INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

THURSDAY, APRIL 19, 2018

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

PRESENT:

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

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

JAMES BALL, Ed.D., B.C.B.A.-D, JB Autism Consulting (attended by phone)

LINDA BIRNBAUM, Ph.D., D.A.B.T., A.T.S. National Institute of Environmental Health Sciences (NIEHS)

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

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

PRESENT: (continued)

ALLISON CRUZ, (representing Jennifer Johnson, Ed.D.) Administration for Community Living (ACL)

GERALDINE DAWSON, Ph.D., Duke University

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

MELISSA HARRIS, Center for Medicare and Medicaid Services (attended by phone)

ELAINE HUBAL, Ph.D., (representing Ruth Etzel, M.D., Ph.D.) Environmental Protection Agency (EPA)

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)

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

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

DAVID MANDELL, Sc.D., University of Pennsylvania

EDLYN PEÑA, Ph.D., California Lutheran University

PRESENT: (continued)

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

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

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

JOHN ELDER ROBISON, College of William and Mary

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

NINA SCHOR, M.D., Ph.D., (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)

MELISSA SPENCER, Social Security Administration (SSA)

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

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

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

PRESENT: (continued)

BUCK WONG, (alternate for Judith Cooper Ph.D.) National Institute on Deafness and Other Communications Disorders (NIDCD)

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PROCEEDINGS

DR. JOSHUA GORDON: Welcome to the IACC committee members and to the public, as well as our newest, Dr. Melinda Baldwin, who will be representing the Administration of Children and Families on the IACC. It doesn’t look like she is here yet, so we will extend that welcome when she arrives.

Also, Ms. Allison Cruz, will be serving as an alternate for Dr. Jennifer Johnson, from the Administration for Community Living. Dr. Elaine Hubal, who will be serving as an alternate for Dr. Ruth Etzel, from the Environmental Protection Agency. So none of those three are here?

Oh. Why don’t you go ahead and introduce yourself?

DR. ELAINE HUBAL: I am Elaine Cohen Hubal. I am with EPA’s Office of Research and

Development. Currently the director of our Computational Exposure Division. Happy to be here. Have worked a lot on our Children's Environmental Health Roadmap.

DR. GORDON: Thank you and welcome. Next we will have the roll call and the approval of the minutes. Susan.

DR. SUSAN DANIELS: Good morning. I would like to take a roll call to see who is here. Joshua Gordon.

DR. GORDON: Here.

DR. DANIELS: Buck Wong for Judith Cooper – Jim Battey.

DR. WONG: Here.

DR. DANIELS: Yes. Diana Bianchi.

DR. ALICE KAU: I am here. I am sitting in for Dr. Bianchi.

DR. DANIELS: Thank you, Alice. Linda Birnbaum.

(No response)

DR. DANIELS: Carrie Wolinetz.

(No response)

DR. DANIELS: Elaine Hubal.

DR. HUBAL: Here.

DR. DANIELS: Tiffany Farchione.

(No response)

DR. DANIELS: Melissa Harris.

(No response)

DR. DANIELS: Allison Cruz.

(No response)

DR. DANIELS: Laura Kavanagh.

MS. LAURA KAVANAGH: Here.

DR. DANIELS: Nina Schor for Walter Koroshetz.

(No response)

DR. DANIELS Laura Pincock.

DR. LAURA PINCOCK: Here.

DR. DANIELS: Marcella Ronyak.

DR. MARCELLA RONYAK: Here.

DR. DANIELS: Stuart Shapira.

DR. STUART SHAPIRA: Here.

DR. DANIELS: Melissa Spencer.

MS. MELISSA SPENCER: Here.

DR. DANIELS: Nicole Williams.

DR. NICOLE WILLIAMS: Here.

DR. DANIELS: Who is on the line?

(No response)

MR. JOHN ROBISON: Are we going through this in order? Did you say me, and I did not hear?

OPERATOR: We are unable to hear the auditory at this time.

DR. DANIELS: David Amaral.

(No response)

DR. DANIELS: Jim Ball.

(No response)

DR. DANIELS: Samantha Crane.

(No response)

DR. DANIELS: Geri Dawson.

DR. GERALDINE DAWSON: Here.

DR. DANIELS: David Mandell.

DR. DAVID MANDELL: Here.

DR. DANIELS: Kevin Pelphrey.

(No response)

DR. DANIELS: Edlyn Peña.

DR. EDLYN PEÑA: Here.

DR. DANIELS: Louis Reichardt.

DR. LOUIS REICHARDT: Here.

DR. DANIELS: Rob Ring is going to be on the phone. Rob, are you on the phone.

(No response)

DR. DANIELS: John Elder Robison.

DR. ROBISON: I am here.

DR. DANIELS: Alison Singer.

MS. ALISON SINGER: Here.

DR. DANIELS: Julie Taylor.

DR. JULIE TAYLOR: Here.

DR. DANIELS: Did I miss anyone? All right, so we have the roll.

Next, I turn your attention to the minutes from the January 17, 2018 meeting. Did anyone have any corrections or comments on these minutes? Hearing none -

MS. KAVANAGH: Sorry, Susan. This is Laura Kavanagh. While I appreciate the honorary degree, I am not a doctor.

DR. DANIELS: Thank you.

OPERATOR: This is the operator. We are unable to hear you from the room.

DR. DANIELS: All right, anything else? Hearing no further comments, can we have a motion on the floor to accept the minutes?

DR. REICHARDT: So moved.

DR. DANIELS: Thank you. All in favor?

(Chorus of "ayes".)

DR. DANIELS: Any opposed?

(No response)

DR. DANIELS: Any abstaining?

(No response)

Sounds like a unanimous vote to accept the minutes as written, with the correction of Laura Kavanagh’s title. So we will be posting these minutes after the meeting. Thank you

DR. GORDON: Do we have the audio working? We will take a couple of minutes to see if we can get it up and running before we proceed.

(Pause)

DR. GORDON: Is it working now? Who do we have on the phone, committee members?

DR. JIM BALL: Jim Ball.

DR. GORDON: Thank you, Jim. Anyone else?

MS. MELISSA HARRIS: Melissa Harris with CMS.

DR. GORDON: Thank you, Melissa.

OPERATOR: This is the audio operator. We are barely able to hear you.

DR. GORDON: Barely able to hear. I am loud and clear in the room, so we will have to try to adjust the volume up on the phone. Barely will have to do for now. Hopefully they will be able to get it better. In the meantime, we will go ahead and proceed with the meeting.

It is my pleasure to introduce my colleague, Dr. Ann Wagner, who for longer than we can figure out, has been the lead for all of NIH and autism research. She is the chief of the Biomarker and Intervention Branch – sorry, for Childhood Onset Mental Disorders Branch in the Division of

Translational Research, at the National Institute of Mental Health.

About six weeks ago, I am guessing, was appointed as the National Autism Coordinator by Secretary Azar, for the Department of Health and Human Services. Those of you who had been on the Committee, know that Dr. Tom Novotny had filled that roll during his tenure at HHS, but he left shortly after presenting the report on Transition in Autism, and HHS decided to ask NIMH to nominate someone to fill that role and I could not think of anyone better than Ann to do so.

So I have asked Ann to briefly introduce herself this morning to you all and to provide the usual update from the National Autism Coordinator. Ann.

DR. ANN WAGNER: Thank you. Good morning everybody. I am very pleased to be here. One of the probably most important parts of this new role is the close coordination with the IACC. I am looking forward to continuing or picking up where Dr. Novotny left off and Dr. Daniels who was acting coordinator for a while, picking up where they left off.

But first I want to tell you a little bit about myself just a couple of minutes about me and where my interest in ASD came from and then briefly about my plans--so what I have been doing for the past month and my plans are for the immediate future and then I am happy to hear comments or suggestions.

Just a little bit about myself. As with a lot of people who end up specializing in this field, my interest really started with the relationships and not personal family relationships, but relationships I have developed as a care provider. Before I came to NIH, I was at Children's National Medical Center in DC, I’m a clinical psychologist by training. I started there doing general developmental work. I do not have time to go into the set of coincidences and fortuitous opportunities that led me to start specializing in what we then called pervasive developmental disorders. But I ultimately worked with a colleague there, Ken Tobin, who was a child psychologist who is at NIMH now, to develop and co-lead a multidisciplinary clinic for pervasive development disorders.

We found out quickly that there was not such a specialty clinic in the whole DC area. We became very busy very fast. In my work there, I really came to appreciate the unique challenges that people with ASD and their families face as well as the unique strengths that they bring to bear in facing those challenges and had some really remarkable and marvelous experiences going down that road with several families.

That was the beginning of my career focus on ASD. I came to NIMH in 2001. Since then there have been transitions in my positions there, but I have maintained a focus in autism spectrum disorders as well as a focus on the development and testing of interventions for childhood onset mental disorders including ASD. I have maintained that focus.

One of my roles at NIMH that is relevant here is that for the past several years as ten or more years as Josh mentioned I have been coordinating the NIH Autism Coordinating Committee. That is a committee made up of all of the NIH institutes that are funding research related to ASD. We meet regularly to inform each other of what we are doing but probably more importantly, we work together on multi-institute initiatives like the Autism Centers for Excellence and the Autism Biomarkers Consortium for Clinical Trials to name a couple. We work very closely together and that has been a very gratifying experience. I hope to take what I have learned in that coordinating role and apply it to this broader coordination activity.

What I have been doing for the past month is largely talking to people and listening and looking into what came before. I re-read the transition report in detail. Some people have reached out to me from the government and from outside of the government to talk. But I have also reached out to the people who were the federal people who were involved in putting together the transition report. I am re-convening that working group, but I wanted to expand it because I think it is going to have a broader focus. I have invited some people who have reached out to me to attend those meetings. It is open to anyone. I have not yet contacted who has activities or responsibilities related to ASD.

We are going to have our first meeting in June. My idea at this point is that we will meet several times a year, but in between the full working group meetings, smaller groups will be working on particular projects or activities and then we will get back together to inform each other about progress. We will be starting by looking at the recommendations and the transition report and what people are doing now that can address those recommendations and also what could be done.

I am very excited to learn about all the different programs and what the opportunities and challenges are from those programs. This is going to be a learning experience to me, but I am really looking forward to it and looking forward to working closely with Susan and the IACC. Thank you.

DR. GORDON: Thank you, Ann, and welcome aboard or I should say welcome staying aboard. Most of you probably recognize Ann from lurking in the back of IACC meetings, looking for things that we can do in the research side. Her continued involvement is most welcome.

Next up we have our panel this morning on employment for people on the autism spectrum. This is an issue that many of you have raised that deserves further attention from the Coordinating Committee. Susan and her team have put together with your advice I think a really diverse group of people who have been working on this issue for some time.

The panel consists of Scott Michael Robertson. Dr. Robertson is the policy advisor for the Youth Policy Team in the Office of Disability Employment Policy at the US Department of Labor.

Jose Velasco who is vice president of Operations and Strategy and Global Co-Lead of Autism at Work, a program of the SAP Company.

Marjorie Madfis of Yes She Can, Incorporated. Lori Ireland, co-founder and board member of Extraordinary Ventures. And

Paige Morrow, the managing director of Extraordinary Ventures. I welcome our guests.

Scott is going to start us off. If you would come to the podium at the nominal front of the room.

DR. SCOTT MICHAEL ROBERTSON: Thank you all. I am here from the US Department of Labor, Office of Disability Employment Policy, which has a cross-disability focus. But I will be sharing autism and neurological diversity have increasing importance to especially since it is of great importance to a large group of employers, many of whom have launched autism centers, autism-focused hiring initiatives, recruitment initiatives because they understand how much at the same time there are challenges and barriers requiring supports, but that there is undertapped talent too, that a lot of folks have gifts and talents and strengths.

I will be talking a little more on the opportunity side. I recognize there are very significant barriers out there. There is large unemployment, under employment. We know these things, but we are trying to shift things onto what are the opportunities out there for employers and service provider organizations to be able to hire folks. I will be sharing a little on the autism side of things and what we do on ODEP specifically.

ODEP is a federal agency, Office of Disability Employment Policy, in the US Department of Labor. We have been around since 2001. That is 17 years now. It started in the Bush Administration. We are non-regulatory. A lot of the focus is on guidance, best practices, supporting other federal agencies in other departments across the government and connecting with employers, service provider organizations, and others to increase employment opportunities for all folks with disabilities – unlimited employment opportunities that match the skills and talents of folks who are job seekers and employees with disabilities. We envision a world in which people with disabilities have these unlimited opportunities with the supports folks need.

This is a long-term journey to get there because it is a path forward that is very challenging, not just in the autism end, but for folks with disabilities broadly. A lot of the numbers do not look great when you look at unemployment and under employment although that is starting to change over time with system change. But it is a complex set of systems that connect to that to make sure that folks can get access to employment opportunities and plan work places that match what their skills and talents are.

Some of our current priorities. I just want to share a little on what we are working in ODEP broadly before I move to our autism-centered focuses especially since a lot of this also relates back directly to autism and other neurological disabilities is implementation of the Workforce Innovation and Opportunity Act of 2014 that guides and binds everything that we have at the US Department of Labor and it has a lot of notions in there of competitive integrated employment, enhancement of services, collaboration across all the departments and governments and agencies at the local level, a lot of partnerships and collaborations, customized employment. There is a lot that was strengthened since the Workforce Investment Act of 1998. That law influences and supports and guides and at the same time, we are helping provide technical assistance and support to the states and local areas to make sure that they can effectively implement the Workforce Innovation and Opportunity Act.

Engagement with employers because they are the ones who are hiring folks with disabilities. That is extremely important. Apprenticeship. Employment first. Technical assistance to states and accessible technology and transportation. These are just a few of the things that we are focusing on. But you can see how these can relate easily back to autism.

A lot of people on the autism spectrum do not drive so transportation is a large barrier to be able to get to work, live in our communities. Employment first is being able to make sure the employment is prioritized for folks. Apprenticeship. Often hands-on opportunities in apprenticeship and career and technical education can be a great fit actually for autism and other neurological disabilities because of the fact it is the hands-on, structured. You get on the job training, classroom education training and because post-secondary education can often be a barrier for a lot of folks.

We believe strongly that hiring people with disabilities bolsters businesses. We often try to make a business case for this. We believe this is important, but we also want to back this up with things like what the literature says. There was just a systematic review that was published not long ago actually, just in 2018 in February, that went for 20 years of research and found that hiring folks with disabilities enhances the profitability of companies, their image, their reliability, their advantage, their productivity, their work ethics, their awareness of diverse abilities of folks with and without disabilities in the workplace.

And it benefits without necessarily high cost. There are some myths out there that say hiring with disabilities. It is going to cost. It is going to be expensive. But most workplace accommodations cost very little. In fact, the average accommodations cost nothing. A lot of them are adjustments to attitudes, some time changes, some shifting of schedules and things like that. And the average accommodation where it does actually have cost is about $500, which especially when you are talking about the large employers is definitely affordable. Obviously for small and medium, they may need some collaborations to make sure that accommodation supports can work right, but it is definitely doable. There is a business case to be made for hiring folks with disabilities. We have literature to back that up.

There is a business case particularly on neurological disabilities including autism that benefits businesses. There was a 2017 study, and I am hopeful to see more of this literature coming out in the next few years, from Australia that looked at 59 employers through a survey research. It found that in general their autistic employees had above average performance. The employers noted strong attention to detail, high work quality, high work ethic. Fifty-six percent of them reported things like positive adaptations in the workplace culture. There were improvements in creative skills. And most importantly, they did not note any really significant costs to their businesses. There was a really strong benefit and they made it work with the supports without it costing much.

I think this is something to emphasize on what it feels like from the employer side of things because again employers are the ones hiring into the jobs.

In hand with this, we think in conjunction that job seekers who are autistic also have untapped skills and talents. There is also a study that came out last year that looked at diverse focused interest of autistic people. It was qualitative, but looked at specialized talents and how that can support vocational training and different kind of career development opportunities can be a positive. A lot of times folks have looked at sometimes focused interest as being a negative. But I think when placed in the right way, it can actually be a strong positive to help folks actually find a strong career focus in the directionality that fits their gifts and talents.

And then across the board, folks with and without these focused interests, just who are autistic have strengths, skills and talents that enhance employers' performance, missions, and bottom lines. We have some broad research literature that is developing in that area and that with supports can help tap skills and talents.

There was also another research literature review that came out actually earlier this month that indicates, a scoping review, that indicates some of the supports like trainings for staff, technological age, workplace trainings, customized supports, help with the workplace accommodations in terms of executive function, things like transit to work are really beneficial for folks. Things like enhancing onboarding processes that you have at the business, when you are hiring, recruiting, and bringing folks on to make sure you do that with strengths and supports is extremely really important for folks to be able to make sure they are successful because we do not want just folks hired. We want folks to be hired and then stay in the jobs. It is not as important on the employment side of things unless you actually are able to maintain that employment. We do see gaps at times. I am sure for those of you who are familiar with the literature is that a lot of autistic people have gaps where sometimes a job and then maybe go 8 or several more months and then maybe another job. That is because often there are not the right supports in place to make sure that individual can be successful at employment when they are able to secure it.

As I shared at the beginning, ODEP has been increasingly focusing on providing more resources on autism and neurological diversity. We have a web page on autism. You can either get to it through this address or if you even just Google ODEP and then autism, you will come to this page. It has 25 resources. It is expanding over time on focuses for employers, service providers, policymakers, et cetera.

How many folks are familiar with the Job Accommodation Network? ODEP actually funds that as one of our technical assistance centers for all folks with disabilities and anybody can call that or email including employers, employees, job seekers, et cetera. There is a page now on autism on there that has resources for interviewing, for accommodations, for both the interview process and in the workplace. That is another resource that is helpful. As I said, anybody can call JAN anytime. I can say that it also worked on my end as an autistic employee in the federal government and the first autistic person to work at ODEP. JAN has actually been helpful to me. The resources that we emphasize to folks externally we do often use them internally as well. Sixty percent actually of the staff at ODEP have disabilities ourselves.

There are also just a couple of other initiatives that I wanted to mention briefly. Internally at ODEP we are funding what are called Pathways to Careers Demonstration Grants at community colleges. For those of you who are familiar with the literature on higher education and other forms of postsecondary education for autistic people, a lot of times folks find that community college is really helpful after high school. Some of the literature I have seen says that around 80 to 85 percent of all autistic people pursue community colleges, two-year schools, technical schools, trade schools at least part of their higher education experience if not all of their higher education experience. This really fits really well into this project. We are running at two different colleges, one in Knoxville, Tennessee and one in Syracuse, New York, those being Pellissippi Community College and Onondaga Community College.

I will just mention briefly after that that our Employment and Training Administration at the US Department of Labor also has some grants in the last few years that have a relationship back to autism as well.

Briefly on these Pathways to Careers, they prioritize work-based learning so internships, different kinds of forms of experiences and co-ops, anything in terms of visiting work places, getting that kind of work experience while you are going through post-secondary education, getting your accommodations that you need, which is often an issue because folks often have variability and whether they can access accommodations, and making sure there is persistence to degree completion because a lot of times in community colleges, folks are not able to complete their degrees because they do not always have the right supports. Universal Design for Learning is a major priority for that to make sure that folks are successful.

Because of the supports and other factors on this, which supports youth and young adults with disabilities who are aged up to 24 in these long-term multi-year projects for demonstration grants basically, there is a high percentage of autistic students in both of these. The one at

Pellissippi Community College, UPEP, has 35 percent of their participants identified as autistic people and 19 percent of the other one in Onondaga. There are pretty significant percentages of both.

We believe that what is coming out of this in terms of best practices, how to support interviewing, et cetera is really helpful for folks to be able to be successful in community college and then connect that back to pathways and careers to support employment access.

And the last thing that I am going to mention here is these ETA grants for job development that are autism related. There is a tech hire program grant to the Exceptional Family Center that was just awarded a couple of years ago and supports the Next Step Job Training and Employment Partnership in

California. The plan on this grant – the numbers are still in flux in terms of – I cannot give you process numbers, but I know the grant had planned for the long term to have job development and training for almost 500, so 450 autistic people in health care and information technology fields. You say why those two fields? Because they are a growing part of the American economy. There are many jobs to be had in both health care and IT. When I say IT, that is not just software development, et cetera. That industry is actually very broad as is health care.

The other one is an American Apprenticeship grant to AHIMA Foundation, which supports their Managing the Talent Pipeline in Health Information Apprenticeship program. What is relevant on the autism side on that is it has a specific medical coding apprenticeship track that is specifically for autistic people.

As I say, we have these initiatives that are growing over time. Our web page will have more resources. I think that making sure that you have this emphasis on opportunity is important and have the right supports in place from employers. I think that is great that that this panel represents that diversity of different perspectives including on the employer perspective on what it means for them to be providing the right supports in place to make sure that autistic people who are recruited and hired for jobs can actually be successful and benefit not only their own life pathways, but benefit their employers in terms of the talents, the skills, gifts and strengths they bring to that employer to enhance the work place and all the work performance that is happening at the business.

I have the resources. I am sure we can – I think the slides maybe already online. If not, we can make sure that you on the committee can have access to the slides. I have the references for the studies and review papers that I cited in this presentation. Thank you.

(Applause)

DR. GORDON: Thank you, Dr. Robertson. We are going to hold questions until the end of the panel. Next we have Jose Velasco from SAP.

MR. JOSE VELASCO: Thank you, Dr. Robertson. Looking forward to our meeting here in the next few weeks. Thank you very much for having us. I work for SAP. Some of you might be familiar with the company. Some of you might not. We are one of the largest software producers in the world. We have approximately 75 percent of the world's GDP touch one of our systems. We have an enormous responsibility with our stakeholders around the world.

What I want to talk to you a little bit about today is the Autism at Work Program. In 2013, SAP announced an aspirational objective to have 1 percent of our workforce represented by people on the autism spectrum. When we made that announcement, we had approximately 65,000 employees who were looking at having about approximately 615 employees in the autism spectrum at SAP.

What I would like to share with you quickly is a little bit about the processes of things that we have in place. Before we go any further, I would like to show you a quick video that was made approximately a year ago. We had our cameras go out to different countries where we implemented the program. You will hear the voices of our colleagues on the autism spectrum, mentors, buddies, managers and executives talk a little bit about what the Autism at Work Program represents for them.

(Video shown)

MR. VELASCO: This is a slide that I typically cover with folks that are new to the autism spectrum. But there are two very important elements here that we focus on. The first one is the unemployment rate for individuals on the autism spectrum. Eighty-five percent of people were diagnosed in the autism spectrum are unemployed. The opportunity in my opinion is huge.

About three or four years ago, I found this article in Forbes Magazine that talked about 50,000 unfulfilled science, technology, engineering, and math jobs, which is something that applies to us at SAP that are unfilled in the Bay Area. There is another 50,000 in the New York Metropolitan area. I live in Austin, Texas where I read an article talking about 300,000 STEM positions not being filled. I have stacks of resumes of individuals in the autism spectrum that are perfectly qualified from a skilled perspective to fill these jobs.

It tells me that we have not really been able to as industry to create a bridge between supply and demand. What we are trying to do here at SAP is precisely do that because we see an enormous talent pool here that we have not been able to tap into.

Historically, we do have people in the autism spectrum at SAP. Some are self-disclosed. Some people have never disclosed. We have not created the artifacts, the supports that are necessary for them to be as successful as they could be. The Autism at Work Program is about that.

The question for us is is bias getting in the way. I found a very interesting newspaper clip about five years ago. I cut it and paste it the old-fashioned way as you can see here. It says failure to make eye contact can alienate hiring managers. Again, it was in the advice section of how to get a job and how to retain a job.

It goes on to say that establishing eye contact builds essential rapport. There are other interview killers like, for example, bad posture, failure to smile, a weak handshake and so on. All of these are elements that are getting people – keeping them out of the workplace. There is an enormous amount of talent out there that cannot do these things very well, but can solve incredible problems because they have the intellectual capacity to do that.

The question for us is do we judge everybody, do we measure everybody in the same way? I think that the answer is becoming no. If people are going to come in and contribute in ways that perhaps a customer is facing perhaps the very high social in communication interaction. Yes, you may be looking at some of those traits. But if you are looking at other types of jobs, we need to have a different process.

