak to me and to the importance of that qualitative review. The first is having basic research focused on health disparities that are experienced by. In order to understand an experience, we have to actually ask them what is going on.

The second is that there is a population-specific community-based participatory research. And in that participatory research that means that we are not doing research on individuals, but we are doing research with individuals and funding opportunities for them to do research in their own community.

So in looking at that, one thing that our lab at Duquesne University, which is

called the Equity x Innovation Lab, one thing we do is we take a look at the system dynamics that are a part of a given problem and then we also drop all the way down to individual experiences. So I am going to give you an example of what that looks like today.

So System Dynamics models the relationships between all parts of a system and how those relationships influence the behavior of the system over time. So as a - I am a behavior analyst and look at behavior analysis and how it can support lots of individuals with disability. But one thing we forget when we are in that room and working one-on-one with an individual with autism, is the system that has created the experiences that people are going through.

This System Dynamics view was created by Dr. Forrester at MIT, and it utilizes informal maps and formal models through

computer simulation to understand and uncover the system behavior. This will become clear in a second once I show you a diagram.

It is a computer-aided approach to policy analysis and design.

Systems Dynamics allows us to focus on the systems level and it correlates with desirable change for the individual.

When we look at a particular part of Systems Dynamics, which I am involved in, which is the community-based system dynamics, it aims to understand the mechanisms that drive dynamic behavior through collaboration with the community. And we are able to identify causal relationships, feedback loops, delays and unintended consequences, in terms of decision making.

So this looks a little bit crazy. Let me explain to you how we got from voices to this thing. So in essence, what happens with the

causal loop is - and we look at community-based system dynamics - is that we create these with the community. So we start with a barrier - and it is hard to see here but I will give you a couple different views in a second. But we start with one variable and then we ask them to think about how does that variable relate with another variable?

For example, if I look at the fact that the prevalence of autism, that there is a disparity there as it relates to individuals with autism, then we know that when we see that, that could impact the amount of funding, right, that is received and given to particular communities. Once you start to link those factors together you start to see how they kind of impact each other in this systemic view.

This is what it looks like in the actual causal loop. In that you will see things such

as reinforcing loops, balancing loops. So reinforcing loops means that if we don't have enough money then we don't have enough for intervention, right, we don't have enough for care. Whereas, a balancing loop tells us that if we see that there is something negative happening, we can introduce a new intervention to kind of balance out that disparity and that is where a large majority of our work happens.

So, looking at that a little bit differently. In this causal loop, which is identified, we use these factors along with some of the individuals that you will hear their voices later in my presentation. But we took and worked with them on what their causes were in terms of what is happening in their lives with autism. We also combined that with the voices of families that are involved in a national group, which Camille

actually will talk about a little bit later. So we combined that work which summarized about three to four years of work, and we came across their ideas of what are the causes or what are the things at the systems level that starts to impact.

So using this first one as an example, one thing you will see is that they said that we need an operationalized best practices in looking at cultural and linguistic diversity in children with autism, right. So instead of just assuming we need somebody to look at what are some operationalized definitions in terms of their experiences? How do we begin to elevate this wider understanding of their experiences?

So once we have that, we are then able to really impact and look at behavioral supports. We are able to look at parent training. We are able to look at policy in a

much more deep and rich way. We are able to look at push-out and drop-out from school, right. So once we start to center their voices and understanding, we are able to understand these other things more in depth.

One thing you will see is that a causal loop technically can go on forever. However, sometimes we get to the end of that and so we see that with each of these areas, parents started to see kind of how their ideas would loop back, you know, and that loop back is what you see in the parentheses, and that is where the loop kind of ended for a parent.

We also saw that with policy. That with policy we were able to see that when we start to have a strong handle on policy for CLD children with autism, we are able to understand more frequently - understand more deeply where autism funding should go. We are able to understand the fact that we can

positively impact considerations of autism as a diagnosis for CLD children more earlier and more frequently and that we have a more correct diagnoses for them.

The last one is that looking at how can autism funding really impact CLD children. You see it can impact them by having culturally sustaining research methods. So when we look at the research methods we use right now or the tools that we use, they are not built with culturally and linguistically diverse people in mind.

We are also able to impact prevalence rates. We are also able to impact policy in having reliable and valid ASD-focused interventions for CLD students.

So once we start to look at that causal loop and that impact, one of the things that we are doing in the lab is that we are then using that and then taking pieces and parts

of that and bringing qualitative data to the forefront.

So the study that we did, and it was published in 2018, looks at the voices of African American mothers who take care - who have sons with autism. We are going to walkthrough and I will walk you through, their experiences and their voices. So we are looking at the African American experience. The biggest four things we saw is that they spoke a lot about the diagnosis process. They spoke a lot about collaboration with service providers, as well as with school personnel. And then their collaboration with others.

So looking at diagnosis first, one thing that we found is that often when families are trying to - they are starting to explore some things they are concerned about with their families, that these mothers stated that they went the route of their family doctor and

they did not get a diagnosis of autism. They often got a diagnosis of emotional behavior disorders or something else, but autism was not the first diagnosis. But that it was through working with their daycare provider or through early intervention services, that autism was first brought up to them as a, as a, as a potential diagnosis for their young one.

So for example, Viola states that, "Yes, absolutely. It took longer to actually get a diagnosis. It took another 2 years to finally get a diagnosis because pediatricians kept writing it off." And when we talk about the importance of early interventions, six months is huge, two weeks are huge, especially in ABA. When you start talking 2 years, that significantly impacts the ability of independence, the ability to communicate. So that 2 years is massive.

We have Tina here. She says, he showed signs as an infant, but by the time he was 1, he was completely nonverbal and wasn't responding at all to his outside environment. However, so we started seeing obvious signs at 1, but you get brushed off, you get brushed off. By the time he was 3 no one could understand what he was saying, and I knew, that this was autism.

So when we look at collaboration with service providers, we have some positive experiences, but our mothers - I don't know if it was because somebody was finally sitting down with them and talking to them one-on-one, that the large majority of their experiences we coded as being negative experiences as they were along this journey.

What you will see on each slide is I have other studies that may be qualitative or

quantitative in nature, that support the findings that we saw in our own study.

So Latisha states that, "They had worked with him. They had expectations that matched mines, just they were willing to do things with my other son too, they didn't exclude him." So that was an example of a positive experience that she had. So she said that, in talking with Latisha, she talked a lot about the fact that this one African American TSS, right, so we start to see how having a TSS, which is a therapeutic support specialist, is language that we used in Pennsylvania, that they were able to connect at a cultural level which propelled them forward in a positive interactions.

Now we start to look at negative interactions. Latisha states that, "I guess Cory was just too autistic." So she no longer could work with African American TSS. In her

experience she says, you know, "They were like well, he sounds like he is too severely autistic." She is talking with a service provider whose data supports her with her son. So I said, what you're telling me is, your autistic program only accepts certain types of autistic people? And she was like, "yea".

So imagine scaling the barriers to find somebody who has services for you, to find somebody who accepts your insurance, right, to finally get that person on the phone and to hear that your son is too autistic, is very, very demoralizing.

She also states that, and I know the way I speak, I don't sound like an African American person. Once I started saying, well, my son has this, and where I lived at, and people start doing the math, they are like, oh, no, no, no. So she is talking about the

impact that once they start to maybe figure out that she may not be white, right, or she may not match the culture of the service agency, that they start to deny services or maybe back away from what they are willing to offer.

So Latisha says, you know you hate to say that it is because of your color. I hate to say that. I try to look at everything else and then when everything else doesn't all line up, then you have to say maybe it was my color. Maybe it was because I was black.

She says she didn't want to go, so she talks about this experience with the therapeutic support specialists. She talks about having community-based outings, right, so not just having therapy in the home.

Latisha, she begins to really question what is going on and why this person doesn't want to go into the community that she lives

in. Which would be a community situated in an urban context. She says something that is really poignant, she says I didn't live right in 'shoot'em up central'. She is trying to negotiate within herself why this person doesn't want to work with her family, especially in a community-based setting. Which we know by research is a really important thing to have community embedded interventions and evidence-based practices.

She continues to say that people will try to talk to me like I don't know what I am talking about. That people become very condescending when speaking with her. With all due respect, she had to assert herself, with all due respect, this does not work with my child. I've tried this.

As we begin to kind of delve deeper with these mothers and start to understand their experience, they started to talk about their

collaboration with school personnel. In this there are four areas that I will briefly talk about as it relates to how we coded their experiences.

The first is perception. Then we will look at placement. Then we will look at IEP and then the class and homework.

So Viola starts by saying that at the beginning when she started to really understand autism and the impact on her family, she said I just felt kind of lost. So our parents are starting from a place where they just don't know what to do. Then in order to propel themselves forward they had to educate themselves, right, because there are not a plethora of materials out there available that feature people that look like them, right. So for them, autism feels like something else. It feels like something that they don't necessarily see themselves in.

So she said I had to educate myself. I had to read up on autism. I went to the appeal center and got parent advocate certified because I needed to know what to do for my child. The thing about Latisha is that she began to then offer her services to other families, actually to another family in this study, to be a parent advocate to sit with them. So you see parents taking on this role of having to not only navigate just being a parent of a child with autism, but now they have to advocate, and now they have to actually become an advocate not only for themselves, but with others, because they know that the struggle that is happening is so deep in the community.

Next let me talk about placement. A lot of times what we see is that placement decisions are made without data that reflect the child or their - have incorrect placement

based upon their present levels of performance.

What Tina says is, I don't want to say that this has to do with him being African American, but sometimes it is questionable where his placement is in school. So you have jumped over the hurdle of you know, having your IEP, and now you are playing the placement game. So what you are finding is these mothers aren't able to ever rest. They are always on guard when it comes to supporting their sons.

So she says, I am not the kind of parent who just don't care. Her son absolutely comes first.

Viola says, I am not okay with him just not being taught. We need more help. He does, he just needs more help.

So we often think that the IEP is that thing that is going to help. One of the

things that we found out is that once you start to navigate placement, now you are dealing with what are the things that happen once you have that IEP in place.

So Tina talks about the fact that it was a struggle for her. She says because I didn't know how to go in there and say I am not okay with this. I couldn't breathe going into that meeting. On top of that, there are six, seven, eight other women in the room with me. So she feels like she is along sitting in there trying to fight for her son.

So we talk about changes in IEP. Viola says, you know, that school year so far, we have changed is IEP twice and we have another meeting next month. His needs are not being met at all. So they are having to go time and time again to the school in order to get the services that they need.

So she talks about talking with his special education teacher several times and asking her to adjust this on his IEP and that she is still not getting accommodations even after that continued advocacy.

Lastly, we talk about collaboration with school personnel. Viola says that he needs one-on-one teaching and he is not getting that. So that is accommodation that was written in the IEP. She is also not seeing any re-teaching that is occurring. No sensory breaks. He will routinely come home from school and will not have any idea what to do for homework. It is as if he was gone for seven hours for nothing.

So we talk about this idea, and Sandy brought it up, we talk about this idea of not only having evidence-based practices, but also training education personnel, training service providers as well.

Tracy ends with, sometimes you know it's just like it is prejudice. Or sometimes you know it's like is it prejudice or is it because they don't understand what's really going on.

So she is really having a tough time navigating what is happening to her and her son.

So we have two final areas to talk about. One is the African American Experiences. We are going to talk about knowledge about autism and underrepresentation.

So Latisha starts by saying, that my family assumed that it was just something that I did wrong because Chance came out with autism; it was my fault. You must have been drinking or you must have been using drugs.

What this speaks to is the fact that information is not - about autism just as a

disability - is not found in our community at the rates it needs to be, right. So we look at ways in which we need to support it having a plethora of information available so that families understand just what autism is.

They just could not understand that. I was educating everybody. Everybody in my circle started to get educated.

Viola states that, they just don't understand it. It's difficult to try to explain why his behaviors are the way they are.

So we look at support. Yes, it is important to support the individual. It is important to support the parents with them. We start to look at larger family interventions so that families can become caregivers beyond just the immediate parents or guardians.

Tina states, I think it's just a culture that they're so used to. My grandmother, my mother on both sides for years, they were like he does not need to be in all that therapy. I don't know if it's a pride thing. I really don't know what it is but I know that I'm not like them.

Then we talk about access for services as a part of the African American Experience. Tina says, I think that the information just needs just to be out there more.

Latisha says, there was no place in my own community that I could go to so I was forced to travel far out.

This becomes the disproportionate barriers that are placed in front of families that they can't walk you know, a mile - not walk, but they can't just a mile out find information. They are having to go to communities that are two and three

communities over, which we know can be barriers in terms of transportation, whether they have transportation or not.

Viola states that, I think that early diagnosis and screening are one of the biggest issues that African Americans face, and I think that putting more knowledge out there is important. She says, examples of African American children - African Americans that have children on the spectrum that are getting services that are actually benefitting in some way and encouraging them to be more involved in their child services and their child's education as well, it would really, really, really, really, help.

As we back away from that very individualized understanding, NAAACN is a national organization that is led by Camille Proctor, and that organization over the last year, has created three Town Halls. The Town

Halls were in Detroit, Michigan, Washington, D.C. and Birmingham, Alabama.

Just a small snippet of data that we have are some surveys and conversational interviews with over 100 participants across those three Town Halls. The survey results however, are just on the 70 from Detroit and Washington.

What you see here is that when we put out the plea in communities to have them come around to understand more about autism, we got people with ASD that were there, parents, family members and professionals. So the group was quite diverse in each of the cities.

So here is what the community has said that they need more information on. We had about 60 percent of individuals in Detroit and about just shy of that in Washington.

They just needed general information on autism.

Early intervention, we had about 30 percent in Washington and about 12 to 15 percent said they needed information on early intervention. Now ABA is something that has been around for quite a while. We found in Washington that over 50 percent said that they really wanted information on what ASD was - what ABA was.

School-based services had a similar rate in terms of their information needs. And then we follow that with transition and independent living, having approximately 40 percent of participants wanting to learn more about that. And then advocacy was another huge part. In Washington, over 65 percent of our respondents said that was a big huge area of concern for them and they wanted more

information. Then approximately 48 percent said that in Detroit.

As we start to take this really up close and personalized view, this is my last slide and I will leave you with this, is that it is hard to understand really what is going on without asking and having that personalized view. So in looking at my recommendations that I would like to offer, I think there needs to be an increased use and support of qualitative and mixed methods studies in order to improve and have an understanding of the experiences of racial and ethnically diverse individuals with autism, as well as their families.

There needs to be increased multi-disciplinary collaboration to improve the participation of racially and ethnically diverse individuals. One of the things that we found is that you know, in special

education, we would be able to grab individuals in school-based interventions when it came to home and community. We really had to lean on maybe our social work colleagues. So being able to come together across disciplines, is really important so we can all wrap our arms around what is going on.

Lastly, I go with what Sandy stated, is that increased support of evidence-based practices created specifically for racially and ethnically diverse individuals with autism is incredibly important. We also need to focus on their caregivers so that we can decrease the latency. Because if we can gain that two years back, there is so much more that we can do for individuals.

So thank you for your time.

(Applause)

DR. GORDON: Thank you very much, Dr. Lovelace. Next we have Dr. Sarah Dababnah, Assistant Professor at University of Maryland in Baltimore, who will be talking about Using Community-based Approaches - Using Community-based Research to Tackle Racial and Ethnic Disparities.

DR. SARAH DABABNAH: Thank you. Can everyone hear me okay? Is that better? Can you hear me now?

DR. GORDON: Move it very close.

DR. DABABNAH: Can you hear me now? Great. Thank you so much to Dr. Daniels and Dr. Gordon for inviting me. I am really happy that the committee is focusing on this issue. I think it is certainly a cross-cutting issue. I follow the work of the IACC, and I am happy - every topic that you have talked about - I'm like, oh, we can kind of integrate and think about how disparities fit

into this. So I am glad to have an opportunity to come and talk about some of my work.

So today I am going to be focusing on some of my work that is focused on parents. I thank you for the great segue. I used parents - I just wanted you to know that I used the word parents broadly, to mean any of the child's primary caregiver. For some of our children that might mean a grandparent, for example, I just used parents for sort of a shorthand.

I think that both of the previous speakers have already nicely laid out why families are important in autism research. Parents are acting as the de facto "case managers" for their children often times. We know that there are not only high levels of parenting stress and depression in this

population, but high-levels of family financial burden as well.

I think the literature has clearly laid out that there is a relationship between parenting, stress, and child outcomes. I think the field has gotten to a place where we know some - we have some robust evidence about early intervention for the children. I don't think we are at the same place for the family. And there are very few autism interventions that directly address parent wellbeing; parenting stress, parent depression, the strengths of the parent. Oftentimes parents might be involved in an intervention, but the interventions are not directly addressing the parents needs nor addressing parent or family outcomes.

So my work has been to not only improve child wellbeing through intervention research, but also parent wellbeing. I think

we can really build on sort of the natural child and parent strengths that exist within these families. Also, we need to address autism-specific challenges. Sort of mainstream parenting interventions are just usually not appropriate for families dealing with autism because they have some very unique needs.

As one example, I did adopt a empirically supported group-based intervention for parents of young children with autism. We targeted ages two to six, called *The Incredible Years*. So just a really brief - briefly about our results. We found significant reductions in parenting stress and also in improvements and child behavior challenges. There is low attrition, so parents really stayed engaged in the intervention, and high acceptability. So parents liked intervention.

Then we provided all sorts of supports for parents to be involved in intervention child care meals and transportation, which I think should be standard in parenting interventions.

But my nagging thought throughout all of this work was what about those parents who just never - who didn't complete the intervention? Or what about those that never even joined? For the most part, certainly single parents were underrepresented in these studies that I have cited here. Low income parents were underrepresented, and black families were also underrepresented.

So I just began to think about better ways to incorporate and to be more inclusive in our research. I just want to contextualize this. I think we have already heard a lot of really great background about racial disparities, and I think it is important to

say that I am in Baltimore, where people come from all across the world to come to get services in Baltimore. But then many of the families, I was kind of nodding my head as Dr. Lovelace was talking because these are things I hear over and over again from families of color in Baltimore. They are oftentimes not connected to services that are like literally a mile away from where they are.

But oftentimes when we talk about racial disparities, we also are talking about low income families as well. And clearly, poverty and limited education are very clear contributors to some of the autism-related diagnostic and service disparities that we see. I want to acknowledge that.

However, in some of the research that I have done, I found that these barriers do not fall away once families of color get into

middle and higher income. So as one example, this is just an example, a quote from one of the parents, who was a college educated black mother of a child with autism. She was talking about trying to get services for her child and she said, "I would get this whole lip service with the doctor. "Well, you can't do this with Medicaid". I said, "I don't even have Medicaid, I have private insurance." There are assumptions like I'm just this person that has multiple kids. This is a black woman. If you see my three kids, you assume I don't have a husband.

These are things that I would hear over and over again from families as they were talking about the interaction that they had with providers. Where it wasn't - it wasn't sort of saying like, you can't get services here or anything like that. But it is clearly racism and I think we can name it as that

because these families despite - and I think especially for middle- and high-income black families in this study - it was very clear to them that it was racism because they had a high-level of education, they were making \$100,000 or more. So it was clear to them it wasn't because they might live in a poor neighborhood or whatever.

I just want to take a little bit of a side-note to say that I have been really happy to see that in the past five years or so, there has been a lot more studies coming out on the experiences of black and Latino families in the United States. And I hope that we start to see more research about other ethnic and racial minority families. I am involved in a couple of different research projects, and unfortunately I won't have time to talk about them now, but I just want to acknowledge now that for example, the needs

of Korean-American and other Asian American families, and then I have also done some - a lot of work with Arab-American families. So in total, every time you look at a different group you are finding different strengths and also different barriers that they are facing. So there needs to be a lot more research along those lines.

So back to my work in Baltimore and sort of building some of these community partnerships to document and address disparities. I have worked very closely with Social Work Community Outreach Service. This is a picture of my colleague, Dr. Wendy Shaia, who is the Director of this program and this organization has been working in West Baltimore for 25 plus years.

We have assembled an advisory board made of lots of different individuals who are invested in autism services in Baltimore

particularly, for families of color. One question that we had was what is a way for us to increase black family's involvement in autism research? There are a lot of studies going on but again and again, you see the families of color underrepresented in these studies. So we ask families to tell us why.

Some of those barriers were autism-related embarrassment and shame. So the families talked about kind of wanting to not feeling very comfortable talking about autism with people - outsiders, including researchers. Not trusting the research process. I think that is a very well-deserved distrust. There have been a lot of - a long history of research studies that have done very unethical things within communities of color and other communities. And so, I think there is a distrust of sort of like where is my data going to go? How is my data going to

be used? So that makes families a little reticent to participate.

Some families talked about just lack of time and/or interest. Then literacy issues came up a lot in just the research materials not being accessible.

Some of the facilitators - families really were - wanted us to understand that we should emphasize how important it is for - in this example for black families to be included in the research. So what is the value for the research and for our community for us to be involved.

They also emphasized the importance of researchers offering information and support for the child in the family. They also emphasized the importance of engaging with research team members that were from the local community. So there are people on our research team that are in this case from

Baltimore who are African American, who they felt looked like them. Who understood the issues that were going on in this city.

Another huge goal of ours was how can we better get services to families in Baltimore earlier? Given the fact that at our clinics, we were talking about wait times earlier, our clinics, the wait is six, twelve, sometimes 18 months that families are on the wait list just for an evaluation. So how can we get some services to families earlier so they can begin understanding what some of the needs of their child are and some strategies that they could use.

So Dr. Magaña has already talked about Parents Taking Action. So we have taken that in Baltimore and started tailoring that with our Community Advisory Board. It is still a 14-week program, and up until age eight, again, recognizing the delays that many of

these family's experience in getting diagnosed. And also, we include kids who are at-risk for autism. So if they are just screening, they might not have gotten the diagnosis yet.

So we also pair parent leaders who are caregivers of children nine years and older with autism, deliver the program. And they work with the parent to agree when and where to meet. So it could be at home on a Saturday. We focus on the same outcome measures that Dr. Magaña does.

So some of the recommendations that our Advisory Committee had in terms of changing the original Parent's Taking Action Program manual was, first we modified the first session to begin with a story of an individual with autism in Baltimore. So it was personalized in that way.

The original program was created for Latino families and so we added a lot more photos of black and African American children and families in the manual. Many of the narrations were in Spanish, so we recorded new video narrations in English. And many individuals on our advisory board emphasized how important it would be to include resources on police interactions - which we did. We just revised the manual overall with Baltimore-specific resources.

In terms of recruitment, we used whenever possible, we used a warm hand-off. But we are not restricted to referrals from providers so we do pretty wide outreach in the community and members from our research team are at school board meetings, and lots of different meetings within the City; schools, faith communities, childcare centers, et cetera.

One thing that our Advisory Board recommended was to emphasize the signs and symptoms of autism because of within the community a lot of fear and avoidance of the "A" word. Any research study, we spend a lot of time talking about the purpose and research protections in place - that in this study we spent a lot more time on that to explain how we are going to be using the data and so on.

So we are actually just in the middle of this feasibility trial so I don't have a lot of results to talk about but I can tell you about a lot of the barriers that we have experienced so far.

Just life challenges, in general, have been a huge barrier. Actually, I think every single - we are looking at the data - like every single one of our families has some pretty big things going on that are not

autism related. Homelessness, community violence, in particular.

We definitely realize that home is not always the best place to meet due to partner safety issues, the lack of childcare so the child is at home, et cetera. We are also finding that for some families, two hours a week is just too much. There are a lot of distractions because you are trying to help them meet their immediate needs such as for example, homelessness, perhaps because of literacy, and things like that.

So I have been kind of struggling with how to best reach families, especially those who are not already connected to services, I have been drawing on what I know about global autism research to inform some of the work that I am doing locally. I am talking about research that is not in high-income countries like in the UK, but some of the knowledge

from work that I have done in low and middle-income countries where resources and staff are scarce, if they exist at all, delays are the norm and populations are really hard to reach.

So as one example, an intervention that I evaluated in Turkey targeting Syrian refugee families that had children with autism. Some of the takeaways from that was you know, the same as we are doing in Baltimore, engaging those community liaisons to tailor interventions and recruitment to local context. Training parent and non-specialist workers to deliver interventions. But another thing we are thinking about is measuring dosage. Like how much - can we make this a little bit shorter so parents can get what they need out of it and it might not need to be 14 weeks.

Can we offer optional modules and different formats? So maybe for some of our families in Baltimore, can we do a hybrid of group and one-on-one work. Can we deliver virtual modules so we can accommodate some of the really diverse needs of the families that we are supporting. The need to target multiple systems. I can do what I can do as a social worker with families within their homes. Sort of as a counter - you know, to what you were saying, as Dr. Lovelace was saying, working with schools. If we are engaging the teachers and other service providers, then I think we can make a much more sustained impact. And clearly, we need better policies in place in order for us to do this work. Last, but certainly not least, incorporating content on both trauma and stigma.