People ask us, why do we hire people in the autism spectrum? The first point is attracting the best talent in our industry. Talent, as we all know, comes in different shapes and forms. In the past, we have been in the economy to scale model where all the inputs look the same. We have to change that. As Anka Wittenberg, our chief diversity officer, said, we have to think about talent in a different way.

The second is that we need to bring a different perspective to our creative process. Alan Kay said that a different perspective brings 80 IQ points in problem solving. I think it is extremely important for us to be able to reflect the same diversity that our customers have because if we do not do that, we are going to have very monolithic solutions that only cater to certain parts of the market or that solve problems in a way that it is not complete.

Tapping into underutilized source of talent. I talk to universities. I talk to the community. I can tell you today that I have a pipeline of about 520 individuals in the autism spectrum that are qualified for jobs at SAP. We did not make a whole lot of effort to get that pipeline going, i.e. we did not have a specialized recruiting effort. This is basically people that are coming to us and saying I am interested in getting a job at SAP, 500 people. I wish I could hire more than I can right now. But the reality is that we only have certain capacity.

When I talk to universities, I was talking a gentleman from Rowan University just a few days ago. He said that they have 100 self-identified individuals in the autism spectrum at his university. If I talk to University of Santa Cruz and if I talk to UT

Dallas, they have an enormous number of people on the autism spectrum and all of them at some point in time are going to hit the workplace. Are we ready to take these individuals? I think the answer is we are getting there.

We captured the special skills of people in the autism spectrum. Aside from being great engineers, great communicators, yes, we have individuals who are great communicators that are on the autism spectrum. We have plenty of resumes from people that are not in science, technology, engineering, and math. Aside from that, we see that there are other capabilities of individuals in the autism spectrum bring to the table.

Retention is of course a huge benefit for us. In our industry, the replacement of an individual that is trained and productive can be - the cost can be anywhere between 40 to 100 percent of the yearly salary of that person. I can tell you that in the US that our program has a retention rate that is close to 100 percent of our colleagues on the autism spectrum. There is a loyalty from the individuals. We feel that if we are providing them with the right accommodations and they are performing well, which is another thing. Performance evaluations of our colleagues on the spectrum are really good. Then everybody wins. This is a big point for us.

Lastly, because we can. We hire people on the autism spectrum because we can. We have the ability. If we can produce software that allows us to run some of the most complex enterprises in the world, we should be able to create the means and methods to have an intake of individuals in the autism spectrum that can contribute to our bottom line.

Today, the program is in ten countries, ranging from Argentina to the United States. We have approximately – in the process of opening some – 22 locations right now where we implement the program. In the United States, we are in six locations. We are in Philadelphia – West Coast and East Coast. We have also an implementation of the program in Scottsdale, Arizona in the middle of the country.

We have currently 132 employed individuals in different capacities, full and pat time jobs, internships, contractors, vocational school. The vocational school is not up and running in every country. And internships are not running in every country as well. But the great majority of the people that are working are also full-time employees.

We have provided a total of about 300 opportunities. This includes past and present opportunities. Those 132 are counted in the 300. Recently, we started a pilot program to bring in high school students in the autism spectrum for experiential type of interactions with them. They come with special education teachers. We have two colleagues working in the East and West Coast on this pilot. Sheryl and Peg are doing a fantastic job on this.

The opportunities again range from a one-day experience, where we have high school students that spend a little bit of time with us during one day. They get to wear a badge for the first time, go to a corporate cafeteria for the first time. And then we have a semester-long or a one year-long type of engagement where they come in on Fridays with the special education teachers. They end up becoming project leads for spaghetti mash metal challenges and we have employee volunteers at SAP that make up parts of those teams.

As a result of that, we have seen that out of 18 seniors that participated in that program, 18 seniors are doing something positive after graduating whether they are going to college, military or getting a job, but everybody is doing something. But, again, that is just one small element of the program, a very important one, but it is part of the 300 opportunities that we have provided folks on the spectrum.

We have 21 roles in the company. Oftentimes people tell us that you only hire people in software development. The reality is that that is not the case. We have people that have been brought in positions that range from human resources to graphic design to legal support work. We have individuals on the autism spectrum that are doing task-oriented types of jobs and we have other folks that are doing very creative types of jobs, software development, and graphic design and so on. We have really a spectrum of jobs.

We have individuals that range in age from about the low 20s to late 50s. We have people that grew under the IEP world, people that were diagnosed late in life. We have basically a whole variety of individuals that have had different lift experiences when it relates to autism.

We have people that are doing things like IT project management. For IT project management, what do you need to do? You need to organize. You need to communicate. You need to socialize. All of those are well known deficits for people on the spectrum. We have identified a number of colleagues that are really great at this, providing the necessary accommodations at the beginning of the support so they can become great project managers or great software testers.

The roadmap for the program spans three different areas. First, we wanted to learn via pilots at locations worldwide. We implemented the program in five countries. They range in location from India to South America to North America to Europe. The idea here was to learn about what we needed to do as a corporation. As you can imagine, there is a lot of things related to labor laws, things related to even how autism is interpreted in different parts of the world. We have to learn quite a bit about that.

From 2016 to about 2019, what we are doing is, because everything was so self-contained in the Autism at Work Program, we are in the process of taking those practices that we incubated as part of the program and transferring those to the mainstream operations of the company. This is where the real change takes place. This is where we scaled. This is where we changed the DNA of the company. It is not easy. It takes a little bit of time, effort, and patience to do this.

Lastly, we have the process maturity onboarding equivalency. Yes, the aspiration for us will be at some point, we would be able to provide without necessarily identification, people on the autism spectrum an opportunity to come and interview, people that request a different path to success will get one.

Lots of change management at the beginning, as you can imagine. A significant amount of mainstreaming of best practices as we move forward. There are a lot of things going on in the program right now. We are in this transition phase right now. Again, we are taking the processes that we created, incubated as part of the program and trying to make them a part of the standard process of the company.

From an implementation perspective, it is super important to highlight that we have partners in our global perspective like Specialisterne. But then in the local countries, we rely on community services providers. In the United States, we work with the Office of Vocational Rehabilitation with the Department of Rehabilitation, so the VR entities. We also get the support of NGOs like The Arc of Philadelphia and Expandability in the Bay Area.

From a high-level perspective, people ask us what is the process of onboarding individuals in the autism spectrum. We do the position search. We do a candidate search. Again, we have a significant amount of people right now in our pipeline. This is not really a big effort for us. We already have the individuals.

Through what we call a soft skills training, which is going to be one week, we put in approximately 25 to 30 people through that training. And then after that this is just a one-week training. It is something that we do again in conjunction with the Vocational Rehabilitation Department and NGOs. And then we go through what we call the pre-employment training. This is five weeks. They come to SAP. They spend five weeks at SAP. They spend eight hours every day coming to training. We start an incremental six hours to try to build up that endurance because it is not easy at the beginning.

What we do is we focus a lot on enterprise-related topics that range from again how to work in a group, structures in an organization. All those things that make our colleagues in the autism spectrum anxious, we try to mitigate those ahead of time. They learn about SAP. They learn about our technology. They learn about strategy with the idea that when they finish this training, they are really well prepared to be enterprise ready. They are not being trained for a job. They are being trained to be enterprise ready.

There is a difference because in other trainings, I have seen that they train you to be a data scientist or they train you to be a software tester. Because we have such a variety of different jobs, we have to train people across the board for various different types of roles. It would be impossible for us to do a very deep content type of training, but it has worked out really well. Again, our training is six weeks pre-employment training.

And then after individuals are identified for a job, then we of course go through filling out the forms, getting people – the facilities, accommodations that might be needed. And then once people are employed and Dr. Robertson, this was one of the important things that you mentioned as well, is it is not just getting the job. It is the retaining the job that is important. And sometimes it is a challenge. What we have created is support circles around employees. We have one that is called the workplace support where you have a team manager that has been trained in autism awareness, an HR business partner also has received training and it supports the manager. Then we have a team buddy that is going to be a person that gets you up to speed on your day-to-day type of job and getting appointed with workload balancing and things like that.

And then we have the Autism at Work mentor who is an employee volunteer that is outside of the team. And this is somebody who is a platform for you to socialize, communicate, and expand your personal network in the company. They do all kinds of fun stuff. They go to baseball games. They do pizza and movie night. It is a group that is no longer just the colleagues with autism, neurotypical, it is just people that go out and do things together, expanding their social network.

And then we have a job and life skills coach. This is somebody that comes from an NGO. It is funded by the Vocational Rehabilitation Department. It is a proxy to the personal life of the employee to the Vocational Rehabilitation counselor, to other individuals. It may be a therapist. It may be family as well.

To give you an example, we had a colleague that came in, graduated with a 3.X

GPA in computer science. Most of his life his tuition was paid for by his parents. Then you had a situation where he was in the meal cafeteria plan at the university and he was living in the dorm. When he got out of that environment and came to work for SAP, he needed to find an apartment, cook his own meals, and get to work. Those were skills that he did not have. That is where the job and life skills coach came into being to ensure that in the private life of the employee, all those things are settled and taken care of so that that employee can be successful in the workplace.

We had a great impact on talent in the company. We have been able to hire. These are just three examples. I have 132 colleagues, and everybody has a story. They have been extremely generous with me in allowing me to share a little bit of their perspective of where they have been.

Patrick is a person that was in 60 plus interviews right after he graduated with honors from the university. He was not able to get a job. He came to SAP and within one year, he was one of our representatives at the United Nations.

Janis came to SAP after 14 years of unemployment. Within the first year, she won our programmer's competition, the hack-a-thon in the Bay Area where there were 60 other programmers competing. You kind of scratch your head and say why is somebody so unemployed or underemployed for so long and comes in and performs as well within one year of being in the organization. I guess the answer is that we did not have the accommodations needed in the past to bring people like Janis in.

Then you have Mark. Mark at some point in his life not immediately before proceeding his employment with SAP, but he used to be homeless. He was an engineer. For people that ask me about the impact of hiring people on the spectrum, when you have a colleague that sits next to you who used to be homeless, it has to change your perspective. You have to help you value your job. It provides a completely different view on things.

I think it is not just the perspective to solve a problem, but the perspective of their life experience that is also going to be transformational for us. We are grateful to have individuals like this in the organization. Thank you.

(Applause)

DR. GORDON: Thank you. Next we have Marjorie Madfis from Yes She Can.

MS. MAJORIE MADFIS: Good morning everybody. Thank you for having me. I am Marjorie Madfis. I am a parent of a young lady who is about to turn 22 with autism. She was diagnosed when she was about two and a half. I have always been an advocate for inclusion.

My professional background is I started out in economic development actually here in Washington in the Department of Commerce. I earned an MBA and I then had a 30-year career in corporate marketing.

In 2013, I founded Yes She Can. I founded Yes She Can because my daughter, when she was about 11, announced that her career ambition was to work at American Girl store in Manhattan. I was always wondering was this actually a possibility.

By the time she was 15 or 16, her high school gave her opportunities to have employment experience, but their focus was really on task completion. She went to different locations and she was supervised by a teaching assistant who had no business background and was making sure that she took out-of-date merchandise off the shelf. She did not know why she was doing that and she really was not learning what I would consider transferrable job skills.

I felt that we needed to look at what really made a successful employee. These are the characteristics. Being motivated and ability to persevere. Having good communication skills. Being able to problem solve. Cognitive and emotional flexibility and adaptability and good emotional regulation. These are all challenges for people with ASD regardless of their intellectual or academic success.

I looked at where there were some challenges in the world of special education versus work. I saw this as – again, this is my observation. This is not scientific. But I saw that in the world of special education, our students were expected to rely on the teaching assistant whereas in the workplace, we cannot rely on a manager. We need to learn how to rely on our peers.

The goal in school, as I always said, no meltdowns, which meant that there was no opportunity to take any risk whereas at work, your job is to problem solve. At school, everything is structured and predictable. But in the work environment, it is fluid. It is flexible. There are hidden rules. In school, you are expected to work independently. But in most job environments, there is some collaboration and there is a lot of discretion expected. Expectations are on intuition. In school, communication is really selective and you are oftentimes dependent on somebody else to help you do it whereas in work, you need to take initiative. In school, you are in a 50-minute class and lots of time there are breaks in the class whereas at work, your job is to do it until it is done.

I felt I needed to create a business model that really focused on what I thought was lacking in the school environment. As I said, my daughter really wanted to have a career in working in American Girl. I thought what is really required. She needed to learn how to do tasks, but not tasks for any reason. She needed to know the why because to be able to generalize, you need to know why you are doing something.

Process is really important which is about how to get things done. Process is what is really generalizable if that is a word.

Problem solving. Our people are typically not put in the world of problem solving. They are given rules and they are supposed to follow the rules. But most of the time, there is some type of variable that happens where a rule is not going to apply.

Dealing with uncertainty, being able to collaborate, understanding shifting priorities and taking responsibility.

One of the things that I realized is I truly believe in the theory of mind issue. It is not about you when you come to work. It is about the customer or the manager. That is definitely a challenge.

I created a business based on this ecosystem of creating a store where we had donated merchandise, which were American Girl Dolls and their accessories. We had trainees, who provide the labor, but we had social workers and psychologists who helped initiate the program and deliver the curriculum. We had market demand. We had customers who basically represent the community.

The one thing that we did not have was what I will call the exit strategy. We do not have the responsibility for helping people find jobs. I saw ourselves as being an incubator where we would help people develop the skills and that we would rely on existing organizations. The vocational rehabilitation agencies in New York. Our disability organization is called OPWDD, Office for People With Developmental Disabilities. I kind of expected that we will just train our people and hand them off and everything will be great.

Who are we serving? We are serving young women and I specifically identified young women because not only are they underserved, but in the work world, women are judged much more harshly on their lack of social skills and their lack of ability to collaborate and integrate into the environment.

My previous 17 years was at IBM and we seemingly always were forgiving of quirky men. But when a woman did some type of social faux pas, it just seemed to be talked about on the Sametime quite a bit, which is the internal communication tool.

We deal with people who have gone to high school and in their last of high school, people who left high school whether they actually got a degree or not, who are not engaged in the community at all and then we also have college students who actually have no work experience.

Some of the things that differentiate us are that we focus on this immersive learning experience. We also use professional staff. In many vocational programs, the people do not have a business background. They might just have a GED. They do not have expertise in autism. That was very important to me.

We practice a lot on what is called the hidden curriculum. We do a lot of work on self-advocacy because as Jose has talked about, people need to be able to identify what are their challenges and can somebody help them accommodate those challenges.

What are we teaching? We are teaching marketing. We are teaching merchandise. And we are teaching sales. We are teaching how to do transactions. We have a lot of tasks related to these things. I created an Excel spreadsheet that we call the Inventory Management System because when you get donated merchandise, you really cannot say we ran out of kit dolls. We should order more. We rely on what is donated. This giant spreadsheet is where our trainees are putting in data. They are concerned about accuracy. They are concerned about making it usable for their colleagues. We put this all on shared Google drives so everybody has access to the same tool.

This is my daughter over here. She is the queen of upsell and cross-sell. She has an expertise in American Girls. Nobody gets to leave the store without buying more than they intended.

We have people who are learning Quick Books.

What we really do at work is teach things that are transferrable so information gathering, being able to make recommendations with rationale. Instead of coming to the manager with their problem, they are supposed to come with a couple of potential solutions. They may not have the answer, but at least they are bringing some value to the manager; otherwise, the manager is going to say what do I need you for if I am doing all your thinking.

We teach them negotiating, decision making, collaborating with your peers, learning how to respond to management appropriately and problem solving. We talk a lot about perspective taking. It is very challenging for somebody to understand what the objective is of the manager versus what their personal objective is. What is the goal of the business and why are they doing something?

They are learning how to participate in team meetings. Once a month, we hold a team meeting at the store and people bring in the issues that they have been having. We also introduce new skills and we also have an opportunity to have some social time.

We are really focused on people doing non-preferred tasks too because we tell them that it is work. It is not play. You may be in an environment that has some fun to it, but you need to do some certain tasks that you may not prefer to do.

We also spend a lot of time dealing with frustration and how to deal with that appropriately, learning various kinds of techniques.

One of the things that I noticed was that some of our trainees were being evaluated for certain programs. Almost everybody needs a break. But they would use the word I need a break. That seemed to be a problem for these evaluators. All of us take breaks. We just do not use that word. We turn to our cell phone and look at our email. We go get a cup of tea. That seems to be okay for neurotypicals, but when our trainees say that they need a break, it seems to be a challenge for the agencies that are looking to eventually place our people.

Here is our team meeting. We have two social workers and a couple of young women. One does not like her picture taken.

I would like to go for one minute on a case study on two individuals. This is Maki. She is a college graduate. She graduated in 2015 from a competitive college. She did have some academic supports. She now lives at home. She is an independent traveler. She gets anywhere by bus. She is bilingual. She speaks both Japanese fluently and English. She was with our program for almost two years. During the time, the Vocational Rehabilitation Agency came to – the outsourced to social service agency. It took them almost a year to find her a job. She has very good skills in – she said she wanted a job working in an office. She has very good skills. But they eventually found a placement for her in their own agency's office. She is being paid 15 hours a week, but the VR is paying for that.

We have been doing some assessments and we can show you how the improvement Maki has made in over a four-month period of time. The yellow line at the top is the base, the total number of points one can get. The red line is the starting point four months earlier. And then the pink line is after four months so the improvement.

Maki always had pretty good self-advocacy skills. She really made some nice improvements in her technical skills and her social emotional skills. Her general work skills are in my opinion adequate to be able to work, but she continues to join our program even though she is working five days a week in the morning. She comes in the afternoons because she knows that she is benefitting from our program. She also likes the social experience.

One thing I would like to point out is our women are very isolated. Coming to our program is a highlight of their life. Most of them are at home doing nothing. Otherwise, a few of them might be going to community college.

This is a case study of Isabelle who completed high school, did not get a Regents Diploma. She did participate in a work experience program there. She lives at home and is capable of taking para-transit. She is attending a community college program with peer mentors supporting her.

She only is coming once a week. This is how she has been making some improvement. She has improved a little bit in her self-advocacy skills. She was also pretty good.

The area that she is going to be challenged in is her social and emotional regulation. She has made some improvements, but she can get pretty agitated when things just do not go as she expected.

We have done assessments and we feel across the board though that everybody has really improved in flexibility, in stamina. I would say that when they are in our program and they are there for two to three hours, they are exhausted after being there for two or three hours. We are trying to build up the amount of time that they can sustain work. They have all improved in social engagement and ability to accept critical feedback.

At home, all their parents have observed increased independence, which they have been able to engage more at home in decision making and offering suggestions. That was really important for us for them to be a part of decision making. Taking responsibility. They have all reported increased confidence.

I would say that our young women are prone to depression. They are prone to feeling less than. This was very important for them to be working in a place where they were seeing the success of their work effort.

Some of our findings are that intellectual and academic attainment does not predict success. They are all very quick learners though regardless. They particularly accelerate at anything computer related, digital related. But their limiting factor is the ability to take perspective. This leads to inflexibility and anxiety.

Here is a little quote from Isabelle. She was told to go help a customer. She was already working on putting data into the big spreadsheet. Her response was not now. I am busy. We need to teach them to say okay. I am not going to change your neurology. We are not going to change your lack of variant mind, but we are going to teach you a rule. When somebody comes to you and says you need to shift, you are supposed to say okay. Give me one minute. If they can have an out and a way to handle the situation, I think that can help them.

I would say that unlike a number of other individuals, I would say the people in our program do not find autism as an advantage to them. One of them said why was I cursed with autism. They know that they are different. They know they have challenges. They want to learn how to overcome their challenges. As I said before, coming to the program is the highlight of their week.

Our goal really is to replicate our program. We constantly get calls from people across the country asking how can we do this. We are not in the doll business. We are in the job skills development business. We want to be able to prove that our methodologies are effective because it took me four years to build this. I do not want somebody else to go through all this effort and not be able to demonstrate that the methodology has been effective. One of the important things is for them to actually get jobs after our program.

I would say that in our interactions with different agencies, we find that they do not get autism. There is a program called employment training program, as an example. A number of our trainees have applied for it. This is run by the Developmental Disability Organization. They tell me that only 20 percent of the people who apply actually get to go through the program. My expression is that they want to see the cake baked before it goes in the oven. Our people are not going to be baked before they go in the oven. It is disconcerting.

I would say that job developers probably should be working with smaller businesses that have greater flexibility. For example, my daughter had an interest in working at Barnes and Noble. There are job codes and job requirements. Everybody has to work on the cash register. There really is not a lot of flexibility whereas in smaller businesses where they do not have HR and legal typically, there might be greater opportunities to modify positions. I know the word is not well received, but job carving or customized employment, being able to offload certain kinds of things from one person who can do more complex jobs. That is what I would like to see.

I also know that businesses are kind of afraid of some of our trainees. They are worried about a burden. I have looked into some ideas about using technology to enable people to be a little more independent at work, not having to worry about a manager hovering over them and businesses would need to acquire that and buy into that.

Now, I would just like to turn your attention to this video. This is Alex.

(Video shown)

MS. MADFIS: That is it. Thank you very much.

(Applause)

MS. LORI IRELAND: Technical glitch.

DR. GORDON: While you have it, we will announce that next is Lori Ireland is going to be next and is co-founder and board member of Extraordinary Ventures. Will you be separating presenting or together with Ms. Morrow?

MS. IRELAND: We are together. I will explain that I am one of the founders of Extraordinary Ventures and Paige is our current managing director. I brought her because as you will find out, and Jim Ball I am talking to you, I am a much less filtered speaker than maybe my previous colleagues. I will piggyback on some of the things that they had to say.

We are going to show a short film here in a minute, but I will start out while we are waiting for the film to say I wear many hats. I am the vice chair of the Autism Society of America, again, one of the founders of Extraordinary Ventures, spouse of the chair of the Autism Science Foundation. We are kind of all over the place and have been for a long time.

Our original idea in Chapel Hill, North Carolina and again we are in one location. We are maybe two counties and we have about 55 employees. Everyone is paid at least minimum wage.

Some years ago, a group got together. We came completely the opposite, sort of, of everyone else. First of all, I really want to impress upon all of you that there is a huge number of people on the spectrum who are not software engineers. I am so appreciative that those that are get jobs at SAP. You hear from the people from the autism world that can speak and tell you about their jobs and desires. There are a great, great many, very employable people on the spectrum who you do not hear because my son if he were up here, first of all, he would be a nervous wreck. Second of all, every question you ask he would go yes good, yes good. But he is an extraordinarily good worker. It is just he cannot explain that to you, as many of our employees cannot.

Our original idea when we came together as this group was – excuse me, but the government is not going to help us. We cannot count on the government helping us. In fact, the government if anything of both state and federal level is a detriment to our people's ability to work.

One thing that I think as a coordinating committee, you would want to really think about is coordinating all the regulations that there are. They are at cross purposes to employing our people. Paige can tell you later. We have perfectly capable employees that have to be limited in their number of hours because otherwise they will start getting all their benefits cut. As we all know, one cannot live on minimum wage and one cannot live on benefits alone. It is really doing a terrible disservice to our people.

(Video shown)

MS. IRELAND: Some of the anecdotal things I will tell you about starting up Extraordinary Ventures. It took a group of people and we kept having to not take no for an answer. For instance, early on, we had trouble with Voc Rehab in our state because they said we were not inclusive enough of an environment to have job coaches, et cetera. As it turns out, I went to the head of Health and Human Services in our state, not the secretary, but the bureaucrat and I said Dave, we are having trouble with Voc Rehab. He said why. How inclusive are you? I said I do not know. Do you? We are not a medical facility. We do not have anybody's diagnosis. People come to us, apply for a job and we create jobs around the person's skills.

Some are very included. For instance, our bus crew is out with the regular people that work in the buses of the City of Chapel Hill. Some people are just at Extraordinary Ventures sorting laundry. Everybody is as included in the community as they can be.

They all are paid at least minimum wage. We do not accept any money directly from the government. So as not to be disingenuous, many of our people do come with job coaches that are paid through their Medicaid waiver programs. But the point is we do not have to follow all of the same rules and all of that as someone who is accepting money from the government directly.