Maybe in another talk I can talk a lot more about stigma, but in terms of trauma, you know it seems sort of obvious when you are delivering an intervention to a Syrian refugee family, that you should have some content on trauma. But it is not always as commonplace or a default when you are working in Baltimore City. But maybe it should be because lots of our families are experiencing on a daily basis, community violence and different things they are being exposed to. And so the defaults should probably be to have a trauma-informed interventions so all families are getting that support that they need.

I had a lot of trouble creating this slide because we have so much work to do in this area. Certainly, I don't think we can address racial and ethnic disparities without more intervention research that is inclusive

of families and is culturally relevant. I hope I have made that case today. But I also feel that we need to have more interventions that are multi-level, so that involve those schools, teachers, childcare providers, policymakers, and other systems that are in place to support the child and the family or the adult and the family. And also, that are multi-disciplinary. We talked about that this morning on the panel. We all are kind of working on different silos and so the more that we can kind of get together and share some of the work that we are doing to support families, is really critical.

Community partners should never be an afterthought in research studies. They are absolutely essential. Our work is hard enough when we have community members who are helping us navigate in some of the work that we are doing. And I think it would be almost

impossible if we didn't have them to reach out to the most underserved populations.

This research takes a lot of time. It takes a lot of time to build trust in communities where trust has been lost. It takes a lot of time to hire and train new staff. And it takes a lot of time to reach out to individuals that are not already connected to services.

I won't talk a lot about measures because we have discussed it already. I think I am close to being out of time. But I will just end by saying that the more support in funding that could be available for local - by local I mean city, county, state, regional, autism research consortiums, would be absolutely critical. I mean, I think we oftentimes work in silos because that is the way the funding works. So if we can pull some of our resources together, reduce

redundancies, and most importantly, to share knowledge in what we are doing, would really help us to increase collaborations.

So thank you. If you have any questions, feel free to email me or call me. This is most of the members of our team and I would like to appreciate the work that they are doing, probably right now, and then all of our funders. So thank you.

(Applause)

DR. GORDON: Thank you. So we have heard from three academics, talking about opportunities for research and expanding care in community-based approaches, et cetera. Now we are going to hear directly from, if you will, the people on the ground trying to address these disparities.

The first we are doing to hear from is Camille Proctor. The Founder of The Color of Autism Foundation and a Founding Member of

the National African American Autism Community Network, talking about The Color of Autism.

MS. CAMILLE PROCTOR: Good afternoon. I want to thank everyone for being here and I would like to thank the organizing committee for inviting me here. I think this is really, really important to discuss.

Autism and Developmental Disabilities Monitoring reports, the ADDM. I'm sorry I am really bad at reading my own slides because I don't have in my contacts. So I apologize. Reports have consistently noted that more white children are identified with ASD than black or Hispanic children. Previous studies have shown that stigma, the lack of access, healthcare services and services due to non-citizenship or low-income, and non-English primary language are potential barriers to identification of children with ASD

especially among Hispanic children. A difference in identifying black and Hispanic children with ASD relative to white children means these children may not be getting the services they need to reach their full potential.

So this slide will be a lot easier because it is not based on someone else's research. It is based on my beginnings with my son, over there, Ari.

In 2008, when he was two years old, he was diagnosed with autism spectrum disorder. For me it was a little bit easier. Like I knew what autism was. I just couldn't get anyone to say that he was autistic because he did not have what we call "classic signs". Meaning he made a lot of eye contact, he liked women a lot. So if you were a woman he would engage you. If you were a man, he tried to slap you, but that is just how he was.

So I thought the process, because I had this informed eye, I thought. I thought the process would be a lot easier for me but unfortunately that wasn't the case and our journey hit a few bumps along the way.

As I scrambled to find resources, I quickly learned that there were - there was a disparity in the African American community. Support groups didn't understand the complexities of being a person of color and how it would affect every facet of my son's life moving forward.

I remember asking - I remember attending a support group and asking how I can protect my son from police brutality. If he wanders away and he is approached by the police, he may not respond properly because he doesn't know how to yield. He doesn't really know that concept. Even then, I knew that would be a problem. What if he never - like I said,

what if he never understands what yielding means? Everyone in that room looked at me and they said, nothing will happen. They will know he has autism. So at that point, I knew that these people didn't understand what it was like to be a person of color. They thought it was very, very, - I don't know, they just figure he has a disability, they will know.

The irony of this is maybe a few months later, we had cases like Trayvon Martin and Eric Garner and all of these people, and it hasn't ended there.

So, we kind of went through what we went through, bouncing around from place to place just trying to find the right supports for us. Then I realized that I needed to do something outside of myself and help others.

I founded an organization in 2009, The Color of Autism Foundation. It is to raise

awareness in the African American community about autism spectrum disorders. To erase the negative stigma attached to autism by helping families through the early intervention process and providing services. Our goal is to lessen the isolation associated with raising a child on the autism spectrum.

So I am going to piggyback on some of the commentary that was previously made. In the African American community, there is a stigma to having a disability It doesn't matter if it is autism, it doesn't matter what it is.

I literally had parents who said - when I reach out to them and we talk about some of the symptoms that their children have because I get a lot of calls. I get an onslaught of calls and emails and I have an opportunity to talk to parents and they will say to me, well, maybe he is not autistic because I

don't really like the way that that sounds. I do have to warn you all that I am not really the warm and fuzzy advocate, so I said, so, 8915382 sounds better? They go, well, what is that? I said, his prison inmate number.

Because the truth of the matter is is that African American, Latinx children, they are on a fast-track to the prison justice system. They just ride right on in there. And if you don't try and support your children as best you can, that is where they will end up because you don't like the way that autism sounds, or autismal sounds, so you can go with the prison inmate number. It is your choice. It doesn't really matter to me, my son gets services. And then they look at me blankly and they stare, and then they go, okay, what do I have to do to change this?

So what we have done at The Color of Autism is we created a circle of care for

communities of color that provides them with resources that they can use to become their child's best advocate. We also bring the community into this circle so that they can learn more about autism.

The picture that you see here is my son, Ari, and it is the day that we trained a Detroit Police Force. Now this was a great day, but I also need for you to understand that the Detroit Police Force is probably about 80 percent African American. So it was good. So that those gentlemen, and those young women, learned about autism, but then on the flipside, you know if he goes outside of there - and I have to say this, and it is not to be disparaging to anyone, but my son Ari doesn't have the same advantages of his white counterpart. If he goes out in public and has a major meltdown the cops are going to be called. If he gets arrested and he goes

into the prison justice system, I cannot stand there and say, he has autism and pull out tons of paperwork proving that he has autism. They will say he is - whatever it is - he is a killer, he is a this, he is a that. But his counterpart Johnny, will most likely get acquitted of something or because he has autism, and it is just not fair. And I would like to talk about that.

Something happened to this slide. So throughout the years, I have been contacted by other advocates across the country and they would say to me, well, what can we do to be active in our community? Or we have an organization and we would like to do something similar to what you are doing. And realizing that I do - I get calls from all across the country and even outside of this country - I realized that something needed to be done. Meaning, we all needed to come

together and try to work collectively to make changes in our communities.

I figure, it doesn't hurt me to help you. That is my philosophy. So we came together and we created NAAACN. And the mission is to empower and support African American families affected by autism through our network of community partners, and advocate for increased awareness, screening, treatment, and autism, in underserved communities. Since 2018, NAAACN has hosted town halls in Detroit, DC, and Birmingham, Alabama.

My conclusion is there needs to be more fund - funding needs to be provided to organization to work with underserved communities so they can create equitable solutions for individuals affected by autism. Because right now what we have isn't equitable. We literally have people from

outside of these communities of color telling us what we need. Or we have, which is probably not a good analogy, we have people who are kind of looking at us like lab rats and saying, okay, we will try this. Let's try that. And that is not what we need.

I think to genuinely make a difference in communities of color you need to bring in people of color to help you get the data that you need. So for myself, I have a lot of people that approach me and they will say to me, can you help with this study, can you help - Nope, I won't. They go, like but it -, Nope, I won't.

The reason that I won't is because your study is not benefitting me. You are getting grants for a million dollars and that is sustaining you, but that is not helping me and the people that I support. So you are going to get data from me so that you can

write a white paper or a study or whatever it is, it is not going to move the individuals that I serve any further. I say this so that if any of you ever email me and you get a no, I am telling you why now, because it is not beneficial. It is not beneficial to me because I feel like there has been so much research done in the African American community, but I don't see a lot of change in regards to engagement, resources, and just getting these families what they need. If that was the case, I would have a lot less people contacting me every day.

So, again, looking from the outside and assuming what is needed in the inside, it has to end. Building a strong infrastructure of support, training, education, within these communities is really what needs to be done. Structuring for equitable outcomes that goes - that closes the gaps and focuses on

research - resources, sorry, among populations and communities.

You have to make an investment in these communities, and I haven't seen an investment. I have seen a lot of talk about investment. I have seen a lot of posters. I have seen a lot of this, but I haven't really seen a lot of investment, and that has to be done because you can't continue to tell families what autism is but you are not giving them any resources. And that is really important.

So if you commit to being fair, equitable and responsible, in making a responsible investment in public funds, policymakers can play a significant role in building a better, healthier, and more equitable communities.

So I guess I am going to repeat what I said previously, and even in this conclusion,

more needs to be done in regards to supporting families of color. It is just not there now, and I know that everyone in this room pretty much knows this. And we always talk about what we can do to change things, and I think that this is a big step towards change.

But I also think that after this, that something has to be set in place or a game plan. I am always open to contributing and helping with these types of things. So that is it for me. I do apologize but my contacts are driving me crazy today and I had to take them out.

So, thank you very much.

DR. GORDON: Thank you Ms. Proctor.

(Applause)

DR. GORDON: Next we have Matiana Ovalle and José Ovalle, to discuss Addressing

Disparities for Latino Families. They are from Grupo SALTO in Chicago, Illinois.

MS. MATIANA OVALLE: I want to thank you for the opportunity to talk about Latino families. And I am not going to talk about the disparities because since we already heard the disparities and they are very common in Latino families.

What I am going to do is I am going to talk about what is GRUPO SALTO in collaboration with other agencies, such as the TAP, The Autism Program of Illinois and the University of Chicago. The University of Chicago is doing to help address these issues.

Grupo SALTO was founded in 2003, to meet the void that many Latino families experienced. I work for the Family Clinic at the University of Illinois. The Family Clinic is mostly a diagnostic clinic. In 2003, we

started having a lot of families - most of them diagnosed with autism and they did not know where to go. So with parents as the co-founders and the director at that time, Dr. Elina Manghi, -- thank you.

PARTICIPANT: I will go to the next slide when you are ready. Do you want to go back?

MS. OVALLE: Yes, please. We start as a support group. More - another one. Thank you. Dr. Elina Manghi was one of our best advocates for Latino families. She - at that time she was a director of the Family Clinic.

Currently Grupo SALTO is a not-for-profit and dedicated to provide support for families not only for autism. Now we are starting - a lot of families that have other disabilities and every time that they come they ask us if they can come and hear the educational sessions that are done, but our emphasis is autism.

This is done for families that are
mostly -

PARTICIPANT: It is sliding on its own.
I'm sorry.

MS. OVALLE: Next one. Keep going.

MR. JOSÉ LUIS OVALLE: Grupo SALTO is a support that is hosted by the University of Illinois in Chicago. And what happens is that through the support of other organizations, such as the Autism Program of Illinois, where I work, the Autism Program of Illinois is a network of agencies and universities that get money from our organization to provide services, information, resources, and many other important services that the community needs.

It is done culturally competent and it is also - it serves the entire state. The problem with Illinois is that it is Illinois. We went through our share of corruption and

this and that. You know the story because it comes out everywhere, and we have always been the example of what not to do with a state.

But fortunately, we have come back and the state has again, funded most of the programs that were unfunded for four years, with the previous administration. So Grupo SALTO has been also supported in a way by TAP, The Autism Program of Illinois.

So many of the programs that are presented are not only for parents and children who have autism, but the program is presented for the entire family. In the Latino community a family is not - there is no such thing, such as extended family, it is just the entire conglomerate of about 50 people in a single family.

We try to educate everybody; grandma, grandpa, aunt, uncle, cousin, and so one of the greatest things about Grupo SALTO is that

when we have our educational sessions, we have the mom and the dad. It is quote/unquote, known as very much a community, but if dad goes it is because mom says you are going. So dad gets involved a lot in this.

A lot of the information that we give is related to the fact that it has been studied and said, and we know that if a - the incidence of autism is higher in boys than in girls. If there is a boy, we inherited the x chromosome - the y chromosome to our kids. So we have to be there. So that is the reason why we force the parents to be - fathers to be involved, to be participatory, and it has been quite successful that way.

I am just going to close my participation in this by saying, Matie is very nervous right now, for starters. Second, she is a very powerful person. I remember

that when we discovered that our kids had something. We did not know what it was. They were not diagnosed until they were 10, after the spectrum was devised and was applied.

When the new school they went to did not have a special ed program, and the principal was reluctant to bring one. So what happens, she runs for the school council, she wins, she fires the principal and brings another one in. So that is the type of person she is.

MS. OVALLE: Okay. Last year we had approximately 600 families registered at the SALTO. And I think Illinois is the largest of the Latino family support group. I think possibly the United States.

An average meeting, we usually have 50 families. Not only the families but also additional - we have different programs that helps other families to be in the sessions while their children are either in an art

program, a music program, a childcare, and a social group that we have especially for siblings.

Since the beginning, Grupo SALTO has been done a lot of - several collaborations. These collaborations and individuals, parents receive the appropriate and updated training in education on topics of their interest. This in return generates a network of parents with common growth and development as a family.

This cannot be possible without the volunteers - students from the Illinois LEND program, friends, family members, and especially the Latino staff from the Family Clinic at the University of Illinois.

Most of these programs are somehow supported by the TAP, The Autism Program. Every month we have a culturally embracing environment for the entire families. Not only

the family learns about leadership, but also how to cope and take care of their own selves.

As Sandy, Dr. Sandy mentioned, one of the great programs that we have is Promotoras/Parents Taking Action, which is the research that she conducted. Lately we have been trying to tailor this program to the needs of the families. Before there was 14 sessions and the parents used to go to the family's home and give all this information. Now we are trying since - there is lack of funding - we are trying to include also another research that she did, taking care of myself. If I take care of myself, I will take care of my family.

This is one of the programs that we really cherish. Every month we have at least three to four new families come in, either

recently diagnosed or they haven't heard more information about autism.

Tu y Yo is one of the programs that we try to help the young adults. This is peer mentoring, composed of a group of college/university self-advocate graduates with autism. That helps adolescents and other adults - to mentor other young adults.

This is the Child to Child. It is an international concept that was initially implemented, thanks to a grant again, from The Autism Program. These young adults created a "Myths and Facts about Autism." They present information that they think is most important to understand autism based on their experiences.

These presentations that they have done goes from public - Chicago public schools to libraries, and other communities.

They designed, in order to engage the younger children, they designed a storyboard with an emphasis of discussing visible and invisible difference and bullying.

MR. OVALLE: Before we go further, the Tu Y Yo program, or "You and I" in English, it is composed of college graduates, some with associate degrees, others with bachelors, some with masters, that - some with two or three degrees, who had not been able to find a job because they cannot go through an interview. They are very functional. They have the same social problems that all people with autism have, and they are brilliant. But again, they will either be rejected after the interview or will just not be given an interview because they cannot communicate effectively. That is probably a thought that could go into the transition idea that coaching for these youngsters - these are

people who have devoted their time - probably they are professional students by now. These are people who had devoted their time and they demonstrated that they could go to college. They are strong enough. It is not about being smart, it is being about strong. They are strong enough, but they have not been able to find a job.

Some of them have been - have graduated years back, years ago. Here is an example, Virginia Murray was diagnosed with autism in 2005 at age 10. Things have improved a lot. She is very functional. She speaks English and Spanish and she has received a lot of therapy; occupational and psychotherapy, and a lot of support. And she has a degree, she has two jobs, and she still faces a lot of challenges. She has been let go at several jobs because she cannot - she is a person who would laugh at everything and she was a

restaurant greeter. So that was not a very good combination. For a while, they liked her a lot but some of the patrons of the restaurant didn't feel comfortable because of her constant laughing.

Things have been harder for her now that she has a bachelor's degree because she wants to work in the field that she does. She has her bachelor's degree in psychology. She has been working mentoring some adolescents. She is brilliant, again, but again, she has not been able to - she has gotten several jobs, but she has not been able to hold them.

MS. OVALLE: Another program we had with collaboration with Dr. Meghan Burke is a leadership (indiscernible comments). This is one of the quotes that was shared by the parents.

"I learned the importance of educating myself because I didn't know how to help my

children in their education. I also learned how to negotiate and confidently ask the school for services ... to have confidence in me, that the responsibility is mine and I have the mission to find and seek the best education for my children."

Another quote is from another family. "I learned the great power of being informed to make the most appropriate decisions in the education of our children."

The idea of this program is educating the parents that they are not going to get any services and that they need to get in contact with the legislators. They were trained in different areas, such as the IEPs - had to advocate for those services.

With the support of the Family Clinic, we have also a retreat for parents, that is different days in 4 months. It is called Growing and Looking Forward with Hope.

The group has provided new opportunities to learn more about autism and self-care and the open care questions.

Advocacy - that is another thing that SALTO tries to do for the families. As José mentioned we didn't have a budget for a while, and the Latino families were able to help us come to Springfield and advocate for these services. Including the Tu Y Yo attended a press conference to support The Autism Program.

MR. OVALLE: Matie is director - manager of the Family Clinics for Disabilities at the Institute of Disability and Human Development of the University of Illinois in Chicago. There was a Hispanic group that left some members behind - a Spanish speaking therapist. There is a language therapist. There is a social worker. There is her and some other volunteers from the LEND Program,

it is a Program that provides very heavy training on disabilities within universities, but with an emphasis in autism. So we get a lot of support from students within the place.

The reason why we are still at UIC is because the group was born there and also the service that we - the services that SALTO gets from its employees is vital and we could not function outside of it simply because the professional services that we get from that clinic are just vital to what we do.

Along with that, also the clinic was unfunded more than once during the budget impasse that we have gone through. So a lot of the support that the Family Clinic is also getting is through The Autism Program of Illinois.

MS. OVALLE: Once a month Grupo SALTO tries to work with the family as a whole. We have an art program. We have the craft, music, mentoring programs, and in July we have a picnic. That is about the only time the parents really enjoy having the family together. Everybody knows, going to parties is kind of difficult because you don't know if someone is going to say that the kid is not behaving properly. Also, in December we have a family party.

This is one of the myths that Tu Y Yo's have in their presentation. It says that - and also they took this quote, I'm not sick, I just have a condition. I'm different functioning.

One of myths that they say is people with ASD prefer to be alone. Many people think people with autism are just quiet, alone and weird. The reality - People with

autism have a hard time socializing. They have a hard time talking and interacting at school, home, or any other place, because they get so nervous and scared. The reason is, they prefer to be alone is because when they meet new people, they often get nervous or bullied by others.

MR. OVALLE: One of the premise that allowed Tu Y Yo to create their presentation is the idea that - and I mentioned to some people here, that if a person has a physical disability, it will create pity. You will pity the person because he has a disability and you will see him and okay, you empathize a lot with him. But a person with a mental disability normally gives fear to the person who is in front of them.

When we coached these kids, we told them people are basically afraid of you because you go in a corner and start doing all these

movements so they don't know what your next move is going to be when you turn around to them.

So based on that, they developed a lot of information and they developed a program that they present to parents, they present to professionals, and they also present to children in school, especially about bullying. The new premise will be when the parent becomes the bully. That is their next project.

MS. OVALLE: Other service that Grupo SALTO does is autism screening. At least twice a year we conduct screening. Just to give you an example, in October there were 10 families and out of those 10 families, eight of them were referred to a full evaluation.

In April we had six participants and out of those six participants, four were referred to complete evaluation. The need is there.

Unfortunately, Grupo SALTO doesn't have employees and the only way that they can survive is through fundraising activities, such as a banquet, donation, grants, and definitely without the support of The Autism Program of Illinois and the Family Clinic and especially the Illinois LEND students were not able to perform all these services.

To conclude, with the help of parents, volunteers, DD Family Clinic, The Autism Program staff, and Illinois LEND trainees, Grupo SALTO can move forward with its mission. The organization creates opportunities for parents of children with autism in leadership trainings and education, as well as opportunities for young adults with autism to have a voice of their own.

As Grupo SALTO grows, it will continue to lessen the void felt by many families in

the Latino community upon learning someone in their family has autism.

Creating a culturally embracing environment with volunteers that care about providing much needed services is what Grupo SALTO is all about.

I just want to add, as my husband says, I work for the Family Clinic. My work doesn't end at my job. I always bring work at home. Which is kind of difficult because I also have a family. I am trying to leave work aside, but it is kind of difficult. I feel very lucky because I work at the Family Clinic and when I get stressed or I get depressed I have my co-workers, to help me out. That is one of the things that I always think about other families, they have no - that opportunity.

The other speakers, I say, we really need help. I am getting at that time that it is getting too stressed.

MR. OVALLE: There are two things in here. One of them is that all support groups, we insist, why are there so many support groups? Or why do support groups pop up and then disappear? Well, because of the reason there is no funding for them, it is very hard to have a person in charge of them, especially if they are not associated to professional help. So there are a lot of support groups that we have gone to that have disappeared because of exactly not having enough support.

I am not talking about necessarily economic support, but support by entities that have the services that are needed. At least a social worker. At least a psychologist that could go to the meetings.

We will find help from students to do the childcare, to do everything else that is needed at the session. We only have one session the third week of every month - the third Saturday of every month. So by the time we have that session, we get - sometimes we have to - we have not turned people away, but there are times we are full to capacity and there are sometimes not enough volunteers to help us. That is the first one.

The second one is that most of the organizations that run support programs do not have enough funding to create them. The Autism Program has tried several support groups for parents throughout the state and some start, but they finish right away, even if they are associated with university because there is no money to pay for the professionals.

Right here, there is a valiant effort of three or four ladies who decided to go on, and the group was not funded at first. In the Latino community, things are free and bravo, it is fantastic, it is magnificent, but maybe I will not go. So we had to charge, otherwise people wouldn't show up.

At first that was fantastic because that kept us alive for a while, and it was not until we had support from The Autism Program, that some programs were subsidized and we could reduce the cost of the membership and the cost of the programs that we gave.

So this is the information that we have about a support group that exists out of the good intentions of the heart, practically. But that is the fate - that is the way a lot of support groups operate in the United States and they need not only money, but they need training and they need assistance by the

people who have the ability to provide services and information at a higher level.

MS. OVALLE: I will just add one more, besides being a parent with a child with autism, we are dealing also with parents that have cancer and other health issues. Depression is one them that is getting to a lot of our families. So thank you so much.

MR. OVALLE: We are parents to identical twins who are 29 years old, meaning that we are 60. So we are right there. We were talking about this earlier, the aging of the caregiver. So pretty soon we will have disabilities of our own.

So, thank you very much.

(Applause)

DR. GORDON: Next on the panel we have Yetta Myrick who invited to give public comment. The President and Founder of DC

Autism Parents, and also CDC's Act Early Ambassador for the District of Columbia.

MS. YETTA MYRICK: Good afternoon everyone. I really want to thank you all for allowing me to be a part of this group, of this panel, to be at this meeting today, because this really has been a rich conversation. I have been following the Interagency Coordinating Council for - Committee, excuse me, for a number of years. And as parent, it really moves me that all of these agencies can come together on a regular basis to talk about the issues and I hope that my comments today will help propel us forward as we think about the needs of the community on the larger level.

Again, I would like to thank you all for my being here today. I am the mother of a 15-year old son, Aidan, who has autism and intellectual disability and ADHD diagnosis. I

have served as both a study participant and as a Stakeholder Advisory Board Chair of a PCORI Health Disparities Grant.

When my son was initially diagnosed in July of 2007, I started researching everything autism. Just like you heard, all the families we touched based on talked about our own personal experience, have done. Eventually we ended up participating in various research studies. Some of them here at NIMH.

Over time I found that there was a limit to what we could participate in, given my son's verbal ability and his IQ. According to a recent research paper entitled, Are Children Severely Affected by Autism Spectrum Disorders Underrepresented In Treatment Studies: An Analysis of the Literature, by Stedman in 2018, eleven percent of research participants with ASD have an IQ less than

85, and even fewer of participants were characterized as minimal verbal. This to me is a health disparity in and of itself, that needs to be addressed.

People all across the spectrum need to be represented in research. Going further, as all of us have stated today, people of color, people of lower socioeconomic status, and non-native speaking populations, need to be included in this group, too. Everyone, regardless of their situation, need to be included in research.

Now, how do you as a researcher know how to address health disparities? For me the answer is clear. Stakeholder involvement, if we have not drove it home enough today on this panel, is key to successfully addressing health disparities in research.