We always – it was any part of the spectrum. We employ people that drive themselves to work and we employ people who have to be helped in the door. I am going to use an example and I am sure Scott would be okay with this. Our CEO's son is a college graduate on the spectrum. He was having a hard time finding a job. That is pretty debilitating after you have graduated from college. But he did not really know how to have a job. I said to Scott - they had lived in North Carolina at one point. I said, why don't you send Evan down? He can work at EV. He is over qualified, but he will learn how to have a job, what that means and all that kind of thing. Then he can move on. Sure enough, the guy has thrived. He is also a big Tar Heel fan now. Sorry Geri. But he is Tar Heel fan. He has his own apartment. He uses his transportation. He has recently been promoted. He started out in our laundry business just because that was a spot and Paige has recently promoted him. He is bookkeeper now. But he has learned that when you have a job, you have to show up. You have to take a shower. You have to wash your hair. You have to be nice to the other employees. All of these kind of cooperative skills that we are not getting yet in any of our schools. We talk about it, but really nobody is ready.

We do not care if people work at Extraordinary Ventures forever. We want them to be employable. They earn a paycheck. You cannot imagine how heartwarming it is when you see somebody get their first paycheck. One guy got his first paycheck and he wanted to pose for a picture because now he could pay his parents' electric bill. It was not I am now a millionaire. People sometimes say to me but I wanted more for my child than for them to be a bus cleaner. I say really. Who did you want to clean your buses? These are real jobs that are out there that somebody is getting paid to do. Everybody contributes to society in the way that they are best able and our people are very big contributors.

They are a big part of our community and they have not only a workplace, colleagues, et cetera – we run a social program. It is run by UNC students, totally voluntary on both sides. It is called Friday Night Live. One week it will be a dance. One week it will be yoga. But these people choose to go there because these are their friends. This is not segregating them from the rest of the community. This is their workplace. All of us probably have been to a company picnic. We have a company picnic. It is really wonderful.

We also have a volunteer-driven basketball camp in the summer. If you were there, you would just crack up. It is the single most diverse population of both participants and fans that you have ever seen. Every ethnic group, every sexual orientation, everything. That is not a deal to them. They are playing basketball. It is wonderful to watch them.

We also have worked really hard on replicating throughout the United States, not like we would get anything for it – North Carolina, but just to give people incentives that you can do it too. Just get five people together that are not going to be paying that college tuition that they saved up and put that into starting a small business. Again, we run our small businesses for profit. We compete absolutely on the same level as any other vendor of our goods and services.

Obviously, we pick businesses that need quality, not efficiency. We are, for instance, the provider of the laundry business at UNC because who knew that when I went to college I had to do my own laundry, but no kids do now I guess. We do not market ourselves based on you are going to have these special needs people doing your laundry. We do the same job thing at the beginning as everybody else. In about three bags in, we say by the way, a lot of the people doing your laundry have developmental disabilities. We get picked because we do the best laundry. We have a secret there. Part of it is one of our people is so meticulous that the top three items in every bag at the beginning is folded by this one person. It looks perfect. He loves his job. He takes great pride. We worry so much about level again, back to the buses. But this person takes huge pride in their ability to fold laundry. They take home a paycheck. They have friends. This is what we need across the United States.

We need the government to work with us, not against us. Of course, there is a horrible problem with the rotation of job coaches for the people who need them because they are so underpaid, under reimbursed. In my state, you can be a job coach if you have a college degree and you start at about $10 an hour. You can imagine. This is a pretty rotating thing.

The other real important secret to Extraordinary Ventures was my husband's idea. It worked really well. We started out with a regular executive director kind of model. But we were not making enough progress. I said to my husband - he is more creative thinker than I am. I said why don't you go on board. I will go off. He had this idea of hiring these young entrepreneurs. It was a bad economy at the time. It is very in to be a social entrepreneur. They work cheap. That is the good thing. They work very cheap. We got these new college students, most of which have no experience with autism whatsoever or any other developmental disability, but they wanted to be a social entrepreneur. They get to start and run a business. It is a great resume builder. And usually they then move on after two or three years. It is really the Teach for America model.

I wish that we could have that in a much bigger scale across the United States because there is plenty of talent coming out – neurotypical talent coming out of college that could give back in this way. It is exciting. It is very exciting for us.

I am going to turn it over to Paige. You can ask us anything you want. Again, it is really important to get the government agencies to stop working at cross purposes to one another. Between Voc Rehab, Social Security, this and that, it is a huge barrier to employment. You can ask us anything you want in the follow-up period of questioning. But I am going to let Paige talk a little bit more about how Extraordinary Ventures run on a daily basis.

MS. PAIGE MORROW: First, I just want to say thank you for letting me speak to you all about Extraordinary Ventures. I am very happy to see a few familiar faces in the crowd. My partner is actually a resident physician. When I walked her through who is going to be sitting at the table today, she was incredibly jealous. I was very happy to bring this to the dinner table.

Between the video and what Lori just told you, I will probably piggyback off of a couple of those points. But I guess as they say, it takes three times to really remember something.

I will tell you a little bit more – less about how it was founded, how it was created and why and more specifically what we are doing and how it works.

Extraordinary Ventures is a self-sustaining business model. It is just one of many unique solutions addressing the employment crisis. To set the stage of where we are now because we have been operating for about ten years. We now have a budget of about a million dollars, which was a big milestone for us. We are employing about 60 people on the spectrum. With that, we are a real significant contributor to our local market and local economy.

How have we done this? I could talk about it all day, but I have kind of broken it down into about four what I call core philosophies of how we run Extraordinary Ventures. First and foremost, we are a business. And what I mean by that is nothing is going to work if you do not have quality services and quality products behind the business. What we need is the market place to support us. We need to have -- prove the quality before we talk about the mission whether it is in marketing or a sales pitch. We need to bring a customer in and then you can create that sticky customer by then informing them of the mission behind what we do. Without this, without the sales, there will be no jobs and we would not be here today.

That is the main probably distinction of what EV brings to the table over a lot of the autism enterprises that we have seen out there.

Number two, as we started to launch some businesses, we found that the best model for us was a portfolio of businesses. Right now, we are operating six small businesses. One of them, as Lori said, a pick-up and delivery laundry business. We serve a lot of UNC students, residential customers, businesses, all sorts of customers there. About 150 customers. We have a waitlist now. We are ready to expand.

We have a dog walking business that we call EV Pets. We have a bulk mailing operation where we mail now about 50,000 pieces of mail every month. A few thousand letters going out every single day.

We have a gifts business. And there we create handmade candles, soap, sugar scrubs, lip balms, all sorts of products and we sell them online and in retail stores like West Elm and Whole Foods and places of that sort.

We also clean and detail the Chapel Hill Transit, our local transit, buses. And then finally, we have an event center. It is a way for us – we rent the surplus space in the building and we can subsidize the other businesses by covering rent and utilities and expenses like that.

This portfolio model – what it brings to the table is a wide variety of job opportunities for the people we are employing. Instead of running a single business and hiring somebody for a specific position, we have built these businesses around the skills and interest of our employees the specific demographic. When someone comes and interviews, we have a menu of options of where they can work. People are constantly building skills. You have that vocational training built into their jobs.

Probably 30 percent of our workforce works in multiple businesses and some people that probably came in with what I call work endurance of maybe 30 minutes can now work a few hours at a time, five days a week. We can see a lot of growth there. That portfolio model is the second major distinction for what we are doing.

Number three. Everybody that we employ as Lori say makes full minimum wage or higher. That ranges all the way up to about $15 an hour now for some of our employees that have been with us, trained and now have moved into more supervisor roles.

Number four. We employ the full spectrum. I really do mean that. When it comes to something measurable, we do not ask for a diagnosis, as Lori said. At this point, probably 70 to 80 percent of the people we employ require one-on-one job support. We have some people hired contributing to the businesses that need help walking in the building that are nonverbal. But if they did not show up to work one day, either I will or one of the other managers, somebody else is going to have to do that job. That is important to us that we are not just filling hours that these are real jobs and real valuable positions.

In our experience, the difficulty is not how do we create jobs for adults with autism and how do we figure out how to make them successful. We have that. Our day-to-day struggles are pretty similar to anybody else that runs a business. There are financial and economical questions. How are we going to best market this product? How are we going to improve the quality of this service? How are we going to retain our customers?

Our employees do a great job. Some of them have been with us for seven, eight, or nine years now. As people have said before me, retention is not an issue.

I am a direct witness. I have been at EV for six years now. I do not have an MD or a PhD, but I have employed a lot of people. I have seen them grow in their positions. Having a job is incredibly meaningful. There is an impact. You can see a decrease in behaviors. Some of our employees who would typically jump out of a car in the middle of an intersection to direct traffic or have self-harm behaviors – their parents say when they come to EV and they have that consistency in their job that they do not see any of that.

You see incredible improvements in confidence, in physical improvements like dexterity, life skills, all of it. There is no question that solving this and addressing this employment crisis is an important one because it is incredibly meaningful to the people we are serving.

If I were to leave you with a couple of take-a-ways of where we are now and how you could help, the biggest barrier for us and for our employees is kind of what Lori was saying with support staff. If we can find a way to build consistency in the job coaches that are supporting our employees, we do not provide them. They come with those independently. We would not be taking a step backwards every time they have a new job coach. We would be able to continue to grow them in the position and grow the businesses. If we could solve that, I am confident that in a year we could double the size the organization and continue to be self-sustaining. Thank you.

(Applause)

DR. GORDON: Thank you. If we could have all the presenters join us, there is a spot for you at the front. We have some time for the committee to ask questions and make comments.

While they are doing so, I will just remark that we heard some wonderful presentations today about different programs. And what I particularly appreciate is that at least it seemed as if some of the programs might be targeted or at different levels of the spectrum that we have been talking about in previous meetings. SAP might demand a more higher level of cognitive function than some of the programs that are offered by, for example, Extraordinary Ventures. It is nice to see at least on the surface a range of options for differently abled individuals on the spectrum.

We will open it up for questions. I see John's hand raised. If you will raise your hand, I will note you down. We will start with John.

MR. ROBISON: I want to thank all of you for coming here to present on employment and actually I would want to recognize you on behalf of the autistic community that I am charged with representing along with my fellow autistic advocates here. The fact that there is a substantial autistic employment initiative with a number of people is a great thing.

You have all heard me say how strongly I believe that autistic people should be involved in determining our path. You, Jose, have invited me to SAP to speak about how we could do that. You have invited other autistic people. Scott, you are one of us. Others of you have invited autistic people in.

I have been following the conversations online about our committee meeting and your presentations. I think that it is important that we recognize that we autistic people as the affected population, we are maybe sensitive to some of the things that non-autistic people say with the best of intentions about us. For example, to suggest that we need help with self-assessment, I think it is safe to say that all humans need help with self-assessment. If you went out in the street and you asked 50 people if they were good drivers, who do you think would say no? Is there really a case for autistic people being worse at self-assessment than any of you? I doubt it.

I think that we should be mindful of saying things that are unwittingly hurtful to our population and to that end, I would add to my comment that autistic people should be representing in steering your excellent initiatives. We should also be ideally the ones who stand beside you to present those initiatives to the public. If autistic people are standing beside you were less likely to have unwitting hurtful mistakes that can make it harder for us. I do want to commend the efforts.

And the final thing I would like to suggest is that we talk about employment and we need to be I think clear that our goal should be supporting employment where we stand on our own doing real work in the community with market rate wages. And if our government wants to help with that and I believe our government should help, our government should help by giving, for example, tax credits or cash credits to the employers, not by allowing the reduction of our wages, which is inherently demeaning to us.

With those comments, as I say, I just want to thank you again.

MS. IRELAND: Can I make a quick comment? I am the only one without a microphone. I think that is a message. Are they on? Okay. I agree with absolutely everything you say. It is very important that we have self-advocates on the spectrum to speak up and give us insights. I have learned so much from, for instance, Scott's son because he can articulate certain things in spoken language that are just like my son who cannot. It is like Kumbaya. Let's all get along. Let's stop this fighting at the national level between whatever we today are calling one end of the spectrum and the other end of the spectrum. Each person with autism has autism. They have different wants and needs.

Unfortunately because of the limitations of measurement and performance in public or in general, most of what you hear is from people who can articulate their position. Again, I learned a lot from those people.

But we do not want to forget all of the people who cannot articulate their own position in front of you today. I think you are going to see in the next session some very impacted people, not that everyone isn't impacted, but we are all impacted in different ways. It is really important that we not forget like at the Autism Society of America. It is a very wide spectrum of wants and needs. Nobody on the spectrum speaks for everybody on the spectrum.

MR. VELASCO: I would like to comment very quickly also from our side. John, we have taken to heart the recommendations that you have made before. We have known each other for a while. Those words have a big echo on the way that we do things.

We are in the process of establishing a council of our colleagues on the autism spectrum, at least incubating it here in the US. The idea is we have representation from both men and women, that we have representation from people that were diagnosed late in life, people that were diagnosed very early in life, people from different locations, people who are engineers, people who are in the created arts because we need those different perspectives.

We also have people that are self-identified in this committee because we believe that it is important for us to learn about their needs and wants and how we can shape the program. Our training program, the six weeks pre-employment program. We started with A and ended up with A prime because there was a lot of help from our colleagues in the spectrum. That was in and of itself a really wonderful experience.

When we first got together in a room after the first round of training, we had five people that were part of the training out of the seven. I said can you give us some feedback on what went well and what did not. A lot of it was very positive feedback. One person said permission to speak freely. And then the real information started coming to us and say we lack this or this thing worked or this thing did not worked. It has been an incremental improvement process over the last four years.

We are in our third version of the training program. Again, the idea here is that we incorporate our colleagues in the decision-making process here and that we have that representation.

Let me give you an example of something that happened two days ago. We were invited to participate with Senator Bob Case and one of our board members, Jennifer Morgan, who oversees a very high number of employees, about 40,000 employees. The moderator for the conversation was one of our colleagues, a 24-year-old colleague in the autism spectrum. We are putting people right in the front and center of this type of activity.

There is always going to be room for improvement. Again, this is a journey. We are trying to do the best. But with feedback with folks like yourself and the community, I think that we are going to get to a very different state in a few years from now.

MR. ROBISON: Thanks again for your effort and for believing in our community. I do not want to come across as critical of any of you all. I just think we have to be mindful that some of our population is really feeling a lot of pain from trying very hard and not succeeding with employment. We have to be really sensitive and respectful of that. Thank you again.

MS. MADFIS: I just wanted to add a comment to John. We are a startup organization. I am the founder. We take a lot of direction in our training program from our participants. We do not create the curriculum without their input, what they want to learn, and what they feel their challenges are.

We also have a woman with autism on our board. I think you might know her, Amy Gravino. We do have input. I think it is a very important point that you make.

One of the things that Amy recognizes when she comes to visit our program is she sees her prior self among our trainees. She had once said to me, her heart breaks because she sees their struggle. She gives a lot of direction and speaks on behalf of some of ours who are not as articulate as she is. I take what you say with all great seriousness. Thank you.

DR. GORDON: I am going to interrupt at this moment because there are a lot of people waiting to ask questions. I want to make sure they get a chance to do that. I have Lou next.

DR. REICHARDT: First, I just want to applaud what all of you are doing. Secondly, I wanted to ask you – implicit bias is present in all interviews. In a sense, this is the biggest – my personal experience is more with the homeless than individuals with autism. You send them out for interviews and they were not dressed right or whatever and they come back. But what do you think is the best way in a sense to nationalize what big companies like SAP is doing? Do you have thoughts about how one could basically propagate this?

MR. VELASCO: One of the things that we have done is try to share the program with as many companies as we can. We have a model that is continuously evolving, as I was mentioning. But in 2016, we launched what we called the Autism at Work Summit and we had approximately 200 attendees. We had companies like Microsoft, Hewlett Packard, and EY present along with other companies. We had folks from the public sector, from academia, from philanthropy, and civil societies. And the idea was to have one conversation because I noticed that there were all these fractured conversations. They were interacting with a hundred different types of entities interested in doing this type of work.

We organized ourselves. We created the summit. We held the second one in the Bay Area and we ended up having a collective online and physically about 700 attendees. Something that we kicked off at Stanford University and then we moved to our headquarters.

This year's summit we passed the baton to Microsoft. Microsoft is holding the Autism at Work Summit this year. Next year is going to be another company.

It is happening. Companies are reaching out. We have been contacted by 128 companies interested in learning about the program. Some people with interest in trying to see what we are doing. Some people are all ready to jump right in. It is happening.

If we look at the spectrum of jobs that is represented here at the table, I think it is something wonderful. What I tell people when they ask me about the jobs that we have, they are more on the professional side. But I feel that because what we are doing at SAP is bring people in into core functions of the company. These are not token jobs. These are not charity jobs. These are jobs that add to the profit of the company every day.

I think if the core business of a company is to fold clothes or it is to bake bread and they bring somebody in the autism spectrum into those positions, I think it is going to be a very different world a few years from now.

DR. ROBERTSON: May I add something briefly to that? I do acknowledge in terms of the diversity of supports and challenges, which was mentioned. I want to echo that that folks have different abilities, skills, and talents and also have very lively different needs in terms of supports and services and I know for us in government. It was mentioned before that government needs to help in terms of reduce inefficiencies, et cetera. We are hopeful. It is going to take time, but the Workforce Innovation and Opportunity Act is going to help with that. But it only passed four years ago. It is going to take some time for that to show its fruits in the next several years as implementation continues.

I will say also from the national perspective as far as employers who have hiring initiatives, we have an employer team at ODEP. They are often sharing best practices when they learn about them, sharing through webinars, documents and guides. They are integrating them into there and including the technical assistant center EARN and making sure that it is discussed and shared at all different levels and with government, et cetera, to pass that on when we see great practices that are happening out there on a whole wide range of different employers to help bring that national and to help bring it states to make sure that the state policy – it is not just the federal policy. It is the state policy needs to align to make sure that employers can hire the talented folks and develop the skills to make sure that folks can be successful and be retained at work.

MS. IRELAND: From a small business perspective, what we did some years ago is in conjunction with Autism Speaks, we had a couple of people that went around the country researching all the small businesses that were trying to be successful in this area. Marjorie was part of this. They went around the country and did that. Then we found promising examples, et cetera. We ran town halls in about ten large cities in the United States. That culminated in a conference back in Chapel Hill, North Carolina where people came to hear about the possibilities of small businesses. I think Marjorie can attest. It was truly a joyful, hopeful occasion. People were like yes. I can actually do this. That is how we tried.

DR. GORDON: Julie.

DR. TAYLOR: Thank you everybody for the work that you are doing and these great presentations. One thing that I was especially enthusiastic about in each of the programs and the things that you are doing is the focus on daily living skills and job skills, and this is something that we are just not doing a good job in schools and in other settings especially if somebody in the autism spectrum is in a Gen. Ed. setting. They are coming out academically prepared for work, but not in any of the other aspects that are really important in the workplace. Seeing explicit focuses in each of your programs on these skills in particular I think is really important.

I have a million questions I want to ask you, but I am going to limit it to one – something that we research a lot is that retention and stability in employment in particular is a huge issue. This sounds like this is something that each of you is having success with. I would love to hear a little bit more about what – if you had to pick one or two key factors that you think are facilitating stability and retention in your programs, what would those be? What is the secret sauce for stability?

MS. MORROW: I can try and answer that from a small business perspective. We have 60 or so employees right now. We probably employed about over ten years 100 to 150. Any turnover we have had 90 percent of it has been pretty natural. Someone moves away. Someone builds enough skills in their job to go work in another business in the town. But to see someone to be successful in their job so that we can retain them as an employee. The best thing we ever did was raise the expectations and standards in the workplace.

We found that as the businesses grew and we became more and more dependent on the work that our employees were doing, if they did not show up, it really hurt business. If the agency that had the job coach supporting the employee, if their employee show up, it affected our employee, which affected the business. We decided to hold people to higher standards and wrote out expectations that were consistent with other employers, distributed them widely. We met with all the agencies at one table and said here is what we need to see. Let's get together and figure out what your barriers are. Why do you have the inconsistency and the support staff? Talked about it. I think everybody agreed to take it seriously.

On an employee level, we require two weeks' notice. Special Olympics and things like that come around. We would have 20 employees trying to call out all at once. That was just going to destroy the businesses we had.

An example of an employee that had been with us for a long time that was never held to those expectations – he did not give us two weeks. The other people that we employed that wanted to participate listened and gave us two weeks' notice. When he came in and said I am not going to be at my shift on Thursday and Friday because I have Special Olympics. We are incredibly supportive of that organization, but we said you are able to make that decision for yourself. We are going to lay it out for you. If you decide to not show up to your job, you will not have a job when you come back. Or you can skip this round of Special Olympics and you can show up to work and do what is expected of you. We had meetings about it. This was kind of a pilot or a test run for us of holding our ground with policies. He thought about it. He came to me and actually said I know what the consequences are, but I am deciding to go to Special Olympics. He lost his job and he came back right after Special Olympics. I am ready to work again. We said I am sorry. You cannot.

We actually suspended him for a number of months and we eventually interviewed him again, hired him back, and ever since that day he has been working for us again for years now. We have had never a problem again. When it comes to retention, it is in the hands of both the employer and the employee and the agencies, the parents, everybody. But I think if we want to retain employees like other businesses do, we have to treat ourselves like other businesses.

MR. VELASCO: Just a quick comment from a large employer perspective. I think what has been the "secret sauce" for the retention part is empathy. It is really having people trained to understand the autism condition and also self-advocacy from some of our colleagues in the autism spectrum. I think that is extremely important.

I think it is important for us to meet in the middle, meaning that we are always asking our colleagues on the spectrum to become more neurotypical. It has to be difficult to be acting this role eight to ten hours per day. I think it is important for us to be able to educate our counterparts and our other employees about elements of the conditions. Again, we can meet in the middle. There are a lot of trait subtle things that are very positive of people on the spectrum that we should copy ourselves. That is part of the philosophy or guiding principle of the program. Meet in the middle.

MS. IRELAND: Can I just ask? When did those University of Wisconsin statistics first come out about the longitudinal study about life's outcomes for people on the spectrum like 2010? It still is not widely done, held, et cetera in the general population that people need something to do.

DR. DAWSON: First of all, I, too, want to applaud all of you and what - it is just inspiring presentations just sitting here, talking to the people beside me. We are all just again so inspired in so many different ways.

Living in North Carolina, I have been able to witness firsthand the impact that Extraordinary Ventures has had on the community and just the fantastic work they do. I will say that they also have fantastic candles. I do recommend me. I purchase them every year as Christmas presents as Lori may know.

I also want to say I have enjoyed our partnership with DUKE with SAP. One of the things that we were able to do in the partnership with the SAP Autism at Work Program is to bring the MBA students in at Duke so the Fuqua School of Business. These are the future business leaders of the world getting them involved as they learn about creating businesses and getting them familiar. This is another important component in thinking about setting the seeds.

But my question and this is a question for all of us. One of the things that we do here at IACC that I think is very effective is listen to people from the community and to identify things that we could do as an interface between the community and the government and all the different people sitting at this table. I was really struck by what Lori was saying. The government is actually getting in the way.

What could we do as a committee? Is it a letter to the secretary of health? Is it something that is really actionable? We have done this in the past. We did this around wandering. We did this around several important issues where we had an impact on policy. Is there an opportunity for our committee to listen to what Lori said and are there some key issues that we could bring to the attention that could make a difference? That would my question for all of us and perhaps Lori in particular.

I think what I heard is about the job coaches. I also heard issues that have to do with losing your benefits if you are working. Are these things that we could actually change?

MS. MORROW: Dr. Dawson, I would like to comment on one of the issues that we have specifically seen as an employer that Lori mentioned about those of our employees, which is almost all of them that are on Social Security or Medicaid. As we have employed people for a while and they have grown in their positions and increased the number of hours, talking about what living wages are and things, I am now pretty often having to make a decision whether it is with the employee or on my own. Do I give this employee a raise knowing if I give them a raise to their hourly wages that we are going to then have to cut down the amount of hours that they are working for us because many of our employees have now reached that threshold of what they are able to earn? We are constantly monitoring that. What is an ideal balancing act of being able to collect and work that maximum? But the issue is that the gap between them is too large.

Some employees – I talk to them. We have the hours for you if you are willing to basically give up your benefits. We can increase your hours, but that would mean we almost have to promise them enough hours to replace their benefits, which we a lot of times cannot do because as a business, we would have to be able to grow as well.

To me, as an employer, I would love to see that threshold be raised I guess of the amount of hours or the amount of money that someone is able to earn in a given month.