Stakeholders should not just be regarded as research subjects or study participants. I

wrote down a note earlier, Dr. Lovelace, when you said research with, not on.

Stakeholders should not be - stakeholders have lived experience that makes them uniquely qualified to partner in shaping your research projects. It is this unique partnership between the researcher and stakeholders, who reflect - listen to me everyone - that reflect the diversity of the community they represent that can shape a well-rounded, culturally competent research study.

Researchers cannot build their projects alone. It is not enough to invite stakeholders to quarterly meetings to provide feedback on an established project. Stakeholders should be an integral part of the project from inception to dissemination of research findings.

If you want to reach diverse populations, you need to take these ideas to the stakeholders in the community. Simple. That is what you need to do. Otherwise, there is a large chance you are excluding groups of people who could probably benefit you're your research the most.

Excluding groups by not ensuring the project is accessible, can further lead to widening the health disparities gap.

So how do you make research more accessible? First, you need to take the research to the people. Research can bridge the gap for many people, specifically if it is conducted in the community. You have to get to know the community you would like to serve. You will need to establish relationships with people in the communities that you would like to engage for your studies.

Become part of the community. Attend community events. Attend local autism meetings and disability conferences. I have seen personally, that you can go to any disability conference in this day and age, and there is going to be a research component. So, if you are going to just, conferences that are in your discipline, I urge you to step outside the box a little bit on this.

Also, connect with your local support groups. I would recommend identifying established advisory boards to facilitate the planning of your research project or you could start your own board if none exist. Now I doubt that is the case, in any community in this day and age.

You can also conduct qualitative focus groups to assess the needs and preferences of potential participants. Remember, building

relationships in the community takes time. Do not be discouraged. Allow the community to guide you through this process.

I am going to say this again. Allow the community to guide you through this process, as they know what they want and need.

In the last decade, I have learned that the larger community needs to be engaged in research. There is so much that researchers and stakeholders can learn from each other. But a relationship needs to be formed based on mutual understanding and respect.

In conclusion, I would like to see a national survey where the autism community is asked, what do you want researched? Based on the results of the survey, researchers would then work together to use their strengths and expertise to support each other in developing research studies, with stakeholder and community involvement, of course.

Autism research should not be siloed.

Thank you so very much.

(Applause)

DR. GORDON: Thank you, Ms. Myrick, and all the members of the panel, for your presentations, which were really quite compelling.

I now open the panel up for discussion from members of the IACC. I see Louis. We will start with Louis Reichardt.

DR. REICHARDT: First I just want to say it seems to me you gave us each sort of an inspiring stories of personal persistence and courage and some success in meeting these very real challenges.

Second thing, I would like to say in terms of the last challenge is that the Simons SPARK Cohort does have approximately 100,000 families, including individuals with autism, and Hispanics are represented in this

group of research-consented individuals proportional to their presence in the total - American population. We are doing some special efforts to increase representation of other underrepresented minority groups through grants through the University of Mississippi, UCLA and other places.

So I think it could be a starting point through the survey that you were talking about.

MS. MYRICK: That would be great.

DR. REICHARDT: We welcome that. I would be happy to talk to you about how to do that.

The second thing is, since our group is you know, includes a number of representatives of national organizations, as well as the NIMH, and so on, I am a little curious how you think the national organizations have been helpful, not helpful, what other information could be provided?

Since there are so many national organizations; Autism Society of America, Autism Speaks, The Autism Science Foundation, and other groups that are so interested in this. Are there things where they have been helpful or where you think they could be more helpful?

MS. MYRICK: Anybody want to jump in?

MS. PROCTOR: I will jump in. One of the biggest problems with some of the larger organizations is just as I stated previously, they are kind of like on the outside looking in. There really isn't any inclusivity within their own organization. It is kind of difficult, still, to reach communities. You can do a lot of different campaigns with the Ad Council and you can put a lot of literature out there, but if the people behind the literature aren't people like Dr. Lovelace or parent advocates like Yetta, or

even myself, it is going to be very challenging to make a difference in these communities.

MS. MYRICK: I would agree with that. I think that - in another life I worked at C-SPAN as a studio technician. One of the things I learned, every time it was election season, is that all politics are local. So we can have these national organizations. We can have the government. We can have these larger groups, but to your point, it is like, how do we make that - how do we build that bridge. How do we make that connection from the people on the local level to the people who are in these larger organizations.

I think we need to have further conversation to figure that out. Because every group has its own nuances, and I get that. But we need to figure out and do a better job, I think, collectively, of like

identifying each other and being open. Again, it is a mutual respect thing. It is easy to be you know, in a group where everyone knows each other. Even me coming today, it was like, oh, I know you, I know you, but when you are in a situation where you don't know people and you need to make these connections, and everyone is so busy, we still have got to, if we really want to move this forward and we are really thinking long-term about how we are going to affect families and the autistic adult - as they become adults, because the time is ticking, right, everybody is going to become an adult. How do we then set these systems up so that they won't slip through the cracks?

That is what this is ultimately about so we have to figure out how we can come together.

DR. MAGAÑA: If I could just add a little bit. I think that - well, a key issue is bringing people to the table who are equals to you. Depending on what you are doing, right? If it is an organization or if it is a research project. I will say that Autism Speaks has hired some leadership very recently, that are diverse and are people of color and are focusing on some health disparity issues. So that is one organization that maybe hasn't done so well in the past but maybe they are starting to do something.

I have tried to interact with autism societies, and they are all very willing to work on diverse issues, but they don't hire the staff to do it and maybe they don't have that capacity to hire because they are volunteered-based.

But I think you really have to hire people. I will say about research - research

labs, research teams, research studies, I have done a lot of NIH reviews where researchers are trying to - they say they are going identify certain minority populations, but they don't have anybody on their research team that has that expertise. A person of color that is a researcher, that has the expertise.

If I bring that critique up, they say, well, that goes in the other category of representa- whatever that - it doesn't get scored kind of category. I think it is a scorable category, folks, that if you are going to talk about researching minority populations, you need to have the expertise there and you need to bring new investigators that are people of color, through the system and really make sure that they are at the table.

MS. PROCTOR: If I could make just one more comment, and it brings me to why I started my organization of The Color of Autism Foundation to help African American families. I remember when I was contemplating starting this organization for African American families, and I was talking to an Italian friend of mine, and, I was like, should I include everyone? Will it sound racist? Will it sound whatever? And she looked at me and she goes, can you give me a gravy recipe? Oh, that is pasta sauce recipe. I go, I don't know how to make gravy. She goes, well, if you don't know how to make gravy, you can't tell me how to make gravy. So - and so that told me no, if you don't understand what someone is going through, you can't be a great advocate for them.

And so, she is really who propelled me to move along the course that I took, in

realizing that it was very, very important to be a voice and to advocate.

One other thing I would like to say in regards to hiring diverse individuals to work for some of these organizations, hiring isn't necessarily enough if they don't have a voice and they can't make a difference. So, me seeing someone at the table that looks like me, isn't very satisfactory if they are not advocating for me. And I am still seeing that.

DR. GORDON: Other comments or questions from members of the committee?

DR. ELAINE HUBAL: Can you take - this is Elaine Cohen Hubal, on the phone. Can I comment?

DR. GORDON: Who was that? Can you say your name again?

DR. HUBAL: Elaine Cohen Hubal, can you hear me, with US EPA?

DR. GORDON: Yes, go right ahead.

DR. HUBAL: Okay. I just needed to really put - first of all, I can't under - there is no way to really under or overstate the importance of this topic, really, but I was so struck by Dr. Lovelace's presentation. I think her use of the system dynamics modeling to really put some rigor around the very complex systems that are being addressed really, across the board in any of these kind of complex social, environmental and health systems. Is just - I just really wanted to compliment you. Your presentation was outstanding and I think that that kind of approach is - that we are just going to need to do more and more of that in trying to be rigorous and make sure that we are identifying sort of what are the key elements of the system that we want to be studying,

that we want be measuring, that we want to be setting goals on.

I just wanted to compliment you because I think your work and your presentation was excellent.

DR. LOVELACE: Thank you very much.

DR. GORDON: Other comments or questions?

DR. JOHNSON: Hi, Jennifer Johnson. I am with the Administration on Intellectual and Developmental Disabilities and we are in the Administration for Community Living at HHS.

DR. GORDON: Sorry Jennifer, can you just speak more into the mic? It is on but you are not speaking into it.

DR. JOHNSON: Is that better? So I too just want to thank you for your presentations. They are very informative, and it is great to hear all the wonderful work that is going on out there.

I did want to make you aware of efforts we are engaged in. We have long been aware of the issues of health disparities for this ID/DD population and have engaged in a number of efforts to try and address health disparities.

We fund a national network of university centers. There are 67 university centers that we fund in each state and territory. And the Illinois University Center, that you all spoke about, the Institute on Development - Institute on Disability of Human Development - is one of our university centers. It is our university center in Illinois. So I am aware of the work of that Family Clinic and really glad to hear your presentation and the great work going on there.

One of the things that we have done with university centers is to fund minority partnership grants, which has been a really

good way of bringing people to the table and giving them an equal partnership at the table with our university centers, where there can be a knowledge exchange and transfer. Not only in terms of the university center working with the minority serving institution, but the minority serving institution working with our university centers to help them understand what they need to do to build their cultural competence.

We have also done the Diversity Fellowship Grants, to again bring people to the table and have learning experiences to enhance the work of our university centers.

We also have a Diversity Leadership Institute that we have been funding, to build workforce ability, to be more culturally competent. And we are also funding a diversity community of practice.

One other resource that I want to mention that we don't directly fund but is a resource through our Georgetown University Center, is the National Center on Cultural Competence, that you probably all are familiar with, but I wanted to make you aware that that is affiliated with our network of programs.

Laura Kavanagh, who is with the Health Resources and Services Administration, they have also done a lot of work with the LEND grants that were mentioned, in terms of cultural competence and diversity training. So we partner a lot with them on that effort because many of those LEND are at our university centers.

I'd be happy to talk with you all more about your work and the work that we have been doing. I think there are some

connections that are going on there, but maybe there is some opportunity for more.

(Chorus of Thank you from panel members)

DR. GORDON: Other comments or questions from the committee? Nina.

DR. SCHOR: So, thank you as well, for your presentations. Really helpful to hear so many different perspectives and different approaches to a very difficult problem.

I am wondering, it almost seems like to me like there is an opportunity waiting to be brought to fruition. I am not quite sure what to do with it at this point.

Our medical school classes across the country, are increasingly diverse. There is just no question about it, anyway you cut it or measure it. Neuroscience is among the most popular PhD programs in every university in the country and people are looking for ways

to apply what it is that they learned, and they teach.

Our PhD student pool across the country is wonderfully increasingly diverse as well. I am wondering if you know about efforts, or if there are things that we can do - there certainly are some things that NIH is already doing. But are there things you can think of that we can do to tap into that pool to say, here is the problem upon which you need to help us work. Because these are individuals who - you know, I can't say if all of them think the way the communities that you are talking about think. I can't say that all of them are passionately interested in going back to the communities from which many of them came, but surely, some fraction of them are. They come from families, I would guess, many of them, that are exactly like the

families that are in these communities you are talking about.

Are there things we should be doing to lure those individuals to help you with this issue and grow this workforce from within?

MS. MYRICK: I would say I think it is about figuring out how you could build relationship with the people in the community in getting them - like for example, we all were able to come here today, but if there was a way for maybe someone in the community that you have done some work with, could come and maybe talk to the - talk to your students about their experiences. Because oftentimes we are in these situations, you hear someone speaking, it is like oh, that really struck something in me, and I want to keep this conversation going.

So I would say that if there are opportunities - this is literally off my top

of the head - off the top of the head - but, if there are opportunities where you can engage some community members to come in and talk to your students, I think that might be one way.

DR. SCHOR: So, am I correct that you are not routinely asked by training programs or what have you, to come in and talk with people?

MR. OVALLE: We have had about 15 dissertations done related to Grupo SALTO. Some of these students come back to help us, assist us. But we are very open to what you are suggesting, definitely. These are - it doesn't matter the nationality or the ethnic background or anything, it is just that the program - the services that we are giving need all kind of assistance, we would be grateful if something like this happens.

DR. DABABNAH: If I can add, this is not exactly getting to your point, but at the University of Maryland, all of our medical students are trained on specifically on - there is a self-advocate who will come in and train medical students on autism. So I have been working with that organization to try to get more content on racial and ethnic disparities.

So in addition to those medical students understanding more about autism in general, in meeting someone who has autism, but understanding more about the racial disparities that exist because, you know, when we kind of look at Maryland, overall it looks like we are doing okay. But then I think, when you start looking more locally - like in Baltimore, we are still seeing - are still hearing from parents that, I told my pediatrician when my kid was 18 months old,

that I was really worried and they just brushed me off.

So the fact that that is still happening in 2019, is a concern. I think the more we can do to educate all you know, future doctors and other healthcare providers, the more progress that we will make.

MS. PROCTOR: One person that I might recommend that you reach out to - when I lived in Atlanta, he was my son's developmental pediatrician. He was really helpful to us. His name is Dr. Leslie Rubin. What Dr. Rubin does is that he is a private practitioner, but one day out of the month he volunteers at Children's Health Center of Atlanta, and he provides diagnosis to underserved communities.

But another thing that he does is he partners with Morehouse, a historically black university. He partners with their medical

school and he has these young doctors go on rounds with him. He is very encouraging of including the African American community in regards to the career path of being a developmental pediatrician.

He would probably be a great person. I've seen what he does, and I really like his approach. I think he might be helpful to you.

DR. GORDON: I want to thank the panelists and the committee members for a robust discussion. We are out of time but we are going to take a break now so if you have any individual questions you would like to ask the panelists, I am sure they would be happy to chat with you.

We are going to take a 15 minutes break and resume at 4 o'clock. Thank you very much.

(Whereupon, the Committee took a brief break starting at 3:45 p.m., and reconvened at 4:05 p.m.)

DR. GORDON: Next on the agenda, we are here to hear from Dr. Scott Robertson at the Office of Disability Employment Policy, U.S. Department of Labor. He will be discussing Department of Labor's Apprenticeship Initiative.

While he takes the podium, let me just reiterate what I said at the very end after we adjourned in case you didn't hear, but the House just did pass HR1058, which is the Autism CARES Act reauthorization. It next goes to the Senate.

DR. ROBERTSON: I am going to be co-presenting this with my partner over here, Carolyn Jones, who is also from the Office of Disability Employment Policy. I am going to do a few slides and then Carolyn is going to do a few slides and we are going to jump back. So, we are sharing and co-presenting this presentation together.

I am on the Employment-Related Supports Policy Team at ODEP. Carolyn is a senior policy advisor on the Youth Policy Team at ODEP. We collaborate on this initiative, on the Apprenticeship Initiative, which Carolyn is going to share in a second after I just share a couple intro slides on ODEP's mission and we seek to accomplish for improving competitive, integrated employment opportunities for people with disabilities.

So I am going to share ODEP's mission and vision and then Carolyn is going to be defining apprenticeship and discussing the Apprenticeship Inclusion Models Initiative, which we just launched earlier this fiscal year. Then I will be sharing the autism-specific aspects of that initiative as well as some ODEP resources and initiatives that are related in terms of our Technical

Assistance Centers. We have a topic resource webpage on autism, as well.

So ODEP is a non-regulatory, non-enforcement agency in the U.S. Department of Labor that - it seeks to promote policies and coordinate with employers in all levels of government to increase workplace success for people with disabilities. So we are an agency that's been awhile. Not everybody knows about us as much, but we started actually - we are a couple years - moving closer in a couple years to 20 years. So we started in the early years of the Bush administration.

So the focus is on shaping policies and practices through increased access to competitive integrated employment for all people with disabilities. So it is cross-disability, but that includes, obviously, folks with intellectual and developmental disabilities, including autistic people.

So we envision a world in which people with disabilities have unlimited employment opportunities that are commensurate with folks' skills and talents to be enhancing their life opportunities. As folks have often shared today that employment is a really valuable aspect of making sure that folks can have economic opportunities, economic self-sufficiency in life embodied for your skills and talents.

So now my colleague and partner here, Carolyn Jones, is going to be sharing what we mean by apprenticeship and how this differs from other aspects of, for instance, work-based learning and how it differs, for instance, from internships.

MS. CAROLYN JONES: Hi, good afternoon. As Scott mentioned, my name is Carolyn Jones and I am a senior policy advisor with the U.S. Department of Labor, specifically with

ODEP. I focus on youth initiatives, particularly for youth and young adults with disabilities.

Just to give you some background, in 2017, President Trump signed an executive order to expand apprenticeship opportunities across all industry sectors and, in particular, to underrepresented populations such as people of color and people with disabilities, people formerly incarcerated.

Now, apprenticeship has been around since the 1930s. Apprenticeship basically combines classroom learning, on-the-job training - paid on-the-job training, and some type of a credential upon completion.

Up here you will see the DOL has an apprenticeship website in which you can go and you can put - key in your zip code and find specific apprenticeship opportunities in your local area. You can key in the zip code.

You can key in the particular industry in which you are seeking. You can key in the occupation. And all of those opportunities in your local area will come up.

Also, just to further clarify apprenticeships, the apprenticeships are - as we are concerned, for it to be a true apprenticeship, it's either administered by - a registered apprenticeship - so, let me clarify. A registered apprenticeship is either administered by the U.S. Department of Labor or our state apprenticeship agencies.

So there are three components. It has to be paid. So you are paid from day one. Another component - must have related classroom instruction. You also get a mentor. And upon completion, you must come out with some type of credential. Apprenticeships generally last from one up to four years. Generally, they're about two years in length.

The difference between an internship and apprenticeship, an apprenticeship is employer-focused, meaning that the employer pays for the apprenticeship or the industry pays for the apprenticeship. It is a way in which employers can develop and train and skill up their workforce. For an individual, it's an opportunity for them to receive paid training, a paycheck, benefits, and a credential. So those are the distinctions.

With an internship, you know there is a some - you go generally for short periods of time. Often time, it is unpaid. You are not an employee. An apprenticeship, you are an employee. An internship, generally, you're not.

With an internship, generally, you don't come out with some type of certified, recognizable credential that is portable. With an apprenticeship, you do.

So those are some of the differences. And we, at ODEP, we see apprenticeship as a way of supporting people with disabilities, fully supporting people with disabilities, and also people without disabilities as we change and - as we change and technology emerges. So it's a way in which we can train, retrain, skill-up, particularly in shifts in technology when job shifts as well.

So let me just move on to an initiative that we launched actually in fiscal 2018, in September. It is called AIM, Apprenticeship Inclusion Models. Basically, we are researching, testing, developing, and evaluating inclusive apprenticeship in particular occupational skills training.

So we want to know what works, what doesn't work. We want to make sure that there are supports, wraparound services so people can not only get the occupational skills

training, they can also get employment placement and they can get supportive services to keep them in the job.

This initiative is \$2 million, 2 years. It is run by SPR, Social Policy Research, Incorporated, as well as Jobs for the Future - they are also known as JFF - and Wheelhouse Group. These three contractors provide technical assistance to - to Microsoft, Amazon, IMT - Industry Manufacturing Technician program, as well as healthcare program. So these are - these sectors, these industries are emerging industries in which they will actually pay a living, sustainable wage. And those are the reasons which we went to these particular - selected these particular organizations.

Now, two of these - two of our pilot programs focus on autism exclusively, youth and young adults with autism, meaning that

they're recruiting youth and young adults on the autism spectrum to be apprentices. As I mentioned, they are paid. They're employees from day one.

Microsoft is a - Microsoft has an IT, information technology, apprenticeship, as well as Amazon. So they are both focused on IT development, IT - web design, healthcare. They are focused on CNA, sterilization processing, LPNs. Industry Manufacturing Technician, they are focused on advanced manufacturing.

Now, Scott is going to provide some more information regarding the two pilots that are actually focused on autism. So I'll have Scott come back up.

DR. ROBERTSON: Thank you, Carolyn, for sharing an overview of AIM. And one of the things I often emphasize is it's

Apprenticeship Inclusion Models Initiative. I say alongside that aiming higher for greater opportunities for folks.

So I'm going to share a little bit more on our site. Just so you know for - in case the lingo wasn't clear because I know maybe this is Labor-specific lingo is credentialing is like licensure, certifications. It is something that helps you with attaining employment in that field or area. Whether traditionally that was say trades like plumbing and carpentry, now we have that for healthcare, for information technology, for manufacturing, for financial services.

And the reason why we focus on those particular domains is those are where the economy is growing as far as the jobs. Those are the four largest economic sectors. We happen to be focusing on three of them,

manufacturing, technology, and healthcare,
for this particular initiative.

So the Microsoft initiative, there's a -
there's an intermediary organization called
Apprenti, which is supported by the
Washington Technology Industry Association,
that has been doing support for
apprenticeships in technology for several
years now. Our technical assistance
initiative on accessible technology, PEAT -
PEATWorks.org - has been supporting them for
the last few years to coordinate and
collaborate on that and supporting
apprenticeship access for - inclusively for
people with disabilities and how, for
instance, in accessible technology skills
that can be one area for support.

And so in this initiative, Apprenti is
now supporting the pilot sites at Microsoft
and Amazon to be developing apprenticeships

focused on software development and information technology positions. Now, this could grow beyond that at those companies in the future. They do have other positions beyond, for instance, coders and software developers. This is just sort of a start on seeding in that area because they are technology companies.

The healthcare one, HealthCare Career Advancement Program, H-CAP, is already and intermediary organization for Registered Apprenticeship program at the U.S. Department of Labor. And so they don't really need a secondary intermediary organization that is assisting with this. They are assisting as the intermediary with organizations that they're partnering with on this to be setting up on the healthcare end on opportunities. That is focusing on jobs that are medical

coders, community health workers, and central sterile processing technicians.

The Microsoft one I also wanted to spotlight that they already are one of those companies - there's about I would say maybe 70 or 80 large companies now that have autism-focused hiring and recruitment initiatives. Microsoft is one of them. So one of the goals for this also is to cross-connect their existing autism hiring program to apprenticeships.

One of the values this has for benefit for autistic people and other folks with significant disabilities - and when we say autistic people, I mean folks across the range of support needs that folks need for supports and accommodations and accessible and assistive technology - is that, a, if individuals struggle in terms of being able to go to college for say four-year school or

two-year school or maybe had trouble in high school and middle school, they can still be going out to apprenticeship. It's an open pathway for folks.

It's also great - not only is it hands-on learning in a classroom and in the workplace for on-the-job training, but it is also great for folks who, for instance, maybe find that poverty aspect in terms of the socioeconomic adversity folks face - that there is no tuition associated with it. It is paid. So they're being paid as trainee-employees as they are going for the apprenticeship program.

So it is really great. Fits into what we were talking about on diversity on economic. You are talking about folks from a variety of different background. And that was a big emphasis for us. Folks from ethnic, racial, socioeconomic status, et cetera, their cross-

connection on disability with this apprenticeship initiative.

So I just wanted to share just briefly before we wrap up here some other resources from ODEP just while we're discussing improving access to competitive integrated employment, including for inclusive apprenticeship and related work-based learning.

So we do have a Technical Assistance Center on - specifically for employers. It's called EARN, so askearn.org. You can find a lot of different resources that can help connection with employers on how they can make sure that their workplaces are accessible for people with disabilities. And now it includes a lot more resources of neurodiversity and neurodivergence, including autism-specific information that has rolled

out there on AskEARN's website in the last several months.

The Job Accommodation Network, which many of you all on the Committee may be a little bit more familiar with and some other folks in the audience as well. It is free expert, confidential conversations folks can have from experts on the phone, over email, et cetera. They also have resources at the website for job seekers with disabilities, for employers, for friends and family members, for anybody that wants to assist folks with attaining employment.

They focus on how accommodations and, for instance, including accessible and assistive technology can be supportive of folks. That also includes accommodations for the job search. So adjustments and accommodations that can help folks retain their job and be successful in the workplace.

And then PEAT, which I mentioned earlier, the Partnership on Employment and Accessible Technology, peatworks.org, which has previously had blog post articles and other resources on a variety of different topics, including, for instance, those autism hiring initiatives and how they link back to the technology community and their experience with some of these companies like Microsoft and others that have autism-focused hiring initiatives.

Again, the website for the Apprenticeship Inclusion Models initiative is spra.com/aim, here, on the slides. That is at SPRA's site because they are our - one of the contractors leading this initiative in partnership with Wheelhouse Group and the other contractor on that, Jobs for the Future, JFF.

And then the other initiative we have - so, ODEP is a policy shop. We normally focus on enhancing policy and practices through increased access to employment. The one exception of a program that we also run for college students with disabilities and recent graduates, in conjunction with the Department of Defense, is called the Workforce Recruitment Program. Autistic people, for instance, are eligible for that. It helps folks with attaining jobs in the federal government because we have Affirmative Action through Schedule A to be able to access employment opportunities because we are a model employer as the federal government. And that it is also going to be doing more in the future on private sector jobs as well.