DR. GORDON: Pardon my ignorance. Anyone can answer this. Are these federally – there is a federal cap on salaries in addition to – there are two aspects of this. There are the disability checks and then there is I would imagine health care or Medicare --

MS. IRELAND: As all of you know in terms of the Medicaid side, many of our people are on Medicaid waiver programs, which is not an entitlement program. It is vastly different in all 50 states how the Medicaid waiver is adapted to that state. I have an M.B.A. from Berkeley. My husband has an M.B.A. from Harvard. We tried applying for a small business. It is a micro enterprise loan to our state. We know how to do a cash flow statement, but they do not. The person who is deciding whether they are going to give you this money does not understand what a sole proprietorship is. They do not understand amortization.

This guy keeps arguing with me at the state. You have to be charging the going rate. I say my son's lawn care business, yard care business. He charges the going rate. It is really hard to get rich off being that. Whether he makes minimum wage if you figure in his - it is all this ridiculous stuff. It is just unnecessary.

DR. GORDON: Melissa, would you care to comment on this?

MS. SPENCER: I know that the issue of when do cash benefits stop for SSI or for entitlement benefits, a big consideration. One of the things that I think you have not talked about is your employees are working long enough to now get covered by Title II to have earnings of their own where they are going to be able to have the worker's benefit as well as the SSI benefit that is based on income and need. Some of them offset each other. But in the long term, this pays good dividends for the individual who is getting some work credits.

I know that there is definitely the cap on earnings and benefits will stop at some point in time. There are some creative strategies such as an expedited reinstatement if somebody cannot continue to work above that dollar amount.

There is nine-month period where their earnings have exceeded what they are allowed to earn and if they drop below that then there are some strategies there to deal with repayment of benefits. It is not a perfect solution.

MS. IRELAND: And we do not have anybody to help the people navigate those agencies.

DR. GORDON: Let me ask a specific question because it would help, I think, the folks not on the committee understand a little bit better. These rules regarding the caps, the value of the cap, et cetera where are they set, how are they set, and who makes the rules?

MS. SPENCER: Social Security makes those rules. There is a definition of substantial gainful activity that is a dollar amount that an individual can earn and still be considered disabled or not disabled.

You are right. They are very complicated rules about work activity once you are on the rules. And what I just heard stated was help navigating those rules. That is something that I can definitely take back with me. I know we are trying to do some creative things with return to work and employment support programs. These are very key things to hear today.

DR. ROBERTSON: May I just add something just quickly that will also help answer Dr. Dawson's question? From the labor perspective also to add to that is helping to reduce some of the barriers out there. There was a report that was created for the advisory committee that was created by Workforce Innovation and Opportunity Act, that I previously shared here at the IACC. I would encourage folks to take a look at that report. That report is still online on DOL’s site.

I think what also dovetails with that is that report to Congress on Autism on Youth and Young Adults that was mentioned earlier today. I think some of those recommendations actually align really well with some of these challenges in terms of on benefits, et cetera.

I will also say and I am happy to share also at break or whatever with the committee members to bring in more information if needed. We also have emphasis at ODEP right now and return to work state work. And a lot of that emphasis is on folks who are on benefits and how they can access employment opportunities and get through a lot of those complex hurdles. And a lot of this work is being done in collaboration with Social Security and our other partners in government.

When we hear challenges out there from folks in terms of employers who are struggling and other service providers, we are listening and making sure that we have collaborations to work through. It is just going to take time, I think, to navigate this and have change in the systems over time, federally, state, and then local to make the opportunities better including for folks who are on benefits to be able to have the work opportunities they want to.

MS. IRELAND: And often I think we are looking in situations like this from the rules down as opposed to the boots on the ground. Anecdotally, my own son, who is considered easily 100 percent disabled – he gets $500 a month in SSI. That is it. That is what he is supposed to live on. When he moved out of the home, I called the Social Security person who has on their message machine of don't leave me more than one message or I will never return your call. And then when I did talk to her, she said in order for him to qualify for the extra $200, she said he needs to live in government subsidized housing, which there is not any in your area or be homeless. I said you want me to make my adult son who is in the old way of calling things mentally retarded homeless for a while. She said yes. That is what I am saying and you are not going to do it.

I have appealed. I have gone to the judge and everything, but they will not increase. The only question the judge had was if he only makes $500 a month and he pays $480 in rent, how does he live the rest of the month? We pay for it. She goes well you are subsidizing him. I said did you want me to let the guy starve. What the rules are and how they are enforced. That is a really important thing for you all to think about and how the states are not implementing federal law and how federal law is not being followed for the people on the ground trying to live a life.

MR. VELASCO: One comment on the sustainability of these types of programs and what can be done. We operate the program in ten countries and we get very different levels of support from the private/public partnerships. In Germany, for example, we have two job coaches that are assigned to SAP for five years full time. That helps a lot. That helps a lot because autism is a lifelong condition. It is not something that goes away after 90 days of employment. We do need to have those levels of supports. There are companies that are fortunate to have the economic means to provide the self-sustainability of the programs. But if we want the solutions to scale, we need to have those better partnerships.

One of the biggest barriers that I see for people and you were alluding to that earlier is the fear of the unknown from a hiring manager. How am I going to manage this person? That fear goes substantially down when we introduce the fact that there is a support circle around the employee that comes with the job coach. The challenge that we have is that again the system allows for those job coaches to be by law for 90 days and not after that. The question is what do you do in the extra part of the life of the employee. Life happens. There are life events. There are organizational events. All kinds of stuff that happens. They need that support.

In the way that I see this is if we are taking individuals that are in the government payroll for lack of better words right now because they might not be employed and they become taxpayers. The positive impact of that can be anywhere between 20 to 40 to $50,000 depending on the salary arranged for the individual from having been on government benefits to being taxpayers. There is a significant amount of money there that will allow companies to hire and retain job coaches if there was a partnership that would allow for something like that that was sustainable and scalable.

DR. GORDON: Thank you. Just to make sure that everyone gets a chance to ask their questions. Alison, you are next.

MS. SINGER: I was actually going to make the same point that Geri did that both

Marjorie and Lori were describing instances where the government was hindering, not helping, the ability to create solutions to problems. In this group, we like to talk about problems and we like to study problems. These are the ones in the trenches creating solutions. As a parent, I want to just thank you for doing that. You guys are the doers. We need to do something too.

It is not often that people come and present where there is something that we, as a committee, can do. But in this case, there is. It goes beyond just the earnings cap. It is great if Melissa is going to look into that.

For example, Extraordinary Ventures is lauded nationally as an exemplary program. But the way some states are interpreting the Medicaid guidance and then the regulations, a program like that is considered a sheltered workshop and cannot be implemented. Why is it that they can have Extraordinary Ventures in North Carolina, but in other states it is not?

This is something that I think we, as a committee, if we created a list of the policies and the laws that are inhibiting our ability to create jobs and expand opportunities for people and submit that to the secretary through our advisory capacity, I think that is where we can join the presenters and being doers. I am happy to be part of that group. But I think this is something where we have to step up and take action.

DR. GORDON: It is a great idea to at the very least compile a list of the policies that get in the way. One person before you, Walter. Samantha.

MS. CRANE: I think this was a very good overview of all of the different things that people are doing to improve employment in our community. I really wanted to first talk about what I was impressed with and what I thought did work. I liked that groups are really taking seriously how important it is to match people with the kinds of work that we enjoy and also that we can actually do.

I want to say that sometimes people talk a little bit too much about job stability and hold us autistic people to a higher standard of job stability than everyone else in their early 20s. It has become the norm for people to change jobs about once a year and try out a bunch of different things and see what works best.

I tried working in retail when I was younger. It gave me a smoking addiction. I could not survive in retail for long. Sometimes people will say you can do whatever you want because you are not really disabled. Actually, there are lots of jobs I cannot do. I just happen to be in one of the jobs that I can do. That is why I seem like I am doing really well. If I were in another job, I would be doing extremely poorly. I think that is probably true of most people.

I want to ask – what I hope would be that if people are successfully doing work like laundry folding, candle making, et cetera, these are jobs that exist in the economy. One question I have to ask is but if people are doing so well and the businesses is profitable and people are reliably showing up to work and we have gotten people to this point, can't we be in a regular laundry folding business at this point as well?

MS. IRELAND: You definitely can. We do not have contractual employment. We have a right to work state. Anybody can work wherever they want. We are 80 percent self-sustaining. Normally, when you run a small business, what you are solving for at the end of the day is profit. For us, we work under a not-for-profit umbrella. We at the end of the day are solving for hours of employment. Every time a business becomes cash flow positive or whatever, we start another business and employee more people. We are about 80 percent self-sustaining. It would be great if we were 100 percent, but people can leave and go to the regular or a different. We are regular. We do all the same things a regular business does.

MS. MORROW: Just to add to that. There is a difference between the way our laundry business is set up and our competitors or our bulk mailing business and our competitors. We do not undercut the market pricewise. We are very competitive there. Sometimes we take over contracts from our competitors because we provide a more quality service.

The difference is that, one, we will break down tasks. If you were to work at another laundry business, you would probably have some start to finish role. What I mean by that is you would grab a bag of laundry. You would be in charge of sorting it, washing it, folding it, giving it back to the customer. We break our businesses down to where you have a position that is a sorter or a position that is a machine operator, delivery driver. Some people might work in multiple positions. But if they specialize in one, that is okay. There is a little bit of a gap between that skill being transferrable to another business. It is how we are able to accommodate or create a job for someone that might be lower on the spectrum.

And then beyond that, each individual skill can be transferrable for the bulk mailing business. The machines we use – we make a point to use the same equipment that other businesses would use so that whether they want to stay with us or use it as a stepping stone or training ground that we are setting them up for success there.

DR. GORDON: Thank you. Walter.

DR. WALTER KOROSHETZ: I was just following up on what Alison and what Geri were talking about in terms of to push for change. I was thinking that there is probably a much wider group than just the autism community that could get involved in that kind of push because there are issues that would concern anyone with developmental disorders and some injury-related disorders.

Do people know if there are the convening organizations? I do not know the different ones. The American Association for Disabled People. Are there other places where we could go to get stronger traction?

DR. ROBERTSON: In terms of the broader disability if it is helpful too – and one of the collaborations with our employer team. They have an alliance with the US Business Leadership Network. It is I believe about 130 employers that have really shown a strong interest on that hiring of folks with disabilities across the board. As was shared, that can include mobility, physicality, sensory, blind, deaf, et cetera, not just on the neurological although many of the employers are increasingly focused on cognitive disability, developmental disabilities.

I can make sure the committee members can access ODEP's website if you want to later one where you can find out other things that are happening from our employer team. And EARN, the technical system center I mentioned earlier, which is askearn.org is their website. You can also learn about some of those focuses from the employer side that are broader on disability that can be beneficial as far as for autistic people. And some of the things that are learned on the autism side can also be beneficial broader disability because a lot of the challenges on social communication, sensory, et cetera – that affects lots of folks.

A lot of the recommendations, for instance, in that advisory committee report on Youth and Young Adults, you could apply those across the board. I would actually say to folks with and without disabilities in there in terms of how we can bolster up our systems and reduce a lot of the barriers that preventing folks from transitioning to work and being able to secure the employment opportunities that are meaningful to them and actually fit with their interest skill and talents.

I do want to echo what was shared on the comment that a lot of what is -- autism can benefit broader disability and broader disability things can benefit on the autism side. We need a two-way communication stream on that. I think that is something that I tried to prioritize at ODEP as I have been focusing as our subject matter expert on autism and neurodiversity in the workplace is a lot of what is happening on the autism and neurodiversity side in employers, service providers out there on the broader landscape is beneficial to the rest of what we are doing at ODEP. A lot of folks are seeing that when we are discussing a lot of exciting things that are happening on the autism side of things.

MS. IRELAND: At Extraordinary Ventures, we do not know anybody's diagnosis. I could not tell you exactly, but anybody who needs it and can bring with them the amount of support they need anecdotally or by observation because we are located in Chapel Hill, North Carolina, the home of division

TEACCH. We do have a disproportionate number of people with autism are on the spectrum in our community.

DR. BIRNBAUM: Very quick question or just comment, which is I did not know what SAP was and I do not know if everyone knows what it is. Jose, if you could just give a two-second definition. I was able to look it up online, but not everybody is doing that.

MS. VELASCO: Yes. Absolutely. We are a large enterprise software company. We are in 190 countries. We have 300,000 employees. We provide business solutions for medium-sized organizations all the way to Fortune 500s. We provide software that really allows you to run your business from human capital management, managing employees, all the way to supply chain management interaction with business partners. It allows you to run your enterprise from A to Z.

DR. GORDON: I want to give a chance to anyone who is on the phone because I cannot see you raising your hand, any of the committee members on the phone to ask questions. Hearing none and realizing that we are well passed the time, but I felt like I did not want to interrupt this incredibly productive discussion. We are going to take a 15-minute break. It is 11:30. We will be back here sharp at 11:45, maybe even a few minutes early if we can. We will have some committee business to attend to. Thank you very much to all the panelists.

(Whereupon, the Committee members took a brief break starting at 11:30 a.m. and reconvened at 11:45 a.m.)

DR. GORDON: If people could either take their conversations outside or join us the table please. We have a couple of items of committee business. We will try to transact them as quickly as possible.

Susan.

DR. DANIELS: Just acknowledging OARC staff. Thank you for everything that you all did to help make this meeting possible and all of our activities for Autism Awareness Month. It is National Autism Awareness Month. We are really pleased that we have been able to host some activities in the OARC. Many of our federal colleagues around the table have also hosted activities as well as private organizations around the country.

NIMH had a special event for Autism Awareness Month that OARC hosted. It was a panel presentation called The Story Behind

Julia, Sesame Street's Muppet with Autism. It was a really successful and exciting event. It is available online if anyone is interested in watching the panel presentation portion.

We have some links here if anyone wants to go back through the slides and see some of the press releases that came out during Autism Awareness Month including the President's proclamation on autism and the UN Secretary General's message on autism. Some of the other events that went on around Washington and other areas.

The Autism Awareness Interagency Roundtable that was held by the Indian Health Service on April 2. The United Nations event, Empowering Women and Girls with Autism. And Developing Individuals Who Have Different Kinds of Minds, featuring Temple Grandin.

That was hosted by the National Institute of Environmental Health Sciences. These events are available online and you can look at those links.

I would also like to bring your attention to the 2017 IACC Summary of Advances. This document – I do not see it on the table. It is supposed to be on the table. We can distribute it at lunch time if it is not there for the committee members. We also have copies out in the lobby, but the document was finished, and it just was released yesterday.

This document contains lay-friendly summaries of the top 20 most significant advances in ASD biomedical and services research that were selected by the IACC. It covers articles that align with all seven of the IACC strategic plan question areas. I would encourage you to check this out and congratulations to authors of these articles. The full list of nominated articles is in the back.

I just also wanted to bring to your attention the 2016 ASD Research Portfolio Analysis report. The work for that is underway. And at the INSAR, the International Society for Autism Research meeting in Rotterdam, Netherlands coming up in May, the OARC team as well as our partners from the UK and from Canada will be co-presenting the preliminary results of this analysis. We hope that at the INSAR meeting there will be other countries that will be interested in joining in the future and we will present that to you in October at our next meeting.

We also wanted to give you an update on the Autism CARES Act Report to Congress that is due in September 2018. The OARC is leading the coordination of this report. It will cover activities related to ASD and other developmental disabilities across the federal government. We have been in the process of working on it and requests for data have been received from all agencies and we are compiling the report and we expect it to be on time in the fall. We also will present that to the IACC when it is ready.

The next order of business is talking about the Improving Health Outcomes for Individuals on the Autism Spectrum Working Group. We met with Dr. David Amaral and Dr. Julie Taylor by phone to discuss this since the last meeting. We are still working on trying to get the actual working group selected so that we can begin the work.

We have a number of topics that were discussed at the last meeting for discussion in this working group. And the next steps that we would like to propose are having a working group workshop in the summer and Dr. Gordon had suggested that this replace the summer IACC meeting that would have normally been scheduled for July. We could select one to two topics from this list. This is a list of all of the topics that are there but wanted to get the IACC's input on this and potentially to select one to two topics that could be covered in a workshop.

MR. ROBISON: I would just move that we do this workshop in place of the meeting because I think it is important and deserves a full day.

DR. DANIELS: That is what we thought as well that it was something that – there are so many different issues that need discussion that we could spend an entire day on it. We do have a list from the people that have been nominated for the working group already and are just narrowing that down and need to send out the invitations, but then could be working on an agenda for this workshop for the summer. We will confirm a date after this meeting is over. We have not had a chance to really nail down that date yet, but we will try to do that and let you know and try to select like I said probably one to two topics because that way we would be able to really focus the meeting and hopefully get some useful input.

DR. WEXLER: Thank you, Susan. Before we make the decision, or maybe the decision is made, what are we losing by not having that meeting, the IACC meeting? Is there business that needs to be done that we are not going to be able to get done? Are there deadlines? We tend to have a calendar that has requirements.

DR. GORDON: First, our requirements for the number of meetings a year is actually two. We have exactly doubled the number of meetings that we are required to have by the law. We have those meetings for several reasons, not the least of which are to have the kinds of input into ideas we need to focus on such as we had this morning.

We have to revise our strategic plan, but we have already decided to do that minimally since we spent such – we did a thorough revision last year. We do not think that this will impede with the work revising the strategic plan since we essentially just finished it a few months ago.

We wanted to give the working group a maximal chance of getting started since we have had so many delays of getting this work group started that we thought this would be a better use of the time for that meeting. I do not think there is anything on the calendar that we have to be concerned about falling behind on in missing this meeting. Is that correct, Susan?

DR. DANIELS: With the requirement to update the strategic plan, we did talk about at the last couple of meetings that we could use the working group's outputs as our update and so we could focus the update. It does not say in the law exactly how you have to divide that update and we could just focus down on this topic and by the end of the year have some kind of a write up that we could submit.

We also normally take public comment. At this working group workshop, we could take public comment that would be focused on this particular area. There probably would be some significant input the public would like to share with us on that. We would be able to do that.

But in terms of other documents, the Summary of Advances, we would have to make up the time if we are having an October meeting then people would be covering articles from a longer period of time at that meeting to keep up with the Summary of Advances. I think in terms of requirements those are the main things that would be impacted by not having a regular IACC meeting.

DR. GORDON: David, I believe you were going to make suggestions as to which of these to focus on.

DR. MANDELL: I was going to vote for mortality, the reason being that a lot of the other health related issues I think are incorporated in addressing it. It would be a way to synthesize and provide a common goal for those. I would vote for a second one perhaps to be related to other aspects of quality of life.

MR. ROBISON: I agree with what David says. Health care does not help us if we are dead.

MS. CRANE: I would also vote for mortality and also patient provider interactions because that is where we are seeing a lot of concerns. Obviously, if we cannot interact effectively with our providers, almost all of these other questions are going to be affected.

DR. DANIELS: At the last couple of meetings, patient-provider interaction seemed to be a high priority one.

DR. PEÑA: I completely agree with the patient-provider interaction. I am just trying to look there. Related to that would be the medical practitioner training, I think is very much related to that piece of it in terms of the interactions.

DR. DANIELS: Anything else? Geri.

DR. DAWSON: I love the idea of mortality. It does have this kind of downer feel to it. I just wonder whether if you flip it on its head and you really – it is a focus on promoting best health outcomes or health and wellness or promoting quality of life including health with the idea of reducing the – improving the issue of – we know that there are higher rates and lower age of mortality and these are very serious issues. That is kind of embedded in there as a goal that if you do these things that that would happen as a consequence as well as reviewing that literature I think to remind people of just the incredible impact.

I think of framing with a positive is always good, but that is just my thing.

DR. KOROSHETZ: I would agree. I think the mortality – it is kind of a no-brainer. We want to reduce mortality. But to be actionable, you have to go down the list a little bit. You could say that it covers everything. To be actionable --

DR. GORDON: I would say that the mortality issue focuses on the more severe impacting aspects of co-morbidity. I think they are listed up there: epilepsy, suicide, chronic health conditions. Looking at mortality is looking at the cause of serious morbidity and mortality. From my perspective, it is really important to maintain that focus.

Maybe if we have the second part be about patient-provider interactions then that is going to get at more of the wellness. How do we promote prevention? How do we promote wellness? That might be a good counterpoint.

DR. MANDELL: That is why I was suggesting that the other topic be something related to quality of life. Certainly, patient-provider interactions would be – a reason for wanting to focus on mortality – avoiding mortality – I think sometimes there are things that get missed when we do not directly address that issue.

For example, if you look as an analogue, people with serious mental illness even as our treatment for schizophrenia and bipolar disorder has improved, we have not made substantial reductions or measurable reductions in mortality. I worry that something gets lost when we do not confront that issue head on. But I agree with you also. It would be nice to at least have the other half of the meeting be more positively focused.

DR. DANIELS: Any other comments? We will take these comments into consideration. We will talk with the chairs and trying to put something together pretty rapidly because there is not that much time between now and July. We will keep you informed.

Edlyn, do you have another comment?

DR. PEÑA: Just asking to clarify. Are these going to be working groups that meet over the phone or online or in person.

DR. DANIELS: The workshop would be an in-person meeting, but we will also have calls in between. It is just one working group. It is not multiple working groups. It is just one.

DR. GORDON: Is the idea that that will not only take the place, but take the date because everybody already has that date in their calendar?

DR. DANIELS: We are changing the date probably. We will let you know because we need to go by the chair's calendars.

The only other comment that I have is if the committee is interested in doing a letter to the secretary regarding some of the employment issues, we could also convene a call on that topic. That is something that we could put together. Does that sound something the committee is interested in doing between now and October? We will try to put something on the calendar to discuss. Usually with letters, we usually can do it in one to two phone calls and somebody volunteering and just doing some edits. We will work on that.

Any other items that you have?

DR. GORDON: Summary of Advances.

DR. DANIELS: That is not part of – let's go forward with the Summary of Advances discussion. We did not have a lot of nominations this time. We have for Question 1: Screening and Diagnosis. You have the listing with the people who nominated them in your packets.

DR. GORDON: We do have it. This was suggested by David Mandell. Do you want to say a word or two about it, David?

DR. MANDELL: I thought this was a really nice study, showing that even in a high-risk sample of young children with autism that when clinicians use standardized measures, they miss kids. I think the implication was we do not do a really good job of listening to parents and incorporating their concerns and feedback into the diagnostic process. Enough said.

DR. GORDON: Question Number 2. David Amaral is not here, but I think I can say something about both of the ones for Question Number 2. Neuron numbers increase. Post-mortem studies in autism have really been lagging behind post-mortem studies in other disorders. This is one of the few studies that are coming out now that involve the substantial sample size showing not inconsistent with other findings in autism that essentially early in childhood, there is an over exuberance in growth, in this case, an increase in the number of neurons in the amygdala that then declines whereas in typically developing individuals that number increases through childhood before declining like everything else with age. Again, a really nice study with an important revelation at a very fine level and confirmation of what we already know.

Did you want to say something else, Lou?

DR. REICHARDT: (off mic)

DR. GORDON: Yes. We point out that David nominated, and he is an author. We have to note that conflict of interest.

And then the other nomination in this area is looking at another sample comparing children with ADHD and autism spectrum as well as typically developing controls, looking at cognitive impairments and showing some differences between children with ASD and ADHD.

DR. DANIELS: For Question 3, we had a nomination that was also from Alison and Josh.

DR. GORDON: I have said enough. Alison, do you want to present? This is a study, the Gandal et al. study, which represents the output of a very large collaboration, sponsored by NIH by various institutes at NIH, most notably NIMH, to look at genetic predisposition across – sorry, not genetic, postmortem data across a number of different diagnoses.

It points out that there is shared molecular neuropathology, meaning that the molecular disturbances at the level of postmortem brains have similarities across a number of different psychiatric disorders including autism spectrum, schizophrenia, bipolar, major depression, alcoholism. This does agree with some shared genetic predisposition towards these disorders, pointing of course at the potential for generic risk state and also the possibility of a generic resilient state that we need to think about.

Linda, do you want to comment on the next one?

DR. BIRNBAUM: I think that there has been growing evidence that air pollution maybe a risk factor for autism, especially early in utero or early in infantile life. This paper is basically one more paper showing that the complexity of what the air pollution issues may be. There have already been a number of studies shown that near roadway traffic pollution, which is often associated with what is called PM2.5. There is an association there and there appears to be a gene by environment interaction going on there.

There is a recent study that came out showing association with ozone and the association especially with people with CNV and the number of CNVs.

And then this is another paper showing an association with a component of air pollution, which is often not talked about very much. You hear about PM2.5. You hear about ozone. You do not often hear about the volatile organic compounds, which are present and there appears to be an association here.

Heather Volk has been working with air pollution and some of the other investigators here have quite a number of different cohorts that they have been following over the years.

I think that the environmental component is really going to be an important in its association with specific genes.

DR. DANIELS: The next three papers were nominated by David Mandell.

DR. MANDELL: You clearly caught me on a free afternoon. The first one for Question 4 was recent meta-analysis of parent-mediated interventions for young children with autism showing really disappointingly small effect sizes. I think there is a real tension about the extent to which we should be delivering interventions in a center-based or a clinician-mediated model versus working with parents to provide the bulk of intervention. This suggests either we do not know how to train parents or what we are asking them to do is just not really feasible within the life that any parent of a young child has or we really need to think – we are mis-specifying the active ingredients of intervention and we need to think harder about what clinicians are doing that is successful. I thought that was an important and humbling point to get across.

The second one. I am an author on this one, but in the middle. This is a paper on the effects of autism insurance mandates and showing that age caps matter. For those of you who do not know, of the 46 states that have autism insurance mandates, they vary in until what age that mandate is in effect and showing that when for states that have lower age caps, for instance, a kid is only eligible for services through the mandate until they are 10 or 16 that they are really is a significant drop off in the services that they receive once they age out of the mandate. I think it is important for advocates to consider as they advocate for different kinds of legislation. In fact, some states like Texas have been successful in advocating for a higher age cutoff.

DR. GORDON: Let me just interrupt for a moment. Of course, we are not as a government committee recommending any legislative advocacy. But I think it is important to recognize the ridiculousness of having – of putting a stop to the care that is being devoted to individuals who have a lifelong disorder - putting a cap on that and age. Because when that cap ends, those people will suffer.

DR. MANDELL: And that is certainly what we find.

And then the third paper comes from the CDC and is out of, I think, the ADDM network data, showing that a third of the kids who meet research criteria for autism in that study were not in the autism category special education. These are 8-year olds. We would expect them to have been identified and be in that category of special education and they are not. I think it is really important to figure out why and whether the services they are receiving are inappropriate because of that mis-specification and whether there are disparities in whether that happens so that we can do a better job of getting kids the services they need.

DR. DANIELS: Thank you. And then the last paper was nominated by Alison.

MS. SINGER: This paper was in JAMA Pediatrics. It made me incredibly sad. We were talking before about mortality. This is a topic that contributes to mortality. This study basically showed that despite dozens and dozens of studies showing that there is no relationship between vaccines and autism and despite a ton of money and energy being devoted to publicizing that information that parents of children with autism are still choosing to withhold life-saving vaccines from their children with autism and from their younger siblings, which puts both of those groups at much greater risk for infectious disease from which they could die.

DR. DANIELS: Thank you. That is the end of the Summary of Advances.

At this point, I believe – do you have something more, Josh?

DR. GORDON: No. Just then say that it seems like we had a consensus that we are going to – rather than having a next meeting in July of the Full Committee, we will have a meeting of the workshop. Any members on the Full Committee even if you are not going to be in that work group who would like to attend that workshop should feel free to do so. But the focus will be squarely on that one issue as opposed to the usual. We will make sure to have a public comment again that is focused on that issue.

We are going to adjourn now for lunch then. We will return at 1 o'clock. We want to return at 1 o'clock sharp. I will point out that we have an extra-long public comment session and we will talk about – because we had a lot of interest in public comment and we wanted to make sure to allow for that and also to allow for the discussion that we had been enjoying the last few meetings around the comments that are made. Thank you everyone and we will see you back here at 1 o'clock sharp.

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

DR. GORDON: I think it is important that we get started because we have a full session in terms of the public comments. I am really delighted to say that we have ten members of the public who have requested public comment. Rather than restrict the number of people who can public comment, we decided to expand the time allotted for public comment during this meeting from the usual hour to an hour and 45 minutes. However, that still leaves us with quite a tight timeline. I am going to ask all the commenters their forbearance. We have allotted each of you five minutes. That will allow us sufficient time for the coverage of the written public comments that were submitted as well as appropriate amount of time for the committee to discuss the oral and written comments, which is something that both the committee and the commenters have requested in the past.

As a result, we really do need to stick to your five minutes. I am going to apologize in advance. At four minutes, I will give you a warning. At five minutes, I will cut you off, which I hate to do because I know you have all traveled here. You absolutely deserve to be heard, but I do not see any other way we can make sure to give everyone their due opportunity. I apologize for my rudeness in advance, but do consider that and make sure you keep to your time table. Again, I will give you a minute warning, so you will have plenty of time to wrap up.

Rather than waste any more of your time, we will start with going down the list of public commenters. We understand that some may not be available right away. We will put them down towards the end and make sure that everyone has a chance if they are not ready. The first commenter is Deb Cordone. I hope I am getting that right. If you would go ahead to the podium. There is written testimony by the public comments that each of the committee members have in their document.

MS. DEB CORDONE: Thank you for having me here today. My name is Debra Cordone. I am from Buffalo, New York. I am the mother of James, a 12-year-old autistic child with severe self-injurious behaviors and aggression when we try to stop him from hurting himself.

Before I start, I would like to say that I am not here to lessen the struggles of anyone with autism. I am the founder and executive director of Fantastic Friends of Western New York, a nonprofit for all individuals with special needs, regardless of age, abilities or behaviors. Ninety-nine percent of our members are autistic from very high functioning to very severe, some so severe that they require four staff with protective equipment at all times. Therefore, I am aware of and I do understand the struggles of all with autism from very high functioning to very severe.

When I speak publicly on this topic at colleges or legislative functions in New York, I use visual such as photos and videos. Since I am unable to do that here, I stand before you dressed in what far too many parents wear in their homes to protect themselves and their autistic children with severe self-injurious behaviors and aggression. For myself, I have arm guards and jeans to protect from bites and gouges, a baseball cap so my hair does not get ripped out of my head, the blocker for when my son comes at me that I can block him from hurting me because if I get hurt and I cannot get up, he is going to be in danger. This call button that I wear here – one button goes directly to my sister. The other button goes directly to our police department dispatcher, not to 911 because I do not have time to get through all the channels that I have to go through when I need help. Also, in my pocket, I carry a bottle of Haldol.

This is not occasionally, but on a daily basis, sometimes several times a day. At times, my child requires four trained adults to restrain him. I am sure this is unimaginable to most of you if not all of you.

There are far too many families living in crisis on a daily basis. Siblings suffering from depression and anxiety due to their home life. We are failing them. We are all failing them.

The worst nightmare for a parent like myself is to take your child to the hospital. The lack of training is the main reason. James was hospitalized twice before getting him to the Kennedy Krieger Neurobehavioral Unit where we remained for nine months. I stayed with him. One of a handful of inpatient units in the United States that can assess and treat a child like James with a waist list, all of them having waist lists six months to two years.

The reason for James' hospitalization was safety. We could not keep him safe at home any longer. The hospital is an extreme last resort. The length of stay for James was 13 days and the second time was seven weeks. They could no nothing for him, but to sedate him. I stayed with him there at the hospital as well because there was no trained staff. If I was there, it meant less sedation because I could restrain him with assistance.

These lengths of stay were actually short, in comparison to other autistic children with severe SIB and aggression. Many are hospitalized six months to a year or longer in psychiatric hospitals where they can do nothing other than mechanically restrain and sedate. My husband and I both required multiple surgeries due to injuries sustained while protecting James from himself. This is an 11-year-old child.

While one mom is searching for a sensory friendly movie for her autistic child, there is another mom struggling to keep her child from biting her tongue off.

While a mom is searching for a restaurant that is sensory friendly and has food that her autistic child will eat, there is a mom and dad on the floor struggling to restrain their autistic child from putting his head through the wall.

While I am speaking, there is a 24-year-old man now having his 32nd ECT treatment.

These individuals are being left behind and the parents in crisis literally crying for help are being ignored. The individuals I speak of are not even being advocated for by large, national and worldwide autism organizations.

Respite. That is non-existent, non-existent for people like us. No camps. No after school or vacation programs.

DR. GORDON: We appreciate your comments. I really apologize to have to cut you off, but we do have others waiting. Thank you very much.

MS. CORDONE: Thank you. I know you listened, but I hope you truly heard me.

DR. GORDON: Thank you.

(Applause)

DR. GORDON: Next, we have Susan Jennings.

MS. SUSAN JENNINGS: Hello. I am a mother of a dearly loved young man who suffers with autism, intellectual disabilities and schizo-affective disorders. I am a founding member of KIIDS, Keeping Individuals with Intellectual Disabilities Safe. We are a grassroots organization of parents, friends, and families of the residents of the Pennsylvania State Developmental Centers, which are intermediate care facilities. We want to keep these facilities open and we want to open the doors to admissions to eliminate the waiting list for people who need services severely and profoundly affected by autism.

My son, like so many thousands of others, has the same aggressive, self-injurious and disruptive behaviors that make living in a community group home, a family home, or under adult foster care living arrangement dangerous and unmanageable.

My own son was offered only a community group home because of an anti-institutional bias and ideological anti-institutional bias. When he went into the group home, they put him in a one-person group home. He was never more isolated and restricted. He lived in a one-person group home with two staff. He was put on over 21 different medications. The medications did not manage his behaviors, but he did end up with female-like breasts, Parkinsonian-like tremors, Serotonin Syndrome, pre-diabetes and episodes of psychosis.

The community group home staff is poorly trained. They are poorly paid. There is a 30 to 70 percent staff turnover rate in the group homes. Their only recourse is to call 911 to manage behaviors. The behaviorally challenged are a particularly hard clientele for community providers to handle safely. This is where over medication, abuse and a shifting burden to local emergency responders can be found.

The trauma and the chaos in the life of the severely autistic adult in the revolving door between community services and emergency hospital services cannot be overstated and the financial cost is exorbitant. They were paying $369,000 a year to keep my son in a one-person group home. It cost over $340,000 because he kept getting Section 302 into psychiatric wards. He was discharged from three different community home organizations and he was in and out of five different psychiatric wards.

He stayed in psychiatric ward for six months, not because he needed to be there, but because there was no other community group home provider would take him. This was my son in the community group home system.

We had to file a 406 petition. We successfully got him admitted to the state developmental center at the intermediate care facility. This is my son in the intermediate care facility.

Now why did this work and this didn't? Because the campus environment in the intermediate care facility is safe. It is structured. They have a swimming pool, a gymnasium, a café. They have scheduled parties, dance events. The physical building itself – they have Plexiglas on the windows. They have thick walls that minimize light and sound. And most importantly, the staff there are well paid. They have a supportive, caring environment in which to work. They can call upon other staff during behavioral crises. There are clinicians, doctors, nurses, behaviorists on the premises that can be accessed. You do not have this in the community. These congregant care facilities have a therapeutic value.

I implore the IACC to advocate for a full continuum of residential services. There is a broad diverse spectrum of people with autism and they need a broad diverse spectrum of residential options to choose from.

The February 2017 study in the Journal of Autism and Developmental Disorders. The research from Pennsylvania State University found that young people ages 12 to 21 with autism are four times more likely to go to the emergency room than peers without autism. They are also three and a half times more likely to be admitted to a hospital floor at which point they stay in the hospital nearly 30 percent longer.

Young adults languish for months in psychiatric wards and hospitals because they have no safe place to go. I am here to say the intermediate care facility that specializes in this type of care would be the safe place for them to go. Without the intermediate care facilities, if those are eliminated, where will our loved ones with severe autism end up?

DR. GORDON: Thank you very, very much for your comments.

(Applause)

DR. GORDON: Next, we have Cheryl Smith.

MS. CHERYL SMITH: Hi. I am Cheryl Smith from Salt Lake City, Utah. I have a nonprofit called the Autism Council of Utah and I do a lot of educating for our legislators and policymakers, but mostly I am Carson's mom. I did not come here today to talk about the kids, I say kids, they are my kids, the adults that have jobs and can find meaningful employment. I came to talk about the folks who need significant support.

Every day everywhere there are individuals who have autism that have episodes of violent behavior. We never know exactly what triggers them. Sometimes we do. But the level of violence they are capable of is frightening.

We parents that are in the middle of that, do not like to openly talk about that maybe because of fear or shame. A lot of times people do not know what is going on in our homes. We spend our whole life trying to get people to give them jobs and be their friend and be nice to them, not to be afraid of them.

Because physical violence and aggressions are rarely talked about, policymakers and providers may not understand the scale of the problem. Funding sources do not take into consideration the immediate need when families are in danger, giving them no options for immediate help.

Aggressions can make it virtually impossible for a person with severe autism or their family, to function in society. We cannot go to the grocery store or take our kids to the movie sometimes, or adults. And services are really hard to find for those who have significant aggressions.

We are not sure where they come from, but I think it is frustration, sensory overload, even medical problems can cause the behaviors.

This is my son Carson. I call him the man cub. He is 95 percent teddy bear, but five percent tiger. I never know when that tiger side is going to emerge. We have tried medications and behavioral interventions, but with little or no success.

He has severe meltdowns causing self-injury. I am going to warn you these pictures are vivid. He has bitten all the skin off of his hand, requiring him to have plastic surgery and skin grafts.

The first time he bit me – I reached up from the back seat to stop him from jumping out of the car, and I did not go to the doctor because I was afraid of what they would say or what they would do. Would they take him away? I did not know. I ended up being in the hospital for three days with antibiotic IVs.

He will bash his head on the floor. That is me. He will pinch. He will break his teeth off because he bangs his head so severely on the floor, and making holes in our walls, and causing severe damage to himself and others.

He pinches. When I say pinching that is what it looks like. He does not want to do it. When he is finished having his meltdown, he will pet the floor where he hit his head and he will pet my arm where he had bit me. He will say sorry mom. Sorry Carson. He even apologizes to himself. For a guy with few words, he is very sad.

He destroys property. He banged his head on the car window and broke the window right out. We are exhausted, and we have PTSD because we never know when this is going to happen. We do not take him to other people's houses and we do not have people over.

I live in fear that law enforcement will be called and not in a good way, resulting in a bad outcome.

What is the answer? We want to create a program in Salt Lake City that will be a quality, life skills, vocational program along with behavioral supports for this population. It will include all of these different areas. They will practice these skills in the center and then be able to go out into the community and take advantage of that interaction that they have with other people.

You would think that Medicaid would be calling me up saying, thank you Cheryl Smith for trying to make a quality sort of center for these folks who have severe aggressions. But I feel like the roadblocks are extremely huge with the settings rule, trying to make a quality community for these adults with autism.

Autism never sleeps. It does not go on vacation. It is there on Sundays and holidays. It never takes a day off just like taxes. Autism never takes a break; therefore, neither can we. I appreciate you letting me come today and tell my story. Thank you.

(Applause)

DR. GORDON: Thank you. Next will be Joe Joyce.

MR. JOE JOYCE: Thank you very much. Good afternoon. My name is Joe Joyce. I would like to introduce my son, David Joyce, over there with the green neck pillow, and my wife Elise, with the red jacket.

Thank you very much to the IACC for giving us time to tell David's story. I will be articulating David's story on his behalf.

David has autism, severe self-injurious behaviors, and non-verbal. But despite all these challenges, David has become a great ambassador and has raised awareness and acceptance for autistic individuals. He is also now a member of the Autistic Self Advocacy Network.

Elise and I are very committed for David to be a self-advocate in his own very unique way. We have learned over the years how to communicate together as a family as effectively as possible. I would not be standing here today if I did not fully believe that David wants us to be here and tell his story on his behalf. David really respects people who are very patient with him and who sincerely try their best to communicate with him. But unfortunately, too many people just seem to fail to even acknowledge him.

He has lived through a life of many obstacles and has overcome many challenges and has brought awareness and acceptance throughout the country. He has been an inspiration to many. My employer, Keystone, has adopted Autism Acceptance and Awareness in David's honor. We have spoken throughout the country at events to help raise awareness about autism. That young man over there is responsible for making that happen.

Here is David's story. At a very early age, he began engaging in a frightening degree of self-injurious behaviors. We feared for his safety, potential permanent brain damage. He would strike his fist to his head. He often had bloody noses and puffed up ears and severe bruising to his eyes and face. His self-injurious behaviors averaged at that time, 8000 per day. It was just very difficult.

In addition to injuring himself with his fists, he also head banged into walls and windows and his own shoulders. He would bite his hands until his skin was raw. Elise and I in all of our efforts, tried to intervene, we often would get in the middle and have some injuries ourselves from his own self-inflicted behaviors.

We believe that David really never wanted to be doing these things. They were just uncontrollable. Back in the days before assistive technology, David communicated with us through facial expressions, through his eyes. If you meet David, you will see he has the most expressive blue eyes you will ever see. We would communicate while he was in the midst of a meltdown. I would look deeply into David's eyes and I could see that he was pleading for us to find help for him. So help is exactly what we did.

We began working with the Kennedy Krieger Institute, part of Johns Hopkins, through their outpatient program. My wife Elise, is a miracle person and she would drive David 180 miles round trip twice a week to Baltimore for treatments. But it became very much impossible to do so.

To make a long story short, he was in the Kennedy-Krieger Institute in the Inpatient Unit. Finally, at the age of 7, we began to utilize strategies that were recommended at the time by the professionals at Kennedy-Krieger. We were exposed to ECT, which actually was what I think saved David's life. He utilized that strategy for a period of four years until he had a physical condition, which caused us to discontinue those treatments. After he would have those treatments, his SIBs would go from thousands to literally almost zero.

He was then finally able to come home. He now communicates using an iPad. Today, his self-injurious behaviors number less than 100 per day.

He is out front and in front of the community. As you can see, David will ask us to put on self-protective equipment. He has what he calls arm stays and helmets, and he asks with his iPad to put stays on or stays off, or helmet on, helmet off.

In closing, I would just like to say that in my role, I am a volunteer chairperson of the Board of the Autism Society of America. Our role is to improve the quality of life for all people on the autistic spectrum. David travelled here all the way from Pennsylvania today without his aide, because they would not cross state lines, talking about bureaucracy.

David came here today to spotlight being a self-advocate in his own while also being non-verbal and on the autistic spectrum.

Thank you very much. I would encourage you all to please come and meet David. He is very social. He loves to meet people. If you have the opportunity, stop by and introduce yourself to him.

(Applause)

DR. GORDON: Thank you. Dr. Dan Fairbanks.

DR. DAN FAIRBANKS: My name is Daniel Fairbanks. I am the dean of science at Utah Valley University, and also a geneticist. My wife is chair of the Department of Music and a concert violinist.

We have a very severely autistic son who is now 26 years old. I will not go through his symptoms because they are very similar to the ones that you have just heard from the previous speakers. They are also available in the written comments that I provided for you.

Rather what I would like to do is focus on some of the challenges that we have faced as we have attempted to deal with our careers, our family, and also the needs of our son.

First of all, the most serious that I see, is the lack of resources that are available for those on the extreme end of the autism spectrum. Oftentimes, there are resources available for those who are much higher functioning, but we find that we cannot attain resources because they are so expensive and so difficult, and there are so few facilities that will offer them.

Secondly, we found in our experience the waiting lists, changing regulations, requirements for work when my son will never be able to work, contradictory requirements that often come about, have challenged us throughout our careers.

And then also as parents, being able to navigate these changing requirements and finding appropriate resources from governmental entities both working with the federal and state governments is extremely difficult to the point that we had to hire attorneys and still do to help us navigate those and be able to obtain what is needed for our son.

We ended up losing all of our home equity and losing our savings, in attempting to obtain what my son needed. Fortunately, my wife and I are successful enough that we have recovered. I worry very much about families who are not in this kind of situation that we are.

I would like to end, however, on some notes of optimism. As a scientist, I am very impressed by the research that is underway, some of which you have heard today, particularly in my own area of genetics where tremendous gains are being made. I think there are many opportunities there to coordinate the social side with the scientific side.

And then I am also optimistic for what we can do in places like my university where we recently established a center for autism in part because of the experience that I had with my son. My wife and I as professors, have been able to help establish that. I will go ahead and end there.

(Applause)

DR. GORDON: Thank you very much. Jalynn Prince.

MS. JALYNN PRINCE: Thank you. Jalynn Prince with Madison House Autism Foundation. For the last ten years, we have been functioning as one of the only organizations in the country focusing exclusively on the issues of adults with autism. I am so gratified today to hear conversations that are centered around adults with the issues that face people for three-quarters of their lives. It is time to step up and do things.

I still would like to challenge you all. This is the body that can take information to the people that need to hear it, to have policies so we have things that are continual that do not contradict one another that help our individuals.

I have something a little bit lighter in a way that I want to address today. Three years ago, Madison House Autism Foundation moved forward in declaring April 21st as Autism After 21 Day, having it noted in Congress and state legislatures and in municipalities. We are hoping that this will go around the country because we have found that there is a portion in between that is ill informed about our population.

Our awareness for this need to designate this national day, has come about because we hear two phrases. What will happen to my adult child when I am no longer around? What will happen when they are no longer around?

Second, when we tell people what it is that Madison House Autism Foundation does, they make comments like this - and this is from attorneys, business people, very well-educated individuals saying, I have never thought about adults having autism. That is an astounding, but very common statement that we hear.

We want to make certain that there is a portion of the population that has not been engaged in this conversation to come to the table. Not only do we have congressmen, state legislators, and local people involved in this conversation, we also are staging events where we can bring thought leaders together, people that can hire, people that can make policies in their towns and in their counties, that can help our population. We have not engaged them. We talk about awareness. We are calling people to action. We need action. We cannot do it alone.

I am going to consolidate this. We have a brief video here that we are taking out to many people across the country to help educate that in between part. You all know this, but this is information that we are taking out because every business person - because we will have small businesses and large businesses that may be able to employ our people. But if they do not know about our people, if they are invisible, how can they stop forward to be part of the answer? Thank you. Now our video.

(Video shown)

(Applause)

DR. GORDON: Thank you. Next we have Danielle Augustino.

MS. DANIELLE AUGUSTINO: Good afternoon. Thank you for the opportunity of speaking today on behalf of my brother James, my family, and those with severe autism.

Upon sitting down to write this, many emotions surface. Anxiety, frustration, anger, and I am just the sibling. My brother James was adopted at a very young age by my parents. They were older, past the age of raising children, however, they saw the need to give James the love and care he needed.

The past several years of life for my parents and my brother have been completely overwhelming, and to be honest, an absolute nightmare. I am here today to be a voice for those with severe autism and their families who are barely making it through to the end of the day. I understand what they are going through as my family has lived this nightmare for years.

Fast forward a couple of years after adopting James, self-injurious and aggressive behaviors began to present, including head banging, biting, hitting, punching, et cetera. This sadly became a part of everyday life. Restraining including arm guards and football blockers were a daily necessity if we were able to get to them. My parents had no business restraining James. They both had several surgeries. My dad has a history of lymphoma. My parents were prisoners in their own home.

Their grandchildren cannot go to their home because of this dangerous environment. My parents could not go to family functions or even have time to themselves because taking James out of the house was incredibly risky. No, I am not exaggerating.

Forget family holidays. We were not able to be together as a family. I recall Thanksgiving, being away from my two-year-old son so I could help my parents as they had no help in the house. Luckily, I was, because it took three of us to restrain him from punching and biting himself as well as doing the same to one of us. Thankfully, a relative in the area who could quickly get to the house to administer the Haldol, was able to calm him. That was the only option as there was no possibility of one of us letting up on restraining James.

These words cannot begin to convey how heart breaking of a situation this was. It was devastating to see bruises and teeth marks on my parents and sad to know that this was their everyday struggle. Imagine that. Bruises, teeth marks, gouge marks on your parents and there was nothing you could do, but just stand by and watch.

I was fearful every single day that my parents or James would sustain a major injury and need to be hospitalized. It was painful to witness James endure these episodes. No child should have to struggle with this instability. Everyone suffered. James, my parents, my siblings and I and our children.

The most devastating moment and I still have this clear in my mind was on Christmas Eve. We were so fortunate to have one aide, so my family and I could spend time. Everything was going well. James spiraled out of control with a need for five of us to restrain him. Yes, five adults to restrain this child. This went on for some time.