And then we have our contact information here on the slides. DOL's website is dol.gov and then you do slash ODEP to get to our main

website. We also have email address and phone number for ODEP on this - on the slides here.

We often do receive emails and calls from constituents. So if anybody wants to connect with us, they can. I have taken many calls and emails before from, for instance, autistic constituents and family members because in my subject matter expertise as their point on autism and neurodiversity. I have a lot of experience on that so feel free to connect folks with us if they're experiencing any barriers to accessing employment opportunities.

We also have an ODEP Topic Resource Webpage on Autism that includes resources on employers, apprenticeship, for instance, information links, youth and a lot of different other aspects of resources to connect folks with employment opportunities,

including service providers in the autism sphere.

Thank you for listening to our presentation on this inclusive apprenticeship initiative, Apprenticeship Inclusion Models initiative. I don't know whether you have time on the committee if you'd like to ask us any questions.

DR. GORDON: Do we have any questions?

All right. Thank you for your presentations.

MS. CRANE: This is actually Sam. I'm in the other room, but I'm still participating by phone and have a question.

DR. GORDON: Sure, go ahead, Sam. It's not too late.

MS. CRANE: Yeah, one of my concerns is I - if I'm not mistaken, one of the other exceptions, in addition to the sort of disability sub-minimum wage, is there an

exception to the minimum wage for apprenticeships? And if so, are these initiatives that ODEP is sponsoring - they are paid, but are they paid at the minimum wage? What are the salaries that people tend to earn?

MS. JONES: That is a great question. All registered apprenticeships must adhere to the Mavis Beacon Act, meaning that you must pay minimum wage at least.

MS. CRANE: Alright. Thank you. That is a simple answer.

DR. GORDON: All right. Thank you. So the next item on our agenda is a Summary of Advances discussion. Susan.

DR. DANIELS: So I wanted to give you a brief overview of what's going to be happening with the Summary of Advances as the Committee will be going out of session.

So the current IACC members may continue to nominate articles by email through September 30th, 2019. Once a new IACC is convened, new members will also have an opportunity to nominate any other articles published in 2019. This is assuming that there is a hiatus and that the Committee does not continue to meet in 2019, which - you know, anything can happen. We don't know how that will work. But in the past years, there has been a gap.

All nominations will be considered by the new IACC members and they will make the final selection of articles for inclusion in the 2019 IACC Summary of Advances. So if there is a gap in the Committee, then it won't be published right away. It will be published when the new committee comes back.

Alison, do you have a question?

MS. SINGER: If the reappointment process is anything like it's been the last two times, it is going to be 9-12 months until a new IACC is seated. So maybe it makes sense for the current IACC to vote for a 2019 Summary of Advances through September as a placeholder just in case the new committee is not appointed in 2020 so that we can publish a Summary of Advances in 2019. Otherwise, there is going to be a gap in publication.

DR. DANIELS: That is a question. The only disadvantage is that articles that were published after that time would not be considered. That is something up to the committee if you want to only consider articles up to September 2019.

DR. GORDON: But then they could be considered by the next iteration. We could note that somehow in publication.

Any other thoughts agreeing -
disagreeing with Alison?

DR. DANIELS: Not understanding, though,
in terms of - if we publish a 2019 summary
and it is already completed, then there
wouldn't be any more work to do on 2019.

MS. SINGER: My suggestion would be that
the Summary of Advances for 2019 would be
nine months' worth and then the Summary of
Advances for 2020 would start in the fourth
quarter of 2019 and would be five quarters.
At least then there would be no gap in
publication.

DR. GORDON: Actually I think that is a
good idea. I see some nods around the table.
Okay. We'll do our best to make that happen.
That will require us to vote via email the
way we normally vote, but we're not prepared
currently for a discussion here. We'll have
to have some discussion via email.

DR. DANIELS: All right, so we will consider that.

So now we'll move to the Summary of Advances nominations, April through July. You have those in front of you and we have them on the slides. All of the people who nominated these may not be in the room, but we have a number of different nominations.

This one was from - do you want to - so if you like -

DR. GORDON: You are fine. If you are prepared to and you would like to, Nina, you may comment.

DR. SCHOR: No. I mean it is just to say that this is - we thought - our group thought this was an interesting study because it followed phenotypic characteristics of individuals diagnosed relatively early on with autism to say how many of them truly, 18, 24 months out, solidified that diagnosis.

The identification early on appeared to be reliable and robust because all but I think, one or two percent of these individuals turned out to have a definitive diagnosis of autism down the road.

DR. DANIELS: Question 2. There were a couple of articles here.

DR. GORDON: Louis, did you want to comment on Avagliano at all? Looks like it came from your shop.

DR. REICHARDT: (indiscernable comments)

DR. GORDON: Microphone.

Okay. Then the next two were from Walter.

Microphone.

DR. REICHARDT: This is work that I have known about for a long time. Finally got published. So the concept has always been that the ubiquitin ligase, UBE3A, acted by - through control of proteins turned over the

synapse. What this paper showed was actually that nuclear deletion within the nucleus, where it has always been known some resided, was sufficient to recapitulate the autism relevant phenotypes in rodents that has been previously ascribed the actions at the synapse. So it is quite a different conclusion and shows the limits of making models in biology I guess.

DR. GORDON: The next two, Nina, were from Walter - Pagani and Sharon.

DR. SCHOR: The Pagani article actually relates specifically to Phelan-McDermid Syndrome and the fact that if you take mice and disrupt the Shank3 gene, you get a disruption of connectivity very similar to what has been proposed to be the case and etiologic of the phenotype in Phelan-McDermid Syndrome.

The authors actually propose, although they don't show, that this may be a mechanism more common than we think in other etiologies of autism.

The next one I think was - yeah, was also Walter's proposal. This is one - it is kind of interesting. I mean it actually takes gut microbiota from individuals with autism and from individuals who do not have autism and puts them into mice that have been - whose guts have been rendered axenic and shows that those mice, in the case that they got microbiota from individuals with autism, show certain behavioral characteristics that are reminiscent of autism.

Walter, I think, thought that even if it turns out that this mouse model is not truly a mouse model of autism, just the demonstration that gut microbiota have

anything to do with behavioral outcomes is an interesting result.

DR. GORDON: The next one, Velmeshev, is really the fruit of what has been a - important developments in our technology to be able to study single cells in the brain and gene expression within them, even in post-mortem tissue.

The study showed that if you study single cells within the brain, then you can get reproducible changes in gene expression that may help us understand some of the origins of the illness. In particular, it points to two cell types, immune-related cell types called microglia and particular kinds of neurons in the upper layers of the cortex.

I would say, collectively, these three papers that were nominated by - well, actually, these four papers that were nominated in question two point to the fact

that as we get more and more hard clues and better and better technology, we are getting some really quite - more specificity to our hypotheses about what might be going on in autism and portend for I think an expansion in our knowledge in the neurobiologic and perhaps also gastrointestinal manifestations and/or causes of the illness.

DR. DANIELS: Question 3.

DR. KAU: This is a population-based family study on the relative importance of inherited versus non-inherited causes of autism. The study data came from five countries of the MINERvA Network. The five countries are Denmark, Finland, Sweden, Israel, and Western Austria. MINERvA or Multigenerational Familial and Environmental Risk for Autism Network is compiled of the largest family-based database for autism research.

This analysis including the full birth cohorts of children born between January 1, 1998 until the end of 2011, which represents more than 2 million individuals. And according to the analysis model the authors generated, the heritability of ASD was estimated to be about 80 percent, which is consistent with previous estimates.

This study - it is important for two reasons. One is due to the large sample size. So the result is more precise with a more narrow - narrower confidence interval than other estimates. It is important also because it's - all the previous estimates are - estimates were based on - most of them based on twin studies. So this study - current study not only replicated previous results, but also provides the validity in the general population.

NICHD and NIEHS co-funded this Autism Centers of Excellence. I know Cindy has some comments as well.

DR. LAWLER: Thanks. This is - I agree with Alice. This is a really strong study, an outstanding team of investigators. It demonstrates the challenge of communicating pretty complex science findings because what doesn't make the headlines are what are really important limitations of the study approach. These are laid out very nicely by the authors of the study as well as in the accompanying editorial.

Just briefly, the kinds of heritability approaches that are used, including the one in this - that was used in this particular case, don't do a really good job of partitioning the variants in ways that accommodate non-additive effects like gene-environment interaction, epigenetic effects.

We know some of those can be inherited - transmitted across generations.

The maternal effects that are estimated do not include exposures of the mom during pregnancy, for example, infections. These limitations are important because we don't want to dismiss thinking about what environmental contributors to autism there may be, though non-genetic or environmental exposures are ones that can be modifiable. It would be really unfortunate if this study discouraged investigators from sort of further examining environmental contributors.

Many of the studies that NIEHS supports are in that very space, that gene-environment interaction space, that is not accounted for in this study.

DR. GORDON: Geri Dawson submitted the next one. She is gone. Question 4 then, Alison Singer.

MS. SINGER: I think this study speaks to the fact that what works in the lab doesn't always work in the community and that we need to do a better job when we are implementing research in community-based settings. Basically, it showed that across lots of different outcomes using the same intervention the outcomes were much worse when they were applied in community settings than in a research setting.

It sort of works with the next item, which if - question 4, if this study is pointing out the problem, then the next one is really pointing out the solution. This was an example of a study showing how it is possible to target behaviors in a community-based setting. This was one that was targeted in a school setting. Really, the only way that people are going to be able to receive services in the community-based setting,

meaning enough people will be able to receive them, is if we can show that they can be delivered. These two together I thought were important to include.

DR. GORDON: The next two were submitted by us, by me, from NIMH. They are both related to actually things that we were talking about today and yesterday, the state differences in provision of services and also racial and ethnic disparities.

The first one discusses the effects of legislative mandates on health insurance to cover intervention services for ASD and how that is affected by different kinds of insurance plans. In particular, noting that shifts to high deductible health plans actually increased spending for children with ASD, but that spending was attributed to actually higher costs of the services and not increased out-of-pocket spending.

The second one, the LaClair et al., speaks directly to racial and ethnic disparities and the effects of - the ease with which individuals are able to get Medicaid waivers for home and community-based services. It's interesting because there was a lot of discussion about those waivers today and how difficult they can be to get.

And this points out that making HCBS waivers more available to individuals across the state, not necessarily targeted in any racial/ethnic group, but available throughout a state, decreases the disparities in access to care between white and black Americans - I should say citizens of those states where you make these waivers more available. Overall, cuts the unmet needs among black children with ASD by about half.

So one tool to reduce disparities in access to appropriate care for autism would be to expand the access of Medicaid waivers.

It looks like Alison, you're - let's go over David's, but you're the next one, the final one.

Sorry. Please, Julie. Go ahead.

DR. TAYLOR: This was a study with 200 young adults on the autism spectrum, looking at changes in service access before and after high school exit. Instead of finding a services cliff, we found a services slope where we saw that actually services started dropping off years before high school exit.

We saw different patterns for those who did and did not have intellectual disabilities. So for those who didn't have an intellectual disability, services dropped off pretty quickly before high school exit and then just continued to decline after. For

those who did have an intellectual disability, we saw less of a drop off before high school exit, but a big drop at leaving high school. Just showing that if we are thinking - we may need to start thinking a little bit earlier when we are thinking about the services cliff.

DR. GORDON: Last but not least, Alison.

MS. SINGER: This last one actually speaks directly to the invited public comment delivered by Ms. Myrick on the panel earlier. This was a meta-analysis that showed that even though the CDC reports that 50 percent of the population of people with autism have intellectual disability, only 6 percent of participants in autism research are identified as having intellectual disability.

Further, it went on to show that any information about intellectual ability was absent in 38 percent of the studies. So this

really speaks to the fact that we have to find new strategies to broaden our inclusion criteria so that we are including adults and children who have severe forms of autism.

DR. GORDON: Thank you, Alison, and that point was made by one of the speakers on the panel - on the disparities panel as well.

MS. SINGER: Yes, that was the invited public comment from Ms. Myrick. She spoke exactly to this.

DR. DANIELS: With that, we are ready for Round Robin.

DR. GORDON: Great. Thank you. We will go around the table. I think we are going to start with Alison since, Alison, you requested in advance to be able to talk about something.

MS. SINGER: Yes, I even sent in a slide.

DR. GORDON: Can we get Alison's slide up? Do we have it? We don't have it. Sorry.

MS. SINGER: What a way to end my tenure. Anyway. So the Autism Science Foundation together with the University of Pennsylvania has launched a new study. It is a survey. It is called the EXPECT Survey. It stands for Experience of People Enrolled in Clinical Trials. Our goal is to really understand what drives people to participate in autism research and what makes them quit because we know that so many fewer people with autism are participating in clinical trials than in other - with other medical conditions.