Finally, the only option was an ambulance to the hospital. When we arrived at the hospital, it still required five of us. No one knew what to do with this child. Autism has a spectrum, mild to severe; therefore, medical professionals, first responders, et cetera need to be trained on how to manage all individuals on that spectrum.

That evening I recall my mom standing in the hospital hallway crying on Christmas Eve. This was the most heartbreaking moment of my life to see my mom crying with no end in sight. That moment summed up our lives. It was devastating to see James suffer through this. I was at a complete loss. Where is the help? Why aren't the meds working?

This poor child sat in the hospital for seven weeks before finally getting a bed at

Kennedy Krieger. To have to fight with insurance on top of it was mind blowing. My sister, my mom and I and our family took to social media to get insurance to approve his stay at Kennedy Krieger. James was considered lucky to have even received that bed. How sad to think there are so many children waiting for a bed and there are not nearly enough. We are grateful and consider ourselves lucky to have had amazing home aides who were tremendous help; however, they are underpaid for the dangerous environment they need to work in.

James is blessed to have an excellent psychiatrist, Dr. Michael Cummings, who has been an incredible advocate for him, my family and the autism community. Everyone deserves access to good health care, well-trained practitioners, in-home services, and a bed if needed. There are not nearly enough services to help these families that are struggling every single day. They are barely surviving. This is reality of severe autism. Thank you.

(Applause)

DR. GORODN: Thank you very, very much. Lisa Wiederlight.

MS. ANN STROBER: Good afternoon. My name is Ann Strober and I will be presenting for Lisa Wiederlight. She had to leave. She is the Executive Director of SafeMinds.

It is my pleasure to speak to you and the members of the IACC, on behalf of SafeMinds, a national nonprofit organization focused on ending the autism epidemic by promoting environmental research and effective treatments.

A group of parents dedicated to identifying the environmental causes of the autism epidemic started our organization 18 years ago, and we remain dedicated to increasing the safety, health, and independence of people with autism and their families.

The problems facing the autism community are very serious and require urgent responses. Since the IACC was created, it seems the problems facing people with autism and their families have worsened. Autism prevalence has increased with no identified cause. We do not have any widely-recognized causes of autism, either.

It is imperative that the IACC focuses on urgency and accountability. Given the size and scope of the autism crisis in the United States, I was dismayed to find that the only strategic research plan from the IACC is from 2016 to 2017. Do we not have a plan for this year? We are in the second quarter of the year already. Don't the taxpayer and other stakeholders deserve to know how we are going to affect this situation this year moving forward?

There are 23 new objectives in the 2016-2017 Strategic Research Plan, which recommends doubling the research budget from $343 million in 2015 to $685 million in 2020. Unquestionably, more must be spent on research, services, supports, and the like. But what justification is given? Why does the strategy fail to identify and quantify outcomes that can be measured and compared over time? We need a research plan that will support policies and programs that will ultimately make a significant difference in the everyday lives of people with autism and their families.

By way of example, one of the 2016-2017 Strategic Research Plan's objectives is to “reduce disparities in early detection and access to services.” Reduce by how much? From what level to what level, over how much time? In which populations? Other terms used in the Strategic Research Plan include understand and explore.

Another example is “What is the biology underlying ASD” and then the objective is to support research to understand the underlying biology of co-occurring conditions in those with autism. How is “supporting research” measurable? Perhaps “identify X many biological factors that would contribute to the development of seizure disorders” or gastrointestinal disease or suicidality or wandering or sleep disorders.

If the IACC instead coordinated research that supported the policy goals of an Autism Strategic Plan or the goals of participating agencies, our community would see significant changes. For example, one goal could be to reduce mortality rates by X percent in the next five years. The research supporting that measurable goal would identify the causes of and treatments for suicidality and seizures, which are the main reasons for higher autism mortality rates. Then, the agencies responsible for addressing them could measure the effects of policies and programs designed to reduce autism mortality over time. The IACC could also coordinate research into the gaps in knowledge and roadblocks to achieving that goal.

The same can be said for autism prevalence data. How can this data be used, if at all, toward informing policy objectives toward a measurable goal? For example, how many people with autism are over the age of 18 who can be employed? How many are employed, and what services are needed to decrease unemployment rates among people with autism by 5 percent in the next three years? What should and could, that percentage be? How do the agencies represented in the IACC collaborate with the members of the IACC to formulate policies, programs, and metrics toward a stated goal that will positively affect our community's safety, health, and independence?

This is the necessity of our times, in which the majority of people with autism experience gastrointestinal disease. A higher percentage of people with autism have seizure disorders than in the general public. People with autism are nine times more likely than their peers to ideate suicide. The unemployment rate among people with autism is at 80 percent. Autism is costing our country $500 billion.

DR. GORDON: Thank you. Thank you very much for your remarks. We really appreciate it.

(Applause)

DR. GORDON: Tara McMillian.

MS. TARA MCMILLIAN: Hello. My name is Tara McMillian and I have a son who is impacted by autism. More specifically, he developed encephalitis after his “catch-up” vaccinations at 17 months of age. This medical emergency was not treated as an emergency but a neglect. Yet because we were not informed and not educated, my son suffered brain damage without treatment. Following this brain damage, he lost all ability to speak.

He is now 12 and he does not speak. He can communicate in other ways, but his abilities are limited because of what happened to him in the doctor's office. Do we have compensation? No. Do we have help? We do only because a mother and father do not give up. I am here today to speak about the recent article in Time Magazine discussing the study published in JAMA claiming that children with autism were unprotected from vaccine preventable diseases.

The problem with this discussion is that the children with autism were vaccine injured. Parents of children with autism are not going to continue to go back to the very thing that caused their child's brain injury.

Instead of funding a study to better understand why parents refuse to put their children in danger of ACIP guidelines, scientists should be asking, what is different in the families of children with autism. Why are they not vaccinating? This is a question that should be asked, and the answer should be pursued without prejudice from the scientists.

Cause and effect in science can be documented. We have documentation of our children's vaccine injuries. Thousands of children have been injured by vaccines and therefore the parents no longer vaccinate. I implore you to seek out the reasons why vaccines harm instead of seeking to make our children the scapegoats for the failures of the vaccine program in the United States. We are a shame to other countries because we are the most vaccinated among children, and one of the sickest. This is proof that vaccines are more harm than good to our children.

In a recent ACIP meeting, I watched with horror as a new hepatitis B vaccine was added to the schedule even though there is no data to show safety among newborns. With the lack of safety studies and no liability for damages from vaccines, our children are sitting ducks when it comes to these shots. We have no idea what will happen and when the bad does happen, there is nothing anyone can do or will do. Parents are smart. They follow what other parents are telling them. If one child is injured and medically neglected, you can bet that ten parents will know about it. It is the failure of the CDC and all those that toe their agenda that has caused this tragedy. Instead of helping the parents and the child, studies are being conducted to “better understand the dissent”.

If the CDC continues to state that vaccines do not cause autism, there will be thousands and thousands of children not getting vaccinated. You do not have to thank Andy or Jenny for that. It is the parents who see their children disappear after the shots. They only want to keep their children safe from more harm. Nothing good could ever come from a needle that once did harm to that child.

Thank you for allowing me to speak today on behalf of my son and others like him because vaccines took away his voice.

(Applause)

DR. GORDON: Thank you and thank you to all the commenters. I especially appreciate that everyone took forbearance with my need to make sure we stay on schedule.

Before we have the discussion amongst the committee on the comments that were made, we will do the reading of the written comments. I welcome Oni Celestin, a policy analyst in the Office of Autism Research Coordination, who will summarize the written public comments that were submitted.

DR. ONI CELESTIN: Good afternoon. Since the January meeting, the IACC has received written public comments from 33 commenters. For the purposes of this presentation, we have organized these comments into seven broad topics. The committee has been provided the comments in full, but they will be briefly summarized here.

The first topic is individuals with aggression and self-injurious behaviors, which I will abbreviate as SIBs. There were 13 comments received on this topic.

Ms. Susan Jennings wrote in support of a choice-based approach to service provision for adults with SIBs. She believes that the IACC should write a white paper focused on the service needs of this subset of the autism community.

Dr. Neera Ghaziuddin believes that many autistic individuals with SIBs may have co-occurring severe mood disorders or catatonia. She hopes to increase awareness of the symptoms of these disorders among psychiatrists who treat autistic patients and urges appropriate training among professionals.

Mr. Armondo Cordone requests more research and resources on those with SIBs and aggression. He is especially concerned about the small number of inpatient treatment facilities for those with these behaviors. He also urges autism advocates to speak for all on the autism spectrum and requests that the IACC membership should include a parent of an individual with severe SIBs.

Dr. Max Fink shared several references indicating that benzodiazepines and electroconvulsive therapy or ECT may be effective treatments for autistic individuals with symptoms of catatonia including SIBs.

Ms. Wren Vanhooser wants to increase awareness of individuals with autism who are severely impacted by SIBs and requests more funding for research, resources and new treatments.

Ms. Julie Greenan believes that the DSM-5 does not adequately represent the entire spectrum of individuals with autism and recommends separate diagnostic criteria for detailing severity. She also requests more research funding and inpatient treatment facilities for those with severe SIBs.

Ms. Tammy Bost wants to increase awareness of the lack of health care providers, service providers, and residential facilities for individuals with severe autism especially adults. She also requests increased funding for research and resources.

Ms. Caryn Porretta wants to increase awareness of the challenges faced by individuals with SIBs.

Additionally, Mr. Kevin Valazza, Ms. Dana Mullican, Ms. Debra Odineal, Mr. David Phillips, and Ms. Julie Maryjanowski all wrote separately to request increased funding for research, inpatient facilities, resources, and support for individuals severely affected by SIBs and their families.

The second topic was Vitamin B12 deficiency and autism. Six comments were received on this topic.

Ms. Elissa Leonard expressed concern that the symptoms of autism are similar to those of Vitamin B12 deficiency and that dietary recommendations to women of childbearing age are contributing to B12 deficiencies in their children.

An anonymous commenter believes that B12 deficiency should be investigated and ruled out before an autism diagnosis is made.

Ms. Sally Pacholok wants to increase awareness of the symptoms of B12 deficiency. She believes that women should be screened for B12 deficiency at prenatal visits and infants should be screened at three to six months of age. She also requested increase research funding on B12 deficiency.

Additionally, Ms. Ruth Chaffin, Ms. Margaret Tallon, and Ms. Patricia Holden wrote separately to say that they each have been diagnosed with Vitamin B12 deficiency and that they also each have a child diagnosed with autism.

The third topic was the role of the IACC. Four comments were received on this topic.

Mr. Jonathan Mitchell expressed concern that his previous public comments may have been misunderstood by members of the IACC.

Ms. Christie Riehl expressed concern that the various federal agencies that provide services to individuals with autism are not well coordinated, which reduces access to these services and increases cost. She feels that the IACC's main priority should be to propose solutions for increased coordination. Instead, she feels that the IACC has become distracted by disagreements within the autism community.

Mr. Dwight Zahringer requests that the IACC facilitate a survey of parents of children with ASD. He also asks the IACC to investigate whether there is a link between glyphosate exposure and autism.

Mr. Gene Bensinger requests that the IACC creates and adopts a formal code of conduct for members of the committee to foster more respectful interaction within the autism community.

The fourth topic is concern about medical practices. There were four comments received on this topic.

Dr. Debasis Kanjilal shared several emails he has sent to other committees to express his concerns about brain injury, resulting from inadequate treatment of hypoxia in newborns.

Dr. Brian Chiodi expressed concern about the use of hypnosis as a treatment for mental illness.

Dr. Katharine Hikel expressed concern about a potential link between the use of Pitocin or other medications during labor and delivery and autism diagnosis.

Dr. Eileen Nicole Simon expressed concern about the potential harm caused by clamping of the umbilical cord immediately after birth and the potential role of damage to the inferior colliculus in ASD.

The fifth topic was service needs, resources and support. Four comments were received on this topic.

Ms. Lindsay Bessey requested more assistance and funding for individuals with autism and their families, particularly in New York State.

Ms. Kerima Cevik wrote about the challenges faced by her son and other autistic people of color and requests that autistics of color are included in the autism conversation. She also requests more funding for lifelong education and community living programs as well as effective caregiver supports.

Ms. Amy Patterson and Dr. Deborah Napolitano request increased funding for well-trained clinicians in psychiatry, nursing, and behavior analysis for children with profound neurobehavioral challenges and their families. They also requested increases in supports for in-home, school-based, and outpatient services.

Ms. Eileen Kurlander submitted several comments from members of her organization requesting more resources for their families, including more funding for group homes, day programs and residential facilities, hiring and properly training educators and care providers, increase insurance coverage of ABA treatment and respite care for family caretakers.

The sixth topic was vaccines and autism. There were three comments received on this topic.

Mr. John Best believes that autism is caused by mercury in vaccines and expressed frustration with the IACC.

Mr. Dwight Zahringer asked that the IACC make a formal request to Congress to investigate the CDC whistleblower issue.

Ms. Eileen Kurlander expressed concern that vaccine injury causes autism.

The seventh topic is autism research priorities. There were two comments received on this topic.

Ms. Ramey Chisum expressed concern about familial and societal dysfunction and its relation to mental illness, particularly in individuals with autism and co-occurring OCD, anxiety, depression, or PTSD. She believes that more research should be done to understand the commonalities.

Ms. Kerima Cevik requests more research funding on co-occurring physical and mental health concerns, particularly sleep cycle issues.

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

DR. GORDON: Thank you, Oni, and thank you also to all the commenters both written and oral.

I want to now open it for committee discussion. I will note that many of the comments this time around were regarding self-injurious behavior perhaps motivated by the fact that we have a speaker on that this afternoon. We can certainly talk about it now, but we will also have the opportunity to talk about that subject later. But I open it up to the committee who would like to make comments or discuss any of the items that were brought up.

MS. CRANE: I just wanted to highlight what I think is really interesting about Kerima Cevik’s comments, and I think connects to some of what our oral commenters said about the importance of assistive communication. A lot of people who self-injure - and I do not know about Kerima's son, she did not specify this - but I know that her son really struggles with communication. This is one of her greatest concerns in his life and when she is trying to plan for his future.

Kerima is a friend of mine. I will just disclose that. What she really wants more than anything else is for him to continue to live in the community and to live safely in the community as a person of color whose expression can sometimes get misinterpreted. We really need to do more research on communication.

I know that when people self-injure, it is really often because of frustration that we have a hard time communicating. I have to say that if any one of you could not speak, you would probably be self-injuring too. It is so frustrating. We really need to focus on that.

MS. SINGER: I want to express my sincere thanks to the brave parents who came and spoke today - and sibling. I think that is very brave to get up there and tell your story. I know a lot of families are reluctant to tell those stories, but today you showed a bright spotlight on a very important issue. I think a lot of families will gain strength from your presentations.

I think we need to take note as a committee of the fact that parents are here, siblings are here, begging us for help. This is a segment of the population that is being left behind. I know we are going to talk about that after Dr. Siegel's presentation. We have to take note of the fact that there are not enough resources to support those on the severe end of the autism spectrum. We have to be able to do better. We have to have options and choices so that every family member, every individual can make the choices that are right for him or her without taking anything off the table.

Again, I will save some of my additional comments for after Dr. Siegel's presentation. But I was so moved by the presentations today. I do not think there is anyone in this room who did not have a profound reaction to your stories, to the videos, to the photographs that you so bravely showed today. I know how hard it is to stand up and do that and I want to thank you.

DR. GORDON: Thank you, Alison.

DR. REICHARDT: I also want to thank all of you for coming. I just thank the charge that you have given us, not just as a committee, but as individuals to seek federal and state support and make all of your individual and families' lives better. It is just extremely moving and a huge charge for us individually as well as a committee.

DR. GORDON: Thank you. Geraldine.

DR. DAWSON: I just want to echo those comments. I know what a challenge it can be to come all the way here and share your stories it did have a real profound impact on all of us.

I guess three take-aways for me besides just the utter lack of resources and no place to turn in terms of living or any kind of residential program or treatment program. But I think three things that we can do immediately. One is making sure that we focus on this as a research area of a high priority at NIH that we could understand what causes this, what can help it, what are better treatments.

And then I think in our communities, two things that I have seen even locally in our clinical program at Duke that have made a big difference and that is handling kids as they come into the ER because most emergency rooms really do not know how to handle kids when they come in crisis and that is a horrible experience for families and so on top of the crisis they have a bad experience. That is something that all of us who work in our communities can be working with professionals to just having knowledge and know how to change it.

And then the other piece of that is law enforcement. That is another area that we have been doing a lot of work in that you can make very immediate impact on the experience of families who are in crisis by providing information to law enforcement.

We found that everyone is so willing to change. It is just a matter of honestly a lack of information.

DR. GORDON: Thank you, Geri. John.

MR. ROBISON: I would second what others have said about the impact of the commentary today from the families. I would like to make a point that in the case of people who were severely impacted whether we say that self-injury comes from frustration through inability to communicate. There is a whole host of problems that come from inability to communicate.

As the agencies that are charged with solving that problem for the American public, I think that we should keep in mind that even though this is described as a medical problem, the solution is very likely in technology. I am concerned that NIH does not have a large enough body of expertise and we have not funded enough research into how we will use technology to solve the problems of severely impacted people. Right at this moment, there is an autistic fellow behind me who is communicating with his family through technology.

It is not just communication technology for autistic people. There is also the issue, for example, of giving autistic people necklaces, bracelets, and such that we can wear to summon specific relevant help for us. If we cannot talk for us to have a traditional LifeLock button and push it, what good does that do us? We cannot answer when somebody comes. We need dedicated help like that. That technology is not Star Trek. It is not in the future. It is stuff that engineers could make right here and right now. It is an example of what I urge us to be funding as real help for our community.

DR. GORDON: Thank you, John.

DR. KAU: I want to echo all the sentiments about our appreciation for all the people and all the parents and David coming here to make comments. David and your parents remind me of my days as a staff psychologist at Kennedy Krieger Institute. I feel emotional because I remember the struggles that the parents face more than ten years ago. That has not changed.

The treatment is very complicated. We are going to learn more about it in our next presentation. And the services and needs are great. We need to help the parents. It has not changed. Even more than ten years ago when I was there, the parents were worried so much about what will happen to their children when they no longer can take care of them. It is one area that deserves our attention. I am thankful that you all came to make comments.

DR. NINA SCHOR: Having moved here to NIH from a fairly large children's hospital, I feel compelled to point out that although emergency rooms, clinics, medical facilities may well be the place that families and children go to in these situations, I think we need to think very carefully about the environment that we create in those places because so often they are perfect for behaviorally and cognitively typical children and adults, but exactly the opposite kind of environment from what would be calming and therapeutic for an individual with autism. Behaviorally typical children, behaviorally typical adults often feel comforted by large numbers of people by feeling comraderie with individuals in similar situations. They are noisy. They are colorful. There are things for the children to play with on the floor. I think that is extraordinarily frightening for an individual who suffers from sensory overload syndromes.

I think it is not the cure, but it may be part of the symptomatic relief for individuals with autism to come into an environment that caters to their needs.

DR. GORDON: Alison.

MS. SINGER: Once again, I want to try to focus this group on what this group is able to do. I think that we heard some suggestions today of things that we would be able to do. We could for, one, as Geri suggested, identify this as a high priority research area. I want to point out that there is really no research right now that ties self-injurious behaviors to lack of ability to communicate. We do not know what is causing self-injurious behaviors. We need more research in that area.

There are also some things that this group could do in terms of trying to, as we spoke about earlier, remedy policies that are in fact hurting this segment of the population particularly some of the Medicaid settings rules that we heard about and some of the guidance under Olmstead that while being positive for a large percentage of people with autism is actually causing harm to those with the most severe forms of autism. If we are going to be looking at making policy revision recommendations with regard to employment, perhaps we can expand that and also include making some policy revision recommendations with regard to some of the issues that we heard today.

I also want to add that at the Autism Science Foundation, we are going to be convening a research meeting in the fall looking at research for underserved populations particularly individuals on the severe end of the spectrum and particularly those with self-injurious behaviors.

I would invite all of the members of the IACC who are here today and those who made public comments today and those who are watching on the closed-circuit television who want to be part of that conversation, to get in touch with us. We are just in the planning stage and we are looking for partners to work with us.

The goal of that will really be, as Geri said, to start to identify this as a priority research area and within that to determine how we can address some of the gaps in our understanding.

MR. ROBISON: Alison, I know that you are a big fan of evidence and scientific method and we all should be at this table. But as autistic people, I think that it is safe to say that I, Sam, others have come before this committee and talked for years about how we injure ourselves, slamming our heads against the wall in frustration, biting chunks out of our arms because we are frustrated. Why are we frustrated? Because we cannot communicate. We do not need a research study to tell us something that has shaped our lives.

I do not deny that a research study could quantify it, but that is an example of something that to someone like me just feels outrageous to suggest. Of course, communication disability causes those problems. I have lived with them 60 years for Christ's sake and to say we need solutions. That is the kind of stuff that enrages the community. I am all for finding solutions. By all means, do those studies. But don't let’s stand still and don't let’s make people feel that is it being pushed aside over stuff like that.

MS. CRANE: If I can just comment about self-injury and communication, is that a lot of times when people do design these studies, they do not design them in a way that talks to us first. Certainly, I self-injure for reasons other than needing to communicate. I self-injure when I am uncomfortable. I self-injure when I am in pain. I self-injure when I am anxious. I self-injure when I am bored.

But there are lots of different kinds of motivations and some of the worst episodes – I know John will agree with me. The experiences where you have people like throwing – and having a really hard time, those are often communication related and communication can make it harder to find other causes. If I am in pain and I am self-injuring and I cannot express that I am in pain then self-injuring might be the only thing I can do.

I think that it is a good point. We need better research on this experience. But we need research that is actually talking to us and taking our stories into account when we do that.

MR. ROBISON: I agree with everything that Sam said. I agree that the other reasons apply to me too and everyone I know.

DR. GORDON: If I might interject for a moment. The discussion here, which I think is a discussion and not a debate brings up several important points that I want to underscore and then I also want to add in the fact – some facts about what NIH is and is not doing in the area because I think it was mischaracterized before.

First, we have to recognize that as Samantha and John both states and as I am sure Alison would not disagree, there are many reasons why one might self-injure and apparently at least for the two of you and I can imagine for a great number of those who are able to express it, communication difficulties are one of those reasons.

I think a legitimate question to be asked is in someone without communication, if we solve their communication problems, how much of their self-injurious behavior would be – would be reduced by that? I think that is an empirical question that one can ask. But one cannot ask that empirical question unless one finds a way to facilitate communication in that group.

With that in mind, I want to point out that actually there is research that goes on at NIH both from a fundamental, trying to understand why is communication disrupted and how behaviorally we might be able to enhance communication in those with autism and other developmental disabilities, but also specifically with assistive devices in mind.

Particularly I want to point out an institute that we do not hear from much, but that is represented at the table, National Institute on Deafness and Other Communication Disorders, does actually do a lot of work with assistive devices including some that specifically targeted individuals with autism. I think we can recognize that there is work done in that area. Although, of course, there can always be more.

As Susan whispered into my ear earlier, the National Science Foundation is another source, not represented at the table, but another source for research into communicative devices.

Although we do not talk about it a whole lot, the NIH's Brain Initiative, which is a multi-pronged effort to try to develop better tools to interrogate the nervous system, also is focused very much on device development to enhance communication in those who have trouble communicating. We can look forward to advances from that down the line admittedly, in helping in this area.

I think there is a lot of interest in that area and one can hope, I think legitimately so, that that will help reduce self-injurious behavior in the future.

While I do not want to cut the discussion short with regards to self-injurious behavior, there certainly were other issues raised by other commenters. We will have an opportunity to revisit self-injurious behavior in just a few moments. I wanted to make sure that those who had comments or questions about some of the other comments that they had the opportunity to do so.

MS. HARRIS: This is Melissa Harris. I am with the Centers for Medicare and Medicaid Services in Baltimore. I hope people can hear me.

I wanted to address a couple of references that I have heard this morning to the settings regulation for Medicaid-funded home and community-based services and also talk about a reference to intermediate care facilities, that I also heard as well. I will not take up a lot of time. I am happy to have as informal or as in-depth conversation about these various Medicaid funding authorities as you all would like.

But I did want to acknowledge that both of those programs are run out of my Office. I am happy to talk a little bit about what it means for individuals in various stages of life and with various diagnoses, with various presentations of even a consistent diagnosis across the group, how the settings regulation in particular, is meant to really have an individual and those that are closest to them be driving the bus, so to speak, about the types of services they are getting, the types of supports that they are receiving from wherever they are living or wherever they are receiving services.

There is a lot of concern out there about the regulation and its impacts on individuals. I have heard that concern manifested in a lot of different ways and in a lot of different audiences. I am happy to try to peel back some of the layers to figure out what is real and what is not.

To the references of intermediate care facilities, that continues to be an option that is available to people. It is one of Medicaid's institutional benefits. It is reimbursed and viewed as an institutional benefit. It is recognized that those types of settings and facilities are necessary for people, depending on where they are and what kind of services and supports they need.

We try at CMS to make sure that all of the existing options are available to individuals and people are aware of them and what should be available at the state level and where they can go for questions.

Like I said, I am happy to continue the conversation. I do not want to take up everyone's time right now, but however best you all think a discussion about these Medicaid funding authorities and requirements could be made, I am happy to make that happen. Thanks.

DR. GORDON: Thank you, Melissa. We did hear you. Are there other comments or questions? Alison.

MS. SINGER: Maybe at a future IACC meeting, Melissa could present on her interpretation of how these rules are being administered in the real world communities, where our children need to have options and choices. Because I think the experience on the ground is that there is a lack of option and a lack of choice for people who need 24/7 care who would choose to live in settings with other similarly disabled people because they have more in common with them and they share opportunities to engage in activities that they prefer together.

I hear what Melissa is saying, but it does not seem to agree with what I have experienced, with what I have heard from other families that they are experiencing, so perhaps she could clarify that in a future presentation.

MS. HARRIS: This is Melissa. I would be happy to do that. We are, as we speak, working on some additional guidance that will clarify a couple of points that we have made previously, and kind of start some new conversations as well, based on feedback that we have heard over the years from a wide array of stakeholders.

It would probably be of the most value if I could have this conversation with you all after that guidance is on the street, so I can refer to it and you can refer to it as we go. We are targeting early summer for release of that. If that gets delayed, which has been known to happen, I am happy to have the conversation even without it being released, but the best case scenario would be after it is out there so we can walk through it together. But I am happy to do.

DR. GORDON: I think, Melissa, that might work for us to have you on the schedule for the October meeting and hopefully we can make that happen.

Samantha.

MS. CRANE: I just wanted to say that the limited choices are really across the board because we have people like Kerima, my friend, who really wants her son to be in an integrated setting and is very worried that she is not going to be able to find that either. I think we really need to make sure that we understand that this is an issue that is across the board especially for people who have really significant support in this.

DR. GORDON: Thank you. Other comments or questions? I particularly want to invite anyone else on the phone to weigh in. Thank you everyone.

I think at this point, we are a little bit ahead of schedule, which is very nice. We are scheduled to begin a discussion in 15 minutes with Dr. Siegel on aggression and self-injury. Why don't we take a 15-minute break here and that way we will be nice and refreshed when we start that conversation at 2:45?

(Whereupon, the Committee members took a brief break starting at 2:30 p.m. and reconvened at 2:45 p.m.)

DR. GORDON: While you are sitting down, I will just say I really appreciate the active discussion we had about the public comments. For those of you in the public who submitted comments or who spoke today, that we did not discuss your specific comment, I want to assure you that we all review these and we take them into consideration in the work groups and discussions about which topics to address for future meetings. Even if we did not get the chance to discuss your specific issue today, I want you to be assured that we take it quite seriously.

In fact, today's presentation, which I would imagine also triggered many of the public comments we heard today, was chosen based upon discussions that we have had in this committee over the past several meetings around the issue of ensuring that we cover the full spectrum of consequences of autism. And of course, one of those is self-injurious behavior as was really powerfully discussed by many at the oral comments today.

We wanted to hear in addition to of course from parents and individual dealing with autism with regard with self-injurious behavior, but also from academicians and practitioners. We invited Dr. Matthew Siegel from Tufts University, who is also the Director of the Developmental Disorders Service and the Maine Behavioral Healthcare and the Maine Medical Research Institute, to talk to us today about aggression and self-injury from a research perspective. We are very pleased that he accepted our invitation.

Dr. Siegel will speak, and we will have time after for questions and discussion.

Dr. Siegel, thank you.

DR. MATTHEW SIEGEL: Thank you very much. Thank you for the introduction. I am really honored to be here and quite humbled by what we heard today, even though I, as a provider, not as a parent or caregiver, live that on my work days, it is still just remarkable to hear it in such a concentrated dose. And really nothing I can tell you – first of all, I do not have all the answers. I want to dispel that right now. And the second thing is nothing I can tell you that is really more powerful or important than what was said by the parents and caregivers.

And just a quick reframe, there was a lot of discussion about self-injury or self-injurious behavior, and some talk about aggression. I would just say that these are both – so my talk actually focused more on aggression, but these are both severe challenging behaviors, in addition to things like severe tantrums or property destruction. And while in the treatment of them there can be important differences, in terms of talking about this area, we can use them somewhat synonymously. Just a statement was made a few times that we are going to talk about self-injury today, where actually, that is not the topic. The topic is severe challenging behaviors such as aggression and self-injury.

Just disclosures, as you heard, are that I work for a large nonprofit behavioral health care system, as well as do research with several funding organizations and involved in a summer camp.

Today, I want to talk about aggression and self-injury, prevalence and impacts, talk just a little bit about how we approach this in our clinical programs, which is a multidisciplinary approach, talk about a multi-site research collaborative that we have been running for the past four and a half years, called the Autism Inpatient Collection, and give you a little information about that. And then talk about the need and an example, I think, of perhaps taking novel approaches to severe challenging behaviors. I will just use the example of some of the work we are doing. And then identify a few critical areas for further research.

I just want to say that I appreciate the comments of Dr. Dawson and others and the debate that went on or the discussion, which is we do not know. We need to research it. I heard the frustration in the room as well, and I feel it myself day to day, but research does not mean putting it off. Research means really trying to understand what are – because if I ask you, yes, we can use applied behavioral analysis, which has strong evidence for self-injurious behavior, but do we understand the neurobiology and underlying mechanisms of self-injurious behavior? I do not think we do.

Put another way, maybe put a more bland way, Risperidone can be helpful – an atypical antipsychotic - for a few individuals, some individuals who have aggression or self-injury in autism. Do we know why? Do we understand the biochemistry and the mechanistic reasons for why that is? We do not I would dare say.

I think we have a great deal of research to do in this area and it is really a pleasure to be here because for those of us who have been working in this area, it has felt a little bit like we were off in the wilderness. It is nice to be here.

This first slide is really not needed. I did not know we were going to have these incredible parents and caregivers speaking, but I will just go ahead and say this is a big problem, a very big problem, as we heard and yet it is a greatly under-researched and -resourced area.

I received this email just this week. I get emails like this at least two or three times a week similarly to what we heard today. My son is 19. Severely autistic. Can't speak. Getting more and more aggressive. Bites his wrists, bangs the walls, breaks things, comes after us. Self-injury, property destruction, aggression. All of it. I cannot keep locking myself in a room because he will bang the door down. No doctor in our area knows anything of what to do. Please, please. I am reaching out. A cry for help. This is from a stranger and I get these emails with some frequency as do my colleagues.

There are different prevalence estimates as there are for many symptoms in autism. It depends on the sample you look at. But up to two-thirds of youth at some point in their development with ASD will show aggression. When I talk about aggression, I am talking about physical aggression. I am not particularly interested in verbal aggression. That can be a problem, but that is not the problem we are talking about.

It has been shown that aggression, being physical aggression, is one of the primary reasons youth with autism use or show up to behavioral health care settings, being a psychiatrist office, psychologists, et cetera. This I find quite remarkable that there are some families that report that the aggression is of greater concern and negative impact than the autism itself. They can handle and manage and work with the autism. It is the aggression or self-injury or other severe behavior, it does not matter, that is the most impairing element for them. I just think that is a remarkable thing. I think that is part of what we heard today.

Studies also show that compared to other populations, this is a greater problem in autism than either typically developing or intellectually disabled groups, and though we know very little about the natural history of these severe behaviors in childhood or in adulthood, there is already some research showing that it can be a persisting and even increasing problem for some subgroups in the adult population. However, there are no good longitudinal studies in this area, I would say, that I am aware of.

I would say it is particularly a problem. I am not saying we know the cause, but a particularly problem for the minimally verbal, in my view. I think a great part of what makes this a serious problem is the inability to efficiently report distress and makes the aggression seem to occur out of the blue and that it comes out of the blue or it is unexpected. It is unpredictable. That is what we heard, I think, many times today. We do not know it is going to happen.

The parent who presented the – I forget what she termed her son. The man cub, I think. He is 95 percent sweet, 5 percent a tiger. And the 5 percent is obviously the problem. But what I got from her is the problem is she does not know when the tiger is coming. If she knew, that sets up a whole different series of potential actions, interventions, de-escalations, et cetera. I am already jumping ahead of my presentation, but I cannot resist. It was the unpredictability that I think was the key piece that I heard from her and others.

What happens when you cannot predict it? You cannot anticipate it necessarily, at least not reliably? So then it is that unpredictability that then results in restrictive educational settings or exclusion from those settings. You cannot go out in the community. You cannot go into a restaurant because 95 percent of the time, it will not happen, but the 5 percent it does that that is not going to be okay – can relate to high utilization of various treatment modalities, including out of home placement.

I think also really shuts off an entire opportunity for intervention, which is the window before it happens, or it really limits that window.

I would say that there were identified in the research advances document today. There was one about trajectory and long-term outcomes. I have not researched this, but this is my read on things, is there is a real unmeasured effect of serious problem behaviors, which is that it can bend the developmental trajectory of the individual downward. In other words, they will not reach their potential because they cannot participate in the very educational communicative community and other experiences that they need to reach their potential. Really, in some ways, that is the worst effect of it beyond the acute effects.

Just a little bit on how do we approach this in the clinical programs that I am involved in. As an example, so we have a continuum of care near Portland, Maine where we have a specialty inpatient unit. You heard the Kennedy Krieger unit referred to several times today. This is a unit styled in that way, though certainly not at the same intensity. There is no other unit at the same intensity, I think in the country, but a unit that specializes in working with this population, and a school that only serves that unit. A day treatment program where kids are living at home, and then an outpatient clinic, and then of course we have our research team. It represents a continuum of care for kids from less intensive to more intensive, all of whom have significant emotional or behavioral challenges in addition to their autism or developmental disability.

Aggression. I think it is worth saying that it is not a disorder. It is not a diagnosis. It is, I think we can call it a symptom. Then what that leads you to if you think of it that way is what is causing this symptom. In other words, I do not actually want to treat aggression. What I want to do is look at what might be leading to it and try to treat upstream if possible.

In no particular order, because we do not understand the relative weights of these things, there is psychiatric co-morbidity. There is behavioral function and reinforcement, functional communication, we heard about today, side effects of treatments both medication and non-medication treatments, sensory challenges, mismatch and demands' abilities, family changes, medical illness or pain, occasionally genetically linked and also challenges with emotion regulation. This is not a complete list by any means, but this is a common list of factors you might think about that might lead to aggression, one or more of these factors. You can put at the top of this pyramid self-injury or other severe challenging behavior.

In our program, the foundation of the treatment is – since we have strong evidence for applied behavioral analysis, the foundation is applied behavioral analysis that is inclusive and embeds other supports within the behavioral plan being occupational therapy supports, communication supports, et cetera. It is all embedded within one plan.

Targeted psychopharmacology when it makes sense. And importantly, trying to transfer the skills that happen in these programs to the people who are with the individuals the rest of the time because really we try to remind ourselves that it really does not matter if they look good during the six hours in our program. What matters is what is happening 168 hours a week. We would like that to include the time in our program. In our day program, there is 138 hours that they are not in our day program every week. That is what we try to get to.

If you are going to do that and be serious about it and do a multidisciplinary approach, then you have to employ and pay for a multidisciplinary team with lots of different disciplines. There are different ways to come at this. This is how we have both with psychiatry and pediatrics, behavioral specialists, special education, speech pathologists, OT and others. There are certainly other disciplines you can involve here, but this is how we have approached it.

Here are some of the major -- following those disciplines, here are some of the major therapeutic approaches for challenging behaviors so applied behavioral analysis, psychotropic medication, communication strategies whether they are subtle and higher level all the way to assisted augmentative communication devices, treating the medical problems, family work, parent training, sensory regulation strategies, social skills, social cognitive strategies and psychotherapy strategies for those who are more verbal or more able.

Just up on the right, the two areas that we probably have the best – I think we do have the best research evidence for ABA and psychotropic medication. Both have significant issues. The issue with ABA first of all is access. Getting to quality ABA is not easy and then to get it consistently and then to get it to generalize across settings, not just the six hours or whatever it is is very challenging.

Also, I think there is the belief that if you have excellent ABA, it is going to solve everything. There is a good percentage of FBAs, functional behavioral analyses, that do not clarify the function or functions of the behavior or even if you do, there could be other things operating. I have no particular preference for one or more of these modalities. In fact, medication even though I am a psychiatrist is my least preferred modality. I think it is important to recognize that they all have benefits and drawbacks. Obviously for medication, the drawback is side effects as well as very inconsistent success and very little ability at this point to predict who a medication might be efficacious for or effective for or not. That is a big problem.

Coming out of our inpatient program, I know it is a very busy slide, but just to show you these are some outcomes that we published. Just to try to simplify this, on the left is the Aberrant Behavior Checklist

Irritability Subscale, which is a measure that reflects aggression, primarily self-injury and tantrums. It is a good measure for our population because those are our chief target behaviors. And 0 to 45. High is bad. Low is good. Common fairly severe behaviors, 27, 28. Drop down at discharge to what is really a fairly subclinical level.

And then at two-month follow up, which we did by phone, they are looking fairly similar. We knew they were getting better during our hospital program. We did not know what things looked like two months later when they are back at home. We felt pretty good about that. That is just a quick outcome measure from our study. It is not there is no control group. Very challenging in our setting. But it is one look at this.

Coming out of that and the work we do, we were very conscious that there is limited research on the severely affected population and we thought what can we do about that. Our thought and contribution I think was to form a research network of specialty inpatient units similar to the Kennedy Krieger unit that you heard about although they do not happen to be part of our research network. This is the research network.

I think some credit should be given to the two foundations that have supported this who agreed with us that we needed to among other things be sure we are capturing in our genetic data and other data the more severely affected population. That was the Simons Foundation and the Nancy Lurie Marks Family Foundation.

The rationale for this study and approach was, as we have been saying, that really knowledge that this is an under researched area and knowledge and treatment options have continued to lag for those who are nonverbal, have an intellectual disability and/or display serious challenging behaviors. There is some data there you can look at - or not data, there is a summary there of the data.

We, in these inpatient settings, have a high volume of these individuals passing through. That presents a real opportunity. And I think we recognize but only recently have been to really move forward and operationalize the fact that we really have an ideal setting in the specialty inpatient units to study severe behaviors.

Just quickly where that study stands is we actually come quite a ways. We have enrolled over 1000 individuals with autism and their parents. We do an assessment battery and the population is I think fairly severely affected. Almost 50 percent are minimally verbal, 42 percent with intellectual disability, and certainly adaptive functioning I think on average is about 56 on the violent.

This group will have genetic sequencing done in the near future and then that data – the phenotypic data is already available to investigators worldwide through SFARIBase, which is supported by the Simons Foundation and the genetic data ultimately will be available as well.

This is a collection in other words for researchers around the world. They can access and look at a group that is – it does include some higher-functioning individuals, but it is heavily weighted toward the more severely affected.

In the interest, I will not go through this, but we have published a series of papers on the phenotypic data on this group, which are actually going to be together in a special issue of JADD soon. I will just say one – there are many results I could give you here. There is one thing I will point out, which is we looked at risk factors for psychiatric hospitalization and sleep problems were a prominent risk factor for psychiatric hospitalization independent of autism severity. Sleep, as we all know, is critically important.

I will also since it came up earlier say that we did a paper on actually the relationship of challenging behaviors and verbal ability, which you see on the bottom left because that was discussed earlier. In fact, I would say that there is a still a lot to learn about that because we did not find that serious problem behaviors were clearly higher or associated with more impaired communication.

But rather what we found was that it was more in relationship to impaired coping and adapting abilities. It is not that you could not speak. It was what was your coping or adapting ability. I just have to say. I forgive you all for not nominating any of our papers. Just kidding. If I join the committee then I could self-nominate.

These are the outcomes from the six sites pulled together. This is 350 kids, the first 350 kids who came through the study. It looks similar to our single site study from three years ago. That is reassuring. In the interest of time, I will leave that there.

That is some information about aggression and self-injury, some research resources, and the typical approaches that we take and hopefully what is a fairly good program and programs currently, but it is not good enough as we have been hearing today. Because even if some of these individuals came into our inpatient program and other programs, we get some of them better. We do not get all of them better. We still do not understand most importantly, why is this happening at a mechanistic, neurobiological level, which is what we need to push toward. It is not enough to simply say it is because he wants attention. That may be true, but there is more to learn about that.

As an example of that perhaps, I want to give you – my patient Ryan whose parents allowed me to display this - is not dissimilar to some of the folks we heard today and really has brought forth this idea that we need novel approaches for serious problem behaviors and we need to research them.

He was diagnosed at 2 years old, severely affected. No language until age 4. Single words still to this day, maybe a couple of words together. Primarily echolalia and scripting. He was challenging, but manageable and mostly happy until about the age of 14 at which point he developed aggression and some self-injury, biting his hand, and that is when he presented to us. I got to know him. Everything changed at that point. Again, the autism – they were doing okay with, but then when these behaviors came in, that is when life really went south for the family and a very capable family.

This is what his hospital stay looked like. This is the number of occurrences each day 24 hours a day of aggression. He came in, had some aggressive episodes. They seemed to get less frequent. They also got less severe, which is not represented on this graph. We did our usual treatments. We felt pretty good about that. We sent them on their way. And then they came back the next year and then again and again. He was admitted four times over three years with good resources, great family, all those things, excellent psychiatrists yet still being admitted. It was like what are we missing here because to us this was an improvement. Each time the graph would look this way.

Here he is now, 23-year-old man, still work with him and his mother. He continues to this day to have those intermittent outbursts. They are down to maybe two a month, but they are very severe when they happen as you have heard described today. Even though it is only a couple times a month, he has to live in an apartment by himself with two awake staff at all times and one staff overnight.

This is how his mother describes the problem. This is her interpretation of it. Due to his inability to manage his emotions and communicate, he attacks us when he becomes agitated or stressed. This behavior is very unpredictable and often occurs with little or no warning signs. It has happened in our home, his school, in the community and sometimes while driving a car. It is so bad that we can no longer safely live in our home with Ryan.

The parts that jump out to me are unpredictable and little to no warning. She knows him better than anyone on earth and she still does not know it is coming often.

How do we get some predictability? How do we start to piece this apart and try to have a different paradigm about these behaviors? I think there are a number of ways I hope to come at this. The way that we have been trying to come at it is by looking at physiological arousal preceding, during, and after the challenging behavior episode. We have certainly good information that in typically developing youth if you can modulate your physiological arousal better than you have fewer behavioral problems.

It has also been shown in autism that there is an association between physiologic arousal and problem behaviors specifically in autism, which is not a surprise. But it leads us to a hypothesis that I think is very different than a behavior analytic approach or a psychiatry approach, which is that perhaps the individual with ASD is engaging in the problem behavior as an attempt to alleviate distress and manage and regulate their physiologic state.

Here is a pretty simplified figure trying to illustrate that. Up here is heart rate. We will use that as a measure of arousal, as a crude measure of arousal. Down here is motor activity. Here is an individual at baseline and then they have a rise in arousal or we will interpret this heart rate as a rise in arousal. But there is no change in their motor activity. Then the person engages in challenging behavior. Their heart rate goes way high as does the motor activity. Then there is a de-escalation, back to baseline. It is a fairly simplified figure, but it represents potentially a relationship between heart rate or arousal and the challenging behavior. You can see a relationship in time in this one individual.

This plus our clinical work led us to this conceptual model that a person is at autonomic equilibrium. There is a triggering stimulus. It does not matter what the stimulus is in this model, which I like. It could be that it is a loud noise. It could be whatever. They experience distress. There is a physiologic arousal. There are different factors one could put in here, but one we are very interested in is there is a variable ability among individuals with autism to regulate their emotions. And perhaps in relation to that or other factors then we proceed to either coping and non-aggression or aggression. You could put other challenging behaviors in here.

Then we may return to equilibrium but often as you know if we engage in aggression then we are going to get into a loop of arousal and aggression. That is a basic model for this.

How would we research this and approach this? We have at a pilot level. This represents this cartoon a research study we have been running or we have run with 20 minimally verbal individuals with autism in our hospital unit. We have a child here with ASD wearing a biosensor, basically a very fancy Fitbit that gives you electrodermal activity, which is the electrical current running across your skin, which represents your sympathetic nervous system tone, which represents your arousal level. Your heart rate, your pulse, and a few other things including motion. And then we have a research assistant coding and it is time synchronized the behavior of the individual. Then offline we are feeding that information into machine learning algorithms to basically develop predictors of what is going to happen and then ultimately you send that prediction to the staff member, parent, whoever who could be alerted to what is going to happen in the future.

This is a very ugly, busy slide, but what it shows is over here what we were looking at is at 60 seconds – when we took this data, this is not in real time. We are not there yet. We had to take all the data, take it offline and analyze it. We could look at 60 seconds out in the future if we combined all the signals, motion, physiology, temporal time information, if we combine them all, we could about 71 percent accuracy predict whether there was going to be a challenging behavior in the next 60 seconds or not. That is just a very pilot, 20 kids work.

A long way to go from here, but the reason I show you this is not to say that anything about us, but rather that I think it is a somewhat novel approach to this and trying to think about mechanism and trying to take an approach that is different than the ways we have been coming at problem behaviors or challenging behaviors.

What might this look like ultimately? Here, we are getting probably five years down the road depending on how well people in the room fund us. Just kidding. Some years down the road you could have a display on the wall or again to the staff member of how kids are doing, projecting a risk level of a challenging behavior in the future.

Even better, as I think we heard mentioned today, we could have a child self-monitoring, where it is projecting to some kind of bracelet, or something like that. Even better a screen that is engaging for the child or adult, giving them a cue as to what is coming and their own internal state because as we know for some people with autism, there are specific challenges in reading one's own internal state and identifying emotions, identifying that even that we are getting upset. Maybe we all struggle with that in different ways. That is one I think somewhat novel approach to this area.

In terms of thinking about what we heard today in terms of needs, I am happy to say that I thought that several of those things are critical unmet research needs for the severely affected population that has these behaviors. The first I would say is that we really need novel approaches to aggression and self-injury. I would posit that utilize objective mechanistically informed data or systems and particularly technology to approach this. That is not again saying anything – ABA is an incredibly important modality. We use it in all of our clinical programs. But I think we need to keep pushing forward. I also think these things are not exclusive and can be used synergistically.

The second thing is we still know very little about the natural history of these behaviors in autism, and that is really important. It is really important for parents and families. When a kid comes in to see me and does not have autism or if they do and they have Tourette's, I can say the peak typically is 10 to 13 years old. The ticks will likely get better over time though they may not. I can say a lot of other detailed things about Tourette's because we know the natural history to a fair degree.

We do not know the natural history of these behaviors in autism very well. I cannot say to a family this is likely to get better or it may get worse, or if it is a three-year-old who is engaging in self-injury what that might look like. That is very important. It is not the most exciting longitudinal work to do perhaps, but it is necessary I think.

We certainly need better tools for psychiatric comorbidity, which is a whole other topic. Diagnostic tools.

I think a related and important area is emotion regulation and emerging that is very important.

Sleep is critical. I think we do not understand the relationship between sleep and challenging behaviors or sleep and some other things. It is too simplistic to say if you do not sleep well then you have problem behaviors the next day. There is a lot more to learn.

I think we heard a lot today about services. People going to residential treatment. People getting in-home behavioral services, et cetera. I think we need to research and study real world treatment packages and they are somewhat messy. You cannot do a highly controlled study. It will not be efficacy. That is what is being delivered. We need to look at that. I would advocate for that.