Our goal with this is really to try to help scientists to develop better studies that are positive experiences for families and participants. It's a very short survey. It asks about very specific research experiences at site-based studies.

And also, if you haven't participated in research, we would love you to fill out this

survey and help us understand why. So we're looking at examining philosophical barriers, structural barriers, all of the barriers. Again, the goal is to deliver very practical, granular data back to the sites so that they can improve the experiences for people who are participating.

The graphic is not up, but you can access the survey at bit.ly/expectsurvey. We will post it on our website and I think it's also posted on the IACC website as well.

DR. DANIELS: It is and it was in the last IACC/OARC newsletter. So those of you who have that. And you can also find it on our website. We did have a little blurb for that and you can click on it to get into the survey.

MS. SINGER: I also wanted to add that we have two stakeholder educational events coming up. The next one we are running our

Autism TED Talks for the first time in San Francisco this year. It will be on October 17th. The keynote address will be given by the former IACC chair, Dr. Tom Insel. So we're thrilled to have him.

Then we'll have our New York City-based Autism TED Talks on March 31st of 2020. Our keynote speaker at that event will be IACC member Dr. Louis Reichardt.

So there is information about both of those events on our website. I hope lots of you will choose to attend.

DR. GORDON: Thank you and I will just point out that that survey also addresses many of the points that were brought up in the - by the panel pertaining to participation in research as well as the paper that you cited, trying to figure out how we can enhance participation across the - across the board.

Let's just go around the table. Anyone on this side want to make a comment or announce something? Go ahead, Marcy.

DR. RONYAK: Thank you. Marcy Ronyak, Indian Health Service. I have two announcements.

One huge announcement that Congress has been very interested in is Indian Health Service has just hired a Maternal-Child Health Consultant, who is also my deputy. It will be somebody that I will be getting involved in the autism work as she is a pediatrician. It is Dr. Sharon McKernan. We are extremely excited to have her. And we will be heading out to do some site visits and talking about screening and things of that nature as well.

The other piece is that IHS has been partnering with Autism Speaks on making some connections and developing our own ECHO

project for autism. So we are working on that and hoping to be able to roll something out soon. So please look out for that. Thank you.

DR. KAU: I don't have specific initiative announcement, but I do want to reiterate NICHD's interest in supporting research that incorporate individuals with intellectual disabilities. That is one of our long-term commitments for children with autism and intellectual disabilities.

DR. GORDON: Thank you, Alice.

DR. JOHNSON: Hi. I just have a couple of announcements or updates in regards to new funding opportunities that we have.

One is called Human Dignity and Civil Rights for People with Disabilities. This is going to be a three-year cooperative agreement. It is going to focus on some of what was covered by our last panel in terms

of access to healthcare and disparities, people with ID/DD experience.

It is going to focus on looking at - or will conduct a gap analysis on issues within the IDD population in terms of accessing healthcare and looking at things like access to organ transplants or denial of organ transplants, looking at mental health referrals, prenatal counseling, aging issues, end of life issues, and those kinds of things. Through that gap analysis, we would like the grantee to then develop protocols to better support medical professionals in treating individuals with ID/DD so that they can hopefully get better access to healthcare.

So that is one new project that we will be funding. The other is on supporting decision-making across the lifespan. These will be planning grants.

This is a project that we are doing in collaboration with the Administration on Aging and builds on work that we have been doing in this space to provide alternatives to guardianship and support people in making their own decisions and to ensure their self-determination. This is a concept that we have been exploring across both the - across older adults and people with ID/DD. These grants will be planning grants to states to bring state coalitions together to identify where the gaps are in their state and where is the community of aging and disability groups be able to fill in those gaps through an action plan.

So those are both announcements that we have out currently. Thank you.

DR. NICOLE WILLIAMS: So the Autism Research Program, we are just finalizing our FY18 awards. Once those are finalized, we'll

have the abstracts and all the information posted on our website.

And then we actually have our applications due in a couple weeks that were invited to submit through our three award mechanisms. So other than that, it's pretty quiet.

DR. GORDON: Other than that. Anything Nina?

DR. SCHOR: I think just that we are - at NINDS, are very heavily involved at this point in strategic planning for the next five years, as many of the other institutes at NIH have been doing. I have absolutely no doubt that partnerships with other institutes around intellectual disabilities and autism are going to figure very heavily in that plan. So -

DR. LAWLER: Hi. I just have two really exciting grant awards that were made in the last few weeks and another one late spring.

The first is a study that is looking at the association between air pollution and autism risk. This is an award to Li-Ching Lee, Johns Hopkins University, who will work with colleagues in China to take advantage of a natural experiment, which was aggressive air pollution control measures around the 2008 Beijing Olympics.

So she will be doing screening of children for cases of autism and autistic traits. And the children that she's being - she's screened, of course, will be at different stages, you know, in gestation. So the investigators hope to be able to identify particularly susceptible windows and also they'll be looking to see whether any

associations are mediated by things like birthweight or gestational age at birth.

Then the second exciting project is to Mark Zylka at University of North Carolina at Chapel Hill. This is a special large eight-year award, part of using a mechanism that NIH recently developed, People Not Projects. This is to address the challenge of investigators who spend all their time writing grants.

So there is an eight-year period of award and outstanding investigators with a strong track record and potential for impactful research apply to this. They lay out a fairly high-level vision, set of hypotheses, and general approaches that will be applied. They have a lot of flexibility in that eight-year period to sort of redirect, to move their research in new directions.

Mark Zylka's - a centerpiece of Mark Zylka's project is based on this gene-environment interaction idea. He's developed some methods to identify environmental use chemicals that interact with some of the molecular pathways that are implicated by the genetic findings.

Over the course of that eight-year period, of course, he will be able to continue to sort of leverage new information that comes out. We've heard some of it today about the biology of autism. So those are two really exciting projects.

DR. SHAPIRA: Good afternoon, Stuart Shapira from CDC and this announcement is hot off the press. The National Center on Birth Defects and Developmental Disabilities of the CDC is undergoing a reorganization. And it will be implemented at the start of the new fiscal year on October 1st, but it's been

approved all the way through HHS. And it's just been published in the Federal Register.

The goal of the reorganization was to align similar topic areas in two of the divisions in the National Center. This means we're going to be better poised to leverage scientific and administrative expertise, to maximize program activities and resource management.

As I mentioned, it only involves two divisions in the Center. One of them is our Division of Congenital and Developmental Disorders, which monitors birth defects and infant disorders in order to identify preventable causes of these and also tracks lifespan issues related to children and adults with birth defects, genetic disorders, and other adverse pregnancy outcomes.

The other division is our Division of Human Development and Disability, which

researches and shares important data and interventions that may lead to prevention opportunities and improvements in the lives of children living with developmental disabilities.

Now, the intent of the reorganization was to optimize alignment of the programs in these two divisions and, specifically, the part of the reorganization that is relevant to this committee is that the Developmental Disabilities Branch where autism and developmental milestone programs reside will move from one of the divisions to another division. Patty Dietz, who's here with me from the CDC, she is the branch chief for that branch that's moving from one division to the other. This will allow work in her group, which focuses on autism and monitoring for developmental disabilities, to align with other areas of work on Attention Deficit

Hyperactivity Disorder, Tourette Syndrome, Fragile-X Syndrome, and other developmental and intellectual disabilities.

So we actually anticipate the changes will be seamless to partners. In most cases, partners will continue to work with the staff that they've been accustomed to working with in the past.

DR. GORDON: Thank you, Stuart. Louis.

DR. REICHARDT: I'll use the mic. So Simon's Foundation - I mean the first I should say is I think SPARK, the new recruitment project, is very close to 100,000 individuals with autism enrolled and 200,000 individuals.

Of particular note, you know, we started this program called ResearchNet, basically so scientists can apply for research studies. If families meet the criteria, they are invited to participate. We have been simply

overwhelmed. There were more than 40 applications during the last quarter. So we're very hopeful about the progress of this.

I should say particularly the online studies, the response rate has been incredibly high. I mean it's been more of a challenge for the studies that require clinical visits.

About 6,000 family exome sequences have been released and another 6,000 are in process. For 16p, you know we have been providing the drug to Canadian trial for R-Baclofen that has started and an EU-AIMS trial, which may start, subject to Brexit and everything else I guess.

We also have signed contracts to do a much smaller or earlier phase study on - with just 16p as opposed to general autism on R-Baclofen within the United States. This is

based on some human studies we did, very short-term exposures, looking for normalization of processes such as binocular rivalry in the 16p population. So we are hopeful on that. We have a contract. The clinical organization is verifying the criteria - the qualifications and setups of the individual sites that are going to be involved. Hopefully, we'll get going.

And as I mentioned earlier, we made these special grants to UCLA, CHOP, and actually Baylor/Texas Christian to increase the minority representation in the SPARK population.

Going back to genetics for the moment, I'd say there's one thing that is not SPARK, but it is the Simons Foundation, the Flatiron Institute, that Olga Troyanskaya and her colleagues had a paper that basically involved predicting the impact of non-coding

region genes on - non-coding region segment of DNA on enhancers, promoters, splice sites, and so on. This paper, which was published recently in Nature Genetics basically adds another four percent to the high-risk to the autism genetic contribution. I think it's a very - it basically is predicting - it's predictive and it was verified with the autism cohorts. So I think it's important.

We just finished a new round or second round of our new pilot projects. We had made final decisions over the summer on our now four-year long research grants. We have a new - we also made final decisions on the Novel Outcomes RFA, the second time we have done this. I mean the first series have been completed about three years ago.

And Autism BrainNet - it is unfortunate David is not here, but we are distributing

tissue from the new as well as the inherited specimens.

DR. GORDON: Thank you. Julie.

DR. TAYLOR: (gestures no)

DR. GORDON: Okay. We're just about out of time. I want to, again, thank members of the IACC for their service over the years as I said before when we started the meeting. But I also want to - what we didn't say before - thank Susan and her staff, who is back there, and all around. Why don't you all stand up?

(Applause)

This committee has done a lot. That means that these folks have done a lot. All of those reports, all of the materials for each of the meetings, all the workshops, synthesizing information, getting us information, writing all the summary reports, editing them, making sure they sound good,

look good, are written well, and have impact, it is really due to the team here and we really appreciate your efforts.

Sam, I'm sorry. We missed you.

MS. CRANE: Hi. I just wanted to let you know that ASAN - I mentioned this yesterday, but we published a Community Living Toolkit that was based on a summit that we hosted. It included self-advocates from a variety of backgrounds and support needs.

One thing that is topical because we just heard about the need for community-based participatory research, one of the topics - really common themes we saw in our summit was ideas for future research. So we actually included as part of the toolkit a separate, standalone recommendations for future research on community living. It goes across the whole gamut.

We didn't want to edit it too heavily. So we basically included almost every idea that our self-advocates suggested. Some of - we kind of ranked them by level of urgency. But it includes some really fun questions. Any researchers out there want to pick those up and run with them, let me know.

And then forthcoming because I don't know - you know, hopefully, knock on wood, I will have the chance to say this in the fall, but we have two toolkits that we are producing with the National Council on Disability. They're almost ready to be released. One is a paper that examines the role of quality-adjusted life years in making treatment decisions and disability-right concerns that are associated with quality adjusted life years.

And another examines the problem of discrimination in organ transplantation decisions.

Both of those are really important issues in terms of access to healthcare. I hope that when they are released, people will be able to check them out.

DR. GORDON: Thank you, Sam. Again, thank you everyone. This closes the meeting. Sorry, Susan needs to -

DR. DANIELS: Could I say something before we close off? I would also like to thank the committee, the members of working groups and speakers that were here today and our public audience that has been following the journey of the IACC, some for many, many years.

To some of our very long-term members, who have been with us for a while, we really appreciated you.

With this new bill that is passing through and has now passed the House, it will be proceeding to the Senate. If it goes through as it is currently written, we may be having four new departments join the IACC, including Department of Labor, HUD, DOJ, and the VA.

Just another reminder, with the call for nominations that would come out if this bill does become law, we will - the Department will welcome wide geographic representation across the United States and territories, representation across the entire autism spectrum, representation across many stakeholder, community, and professional groups, and representation across various other forms of diversity.

So we will really welcome those nominations. Please talk within your communities about people who might be

interested in putting in a nomination. There will be, again, self-nominations as well as nominations by others. We will welcome nominations from across the whole country.

Thank you very much. Safe travels everyone.

(Whereupon, the meeting adjourned at 5:05 p.m.)