Finally, residential treatment or intermediate care facility, et cetera, PRTF, lots of names for places that people live when they are not living at home. Usually they are living there or often they are living there because of these challenging behaviors. We have almost no research on those settings. Billions of dollars spent on that. Thousands of kids and adults in these settings and almost no research on it. I know that because a couple of years ago, I asked someone to write a chapter for me for a book we were editing. I said do it on residual treatment and do a lit search and get the research. They had almost nothing to write. Even though it will be messy, and we probably cannot do it in a highly controlled way, we are doing it and we are sending people there and there are better and worse treatment models as we have heard. I think we need to study those things.

In summary, individuals with autism can certainly develop serious challenging behaviors. I think importantly that can become more impairing than the autism itself.

Certainly, many parents report that it is the unpredictability and lack of warning that causes the greatest impairment. It really compounds the problem. They can manage the aggression potentially if they knew it was coming perhaps.

These areas are under-researched as I think was widely recognized today. Importantly, I think their mechanisms and underlying biology are not understood.

We have some pilot data from that small study I showed you that shows that perhaps measuring physiological arousal and other data streams could be used to try to get ahead of these events and predict them in real time. Whether it is that approach or hopefully ten other approaches, there is a need for novel research approaches to this. I have had program officers from unnamed institutes say to me treatment of aggression. We did that. It is true. There were medication studies of that in the '90s and early 2000s. Since then, very little and certainly very little that is novel.

Of our 14 nominations in the research advances under Question 4 or 5 for treatment, not a single study that was nominated for treatment was studying challenging behaviors. There are other things to treat, but none of them work. That perhaps crystallizes it.

I just want to acknowledge my co-investigators and partners, particularly Carla Mazefsky at University of Pittsburgh and Matthew Goodwin at Northeastern University who are strong collaborators in this work and the pilot work I showed you as well as the funding organizations. Thank you very much.

(Applause)

DR. GORDON: Thank you. David is the first with his hand up. I will take names as we go along.

DR. MANDELL: This was a really great presentation, really exciting and really important. I love how you have created this research network.

One of the other things that you have done that you did not talk about is you have a great review, in International Review of Psychiatry that recently came out about some of the policy implications as well. It occurs to me that while you may not be satisfied with what you are doing in your setting, it is a hell of a lot better than what is available to most people across the country.

I wonder if concurrent to thinking about a research agenda we could be thinking about how we scale up this kind of model and what the fixed costs are associated with doing that of which of the federal agencies at this table might be responsible for supporting some of those fixed costs and have a dual set of recommendations from this presentation, one about the research, but the other about funding either existing sites or new sites to become models of excellence in this kind of care.

DR. SIEGEL: Thank you. Thank you for saying that, Dr. Mandell. Very kind of you. I think that is an excellent recommendation. There is a growth of - we particularly focus on these inpatient units. Of course, there is a whole continuum of care that needs support and research. But there is growth actually in these inpatient units here and there, but certainly not in any coordinated fashion. I think definitely very important.

Just one other thing to say about that is actually Dr. Mandell's work and others had shown that the rate of psychiatric hospitalization for kids with autism is much higher than the neurotypical population, which is not something people generally know, but I think we heard about today.

DR. GORDON: I wonder if you might talk a little bit about what efforts there could be in moving some of the recent advances and the knowledge about the neurobiology of aggression globally into the autism sphere. There has been a tremendous explosion of certain technology to explore the basis of various behaviors particularly in rodent models.

One area that has received quite a lot of attention is the role of certain circuits particularly involving the hypothalamus and generating aggressive behavior.

I recognize coming in it might be seen as suboptimal to try to treat specifically the aggression, when we have lots of reasons to believe why the aggression is arising from some other discomfort. But if the major problem is aggression and if we could get a handle on some targets in that realm, it might be beneficial to exploit that new knowledge.

DR. SIEGEL: Yes, I agree. I think my comment about we do not want to treat the aggression if we do not have to. In other words, working upstream is with our current modalities, but we should be pushing toward treating it directly if we have ways that I think makes sense.

Certainly, a lot is known about aggression in other systems in the typically developing population and others, and that is important and it definitely informs. It is part of the reason we went toward physiologic arousal and other things. But we are not making any assumptions about how it operates in autism, and of course there is no such thing as autism, so we are not making any – there are many, many, many autisms. We are also facing the challenge of we think we need to look at fairly large sample sizes to be able to parse it apart because this may operate differently. If we find replicable signal, it may operate differently in the less verbal versus the more verbal or in people who have different associated genetic changes. We are trying to approach it without making too many assumptions.

DR. GORDON: Louis and then Samantha.

DR. REICHARDT: I just wanted to ask you that given that we know sensory hypersensitivities can be very annoying, whether you have characterized those in these individuals and whether you thought there was some role for aggression or self-injury and behavior?

DR. SIEGEL: That is a great question. The whole areas, as many of you, of sensory either hyper or hypo-sensitivity, has been I would say under-researched or under-researched in a rigorous way and has mostly been the province of occupational therapy discipline, which is not typically a well-funded discipline for research. No particular reason that should be.

There is actually a great deal to learn about sensory differences. I also still do not think we have very good measures for sensory difficulties. Most kids, if you give them the basic sensory inventories, the SPI, et cetera, they always look abnormal, but that does not tell you that much per se. I think we need, like the rest of autism, better measures, better outcome measures. And then I think that that would be an important factor to look at.

I am sure some of the individuals in the room could comment on that you could easily hypothesize that sensory disturbances or annoyances or torture whatever it is could lead one to engage in certain behaviors.

I think the attractiveness to us in some ways of the model we are using and the system we are using is that it is somewhat agnostic to the triggering stimulus. In our ABA programs and clinicians, we spend a lot of times trying to figure out what are the antecedents and what is the trigger. There is value in that. But wouldn't it be even more valuable if it did not matter if you could figure out what the trigger is or not, because often you cannot or you think you know, but you do not really know.

Whatever it is it produces this event, let's say arousal or some other marker that then gives you predictability. That would be very generalizable and powerful. If you had a similar thing for a sensory sensitivity that would be good, but that whole area. We could add that as another area. I think that deserves further research. It made it into the criteria five years ago for autism.

MS. CRANE: Thank you for your presentation. It was very interesting. I have two questions. I am going to ask both of them before stopping. The first is it looks like there is – before someone engages in what is called aggression, their heart rate rises. My understanding is that this is generally true of most people even if they are not autistic

– but if they are about to engage in a form of aggression, their heart rate will rise. The one exception is people with anti-social personality disorder.

Is the problem – certainly, the heart rate can give us warning and that could be useful, but I think one of the things that I have definitely experienced with myself is that autistic people often have difficulty identifying their own mental states and sometimes it can help us to learn to recognize when our own heart rate is rising and be able to do something about that.

Unfortunately, I think in my experience and maybe John will confirm this as well, but in my experience, the thing – I was considered aggressive when I was a teenager. I had pretty serious problems, mostly at home, but also sometimes in public. Those almost entirely went away when I became an adult and started being recognized as an adult, because all of a sudden when I said I am out of here and I am going to go do something else, I was just actually allowed to do that. I did not have a parent or a therapist or a teacher saying no, no, no. You have to try to redirect me and have me do something else.

When people are able to be in control, it can complement – it is sort of both of these two things, it is being able to recognize when you are starting to get upset, but also being allowed to do something about it without necessarily having to – sometimes when we get upset, we have a hard time communicating about it. We might just need to bolt out of the room. That can really help.

I guess the question is is the next step helping people identify their own arousal and helping people – actively empowering people to do something else about it?

DR. SIEGEL: I think that is very well said. What I tried and somewhat poorly tried to represent in one of the final slides with the child looking at a bracelet that was glowing different colors, the idea that it is hard for everyone to identify their own arousal rising or their own emotional state I think at times particularly if it is escalating quickly. If you can get a cue that is something is happening with you to get you to think about that and focus on it, opens up a whole window for potential intervention or self-intervention.

I think the corollary would be very common practice of using cognitive behavioral therapy for a panic disorder and part of the treatment for panic disorder in cognitive behavioral therapy is to recognize the beginning of the symptoms and try to recognize that your heart rate is rising or you are sweating and then to do various interventions to try to calm yourself down and keep yourself from going into a full-blown panic attack. I think that is corollary and what we were trying to get at. For ourselves, we are several steps from there because first we have to validate the system. I think that would be the ideal.

Without thinking about any of this, this is what we do just in our treatment programs on a clinical gut level, which is we are constantly trying to work on coping and adapting skills or not even a skill, but just a response such as take a break or giving a person space when they are having a hard time. I think what you are saying makes very good sense to me. Whether this operates differently in people with autism versus neurotypical people, we do not know.

DR. GORDON: John.

MR. ROBISON: This focus on aggression, employment, and some of the workshops we have done, it has really struck me today that maybe what this all speaks to is that perhaps it is time for us to fundamentally rethink how we organize our strategic plan for autism and how we present it to the government. There was a time, not too many years ago, when the public and the Congress thought that the problem with autism was how do we detect it early enough and then how do we deliver behavioral interventions so that the autistic people are fixed. That is not a real thing. People do not say that now.

Instead nobody comes to our committee and says, why aren't you people doing more on Question 3. They do not even know what Question 3 is. Instead they come in here and it is consistent. It is what are we doing about self-injurious behaviors? What are we doing about GI pain? What are we doing about depression and anxiety? I think that it is time for us to think as a committee, should our plan be recast such that the questions 1 through 10, are what are we doing about what our constituents come and ask us for?

I think then that we might think about a change in how we approach this much like how the World Health Organization sees the ICD and the ICF, right? So you have a presentation that we have just received here on aggression. We say that we do not know what the primary cause of aggression is, but we know about a number of possible triggers. And those triggers are things we are called out on every single IACC. Why aren't we researching undiagnosed pain? Why aren't we researching undiagnosed anxiety?

I think that this speaks very strongly to me that it is perhaps time to recast our strategic plan so that we can most effectively communicate what we need both to the leadership of NIH and to the leadership in our government who reads the plan and so that we can be responsive to folks like you who are here and we can provide constructive guidance like these folks who have come to speak to us today.

DR. GORDON: Geri, I know you had a comment, but I think John's statement deserves a little bit more attention before we move on to another topic. Is that all right? I have something to say, but I do not want to co-opt it from the chair.

MS. CRANE: I would say that I think that it is – I do not have a problem with how we are categorizing our questions, but I think that we need to remember that all of the things we are hearing about are coming under questions 5, 6, and 7, and those are questions that are really being under addressed by research funding. People are not getting services they need. They are not getting the help they need through the course of life.

We just heard that parents are asking, is this aggression going to go away? There is literally no research on the life course, and whether or not people get better as they age or worse, or if they develop different problems as they age. We really need to re-prioritize that.

DR. GORDON: I want to respond vigorously to those two comments, with all due respect. I think it is important first of all, that when we make statements like there is literally no research, that we do so from a factual basis because there is not literally no research. There literally is research.

We do not have the results of some of that research. And much of that research on the lifespan was triggered from discussions in this group over the last couple of years. But, again, with all due respect to the urgency with which the community feels that this is an issue, and I completely understand and agree with that urgency, if you want to know how long aggression lasts in individuals with autism, it takes that long to find out the answer. It is not an easy question to answer and it takes time.

While we do have studies that we have funded, and we continue to request more applications in the area of implications of a lifespan at NIMH, and I imagine at some other organizations as well, we do not have the answers yet. I fully acknowledge that.

To the larger issue of whether we should get rid of three, but I do not think that is really your intention because I know you well enough, John, to say that you are not getting rid of that research, but to reorganize it around the issues. That is something we certainly could revisit as we revisit the strategic plan in the future. Because really what you are saying is maybe reorganize those components of three into the different subjects that appeal to individuals in terms of helping them.

MR. ROBISON: I was not suggesting the research –

DR. GORDON: I knew you well enough to know you were not suggesting that. But I want to point out that origins causes causal – they are not really causes, they are more risk factors. Understanding the underlying pieces of neurobiology cannot be easily sorted into those that contribute to aggression, and those that contribute to communication difficulties, and those that communicate to the ability to read social signals or any of the other myriad disabilities faced by individuals on the autism spectrum. I think it is challenging to imagine how one takes that piece of it and distributes it.

I will just give you one example. Take any one syndromic cause of autism, one of these copy number of variants or single gene mutations, that we are now finding out account for something around a quarter of autism cases, and they collect mostly on the severe end. Take any one of those and the presentation of individuals with that one genetic cause, with that one known significant contributor, is itself nearly as heterogeneous as all the rest of autism with the only exception being the concentration on the low end of the functional spectrum.

I think it is challenging to move that into the distribution of different causes because unfortunately I do not think it is a one-to-one mapping or even many-to-one mapping. That presents certain challenges.

But I do agree that we have a lot more research on number three than in these other areas. Some of that is research opportunities and some of that is the applications that come in are not that great. And then, yes, we have to acknowledge. Some of that is the fact that some things are easier than others. Genetics are just easier than environmental causes. Genetics and environmental causes are just easier than doing 100 different badly needed clinical trials on how we help people with aggression. We have to look at those cases where it is just easier to figure out how do we get the hard stuff done.

MS. CRANE: May I follow up?

DR. GORDON: Please and then we have Geri and Julie.

MS. CRANE: I apologize, but I tend to sometimes exaggerate. I will say that – this is another thing that I really agree with the speaker just now. Sometimes the research that we need is messy. We could probably get a lot of research on adults without starting with kids and tracking them all the way through later adulthood. We would not be able to get the same level of control as if you started with kids, 8-year olds, and had a 30-year study to follow up, but you could get something. Something is much better than nothing. The issue is sufficiently urgent. I think it is worth it. It is horrifying that we do not have research on efficacy of residential treatment when people are in residential treatment. Those studies are going to be messy.

I think we need to prioritize them enough that maybe if an application comes in and it is on the right question, but it does not look like it is very well designed, can't we work with people to try and improve the study and really cultivate more research along the lines of things that are most urgently needed?

DR. DAWSON: Thank you for that very informative presentation. I really enjoyed it. You brought up in your list of things twice at least psychiatric comorbidities. I did not hear a lot about that because we actually are funded by NIH to look at a project that has to do with very early psychiatric comorbidities and how it does relate to challenging behaviors down the road. I am happy to expand on that. At least it is one study looking at things that I think are relevant here. But I am curious from your point of view, what you feel like the role of psychiatric comorbidities is in challenging behavior.

DR. SIEGEL: Thank you for asking that. I did not talk about it much, not because it is not important, but because it is a whole universe in and of itself, that we actually think about a lot. Psychiatric comorbidity or co-occurrence, however people want to think about, is quite important. In fact, the kids who – it could be true for adults, but we have a kid program. The kids who are hospitalized often are actually getting access to pretty good ABA. It is that there are other things going on. And one of those things may be and often is frankly psychiatric comorbidity.

The challenge, as I am sure you are engaging yourself in your study, is we do not have good and certainly not efficient diagnostic tools that are validated for psychiatric comorbidity in the autism population. What we are left with is either research tools that are okay, but still are not perhaps at least the ones that are out there are okay, but certainly not efficient. It might take a two or three-hour interview. Or we are left with clinical experience and judgment, which is not meaningless by any means I hope, but of course would like to back it up with diagnostic measures.

That all said, when a child comes in the hospital, absolutely. One of the top things or into an intensive treatment program or into my office I am looking at is do I think that there is a co-occurring psychiatric disorder going on. I think just a very quick read of the existing literature where people have attempted to adapt measures to some degree, well-described psychiatric diagnostic measures to the population or at least portions of the population, it appears that just like in the rest of child mental health, anxiety it appears is the most prevalent followed by ADHD, followed by mood, followed by more rare things or not rare, but less common psychosis and perhaps bipolar disorder. It has been I think what comes out of the research so far. It is certainly our experience. Even in the hospital, anxiety reigns supreme and followed by ADHD, mood, psychosis, fortunately less commonly. It is an incredibly important area that we look at a lot.

DR. DAWSON: Briefly to elaborate, the NIH-funded project that we are doing is looking at the psychiatric comorbidity of ADHD in autism. I think one of the things that we know very little about is when children have both things or three things, anxiety, for example, being one of the more common comorbidities with autism, how are they presenting early?

It turns out that if you have autism and ADHD, not only do you have much poorer outcomes and many more of these aggressive behaviors, but you are 30 times more likely to get a diagnosis of autism after age 6. That means that these kids are really not getting early intervention. It is really during that period where we want to be teaching kids these strategies for behavior regulation. It may sound strange to be thinking about teaching a 2 or 3-year-old how to deal with a frustration and the tendency to have an aggressive outburst when they are transitioning from one activity to another or whatever it is.

But if you can start working on those skills at a very early age, you often really prevent the down the road problems with challenging behaviors that you would start to see when kids are in school age and adolescents where it is even more of a severe challenge to handle them.

I do think the idea of natural course and understanding, what are some of the early risk factors and could we be intervening early in such a way to prevent the development of some of these challenging behaviors later, that that is an important part of the strategy.

DR. GORDON: Julie.

DR. TAYLOR: My thought goes back to John's comment about thinking about how we could maybe weave in some of these issues that are coming up quite a lot in our meetings in the strategic plan. And not that any of us want to make it any longer or do any more work on it, but I wonder if there might be a place for an extra little section at the end that says these are themes over the past year or period of time that have come up and maybe even specifically referencing where those are at in other aspects of the plan. Somebody could - just to say, we have heard this and we do not want to necessarily maybe completely restructure what we are doing, but here is where this is at and we are thinking about these things and working on them.

DR. GORDON: I think that is a great idea particularly for the update this year.

Walter.

DR. KOROSHETZ: Just a couple of points. One is just an anecdote. I worked for a couple of decades with Huntington's patients in a long-term facility. I was mostly managing aggression. Interesting to your point was after about ten years, we understood that the aggression was occurring a half to an hour before meal time and actually frequent feeding had the biggest effect on decreasing the aggression. It goes along with your theory.

The second point is that with regard to what was said about the strategic plan and Question 2, we purposefully when we started to write Question 2, made a list of all the things that are really disturbing in terms of the symptom complex for patients and families. We tried to go after them. Wandering. What is the biology of wandering or what is the biology of aggression? It got pretty long. Most of it got cut out. There was not a lot to say.

But I think it is a good idea to put that out to the research community as opposed to solving autism all at once, but to pick apart how do you understand these different segments that have really important aspects for the life of the individual and their parents. I think we did try and do that at least in Question 2 before. Looking back at it, I think a lot of it got cut out.

The last thing was in terms of the inpatient facility you have, it offers the ability to do research if you can start collecting data like this. So in Huntington's we are testing a drug that is a vasopressin-1 antagonist for aggression. NINDS is funding that. In the outpatient setting, it is difficult. In the inpatient setting if you could do that, it would be great. Do you think that that is possible in your situation with your consortium that you could actually run through a whole bunch of different therapies and see which ones work?

DR. SIEGEL: It is something we have talked about and debated for probably six years and would like to do, but the debate usually centers around would anyone fund us to do it since we cannot – we could do a comparative effectiveness trial, but we could not do a control. We could not have an arm where they do not receive treatment or do not receive a drug, but we could compare a known, Risperidone, to something that is less known potentially. The ethical and design issues are challenging, but I think not insurmountable in the inpatient setting.

Larry Scahill, who is a well-known trialist in our community as part of our advisory board and we have talked a lot about that. It is certainly something we are interested in.

We have also talked about the idea of utilizing a very different thing, but functional, behavioral – just backing up for one second. It bothers me a great deal and I think others that we do not have a good way to select who should receive X medication or who should enter X study.

There are a couple of ways to come at that, but one might be could we use a functional behavioral analysis to parse the functions of the behavior, so an ABA approach, to then determine what arm of a study you might go into. The same could be said for these physiologic measures. I think we need to get past the point, and here I am obviously on a soapbox but just to finish it, that we cannot just a drug to 100 people with autism because ten might do great and they are buried in there because obviously it is not 100 apples. I think we have a lot of design challenges.

DR. GORDON: Samantha, go right ahead.

MS. CRANE: Because I just saw a community member raise the issue and another thing that we need to talk about in terms of research of efficacy and RCTs and in management of challenging behaviors is use of seclusion and restraint. I know a lot of people in my community who are wary of sending their kids to RCTs or residential treatment or also intermediate care facilities, seclusion and restraint is one of the biggest worries that they have that they are concerned that people with be secluded or restrained in these facilities especially if they have a child with challenging behaviors because they know that tends to be a trigger for seclusion – a behavioral trigger for the staff at those facilities to seclude and to use seclusion and restraints. I just wanted to hear what your thoughts were on that.

DR. SIEGEL: We can end with a non-controversial issue. Critically important issue. Huge national push to reduce it in all settings or eliminate as much as possible. I will just say – first of all, I think at least in good settings, people have the right mind currently, which is those are not treatments. Those are emergency safety responses to try to keep either the people in the environment or the individual themselves safe. Whether it does that is a completely different question. But I think we have moved past the idea that that is somehow a treatment response.

I guess what I would say is that if we do not want to have those things happening, we can either legislate that they cannot happen, which is probably not the best approach to take an approach that or we can reduce or eliminate or come up with better interventions to prevent them from happening. That is certainly where we are putting our energy. Certainly, it is highly understandable that parents nor providers I think want to engage in those things and would fear putting people in settings where that is happening.

DR. SCHOR: It just occurred to me as we were talking about this notion of on the one hand devoting a lot of time and energy and parts of the strategic plan to looking for the Holy Grail, the ideology, the approximate cause versus looking for symptomatic treatments of individual components of the syndrome. It seems to me that not only do we need to do both because each is important by itself, but it seems to me that there is the potential for enormous synergy between the two.

In the past, we put a very large premium on going in the direction of understanding the basic science and using that to design therapy and bring something to the clinic. We have now gotten better at what we used to call fishing expeditions because we did not have the analytic tools to know what to do with the data, but we have gotten better at collecting data completely unencumbered by a hypothesis and then mining those data to say in what population does this drug, for example, work.

But I think we need to complete the loop. I think we need to be able to take the data that tell us that we have treated 7000 people with very different looking autism with the same drug and 500 get better and the rest of them do not to go in the direction and say what is it that is different about those two populations. I think we do not do that as well as we go.

If we talk about the translational curve as being bidirectional, but we do one direction much better and much more frequently than the other direction.

DR. GORDON: Well said, Nina. Thank you very much. And thank you very much, Dr. Siegel. We really appreciate you coming down and talking to us about your work.

We are going to take another break now. Let's say 15 minutes. We will back at here at 4:15 and we are right on schedule.

(Whereupon, the Committee members took a brief break starting at 4:00 p.m. and reconvened at 4:15 p.m.)

DR. GORDON: The final segment of the meeting is the Round Robin, which we have a couple of people who have asked to speak. I know that, David, you have to leave so I am going to give you the floor first.

DR. MANDELL: Thank you. I wanted to draw the committee's attention to the recent passage of Kevin and Avonte’s Law, which is a law that in response to the wandering and elopement that often occurs among people with autism, but also people with many other kinds of conditions. It allows the Justice Department to give grants to local law enforcement agencies to develop programs that do things to prevent wandering and the negative outcomes of wandering, including training law enforcement, training other professionals, offering resources to groups to stop wandering. It is a wonderful law. It has strong bipartisan support. Congress has not appropriated any money to actually then give to local law enforcement to allow for the enactment of the provisions that they are now allowed to enact.

It may be that there are existing funds already as the fiscal year closes that may be available to help carry out some of these things. We do not have representation on this committee from the Department of Justice.

A couple of things. I think it would be important for this group to have representation from the Department of

Justice, but also, I think it would be great for IACC leadership to reach out to the Department of Justice and ask them whether there are opportunities to fund some of the provisions in that law now with existing funds.

There are people here are very active in advocating for that law and really understand its provisions much more clearly than I do. I think it would also be nice for us to think about pulling some of them in into crafting some kind of letter we might write or the way and to whom we may reach out to make sure that this really important law is acted on.

DR. DANIELS: Thanks, David. Just to respond to that. We can invite DOJ to give a presentation. We have not had them in a while. It is up to agencies that want to join the IACC to let us know if they would like to join. If they approach us and ask us to join, then we will consider.

DR. MANDELL: Can we encourage them?

DR. DANIELS: If we can talk to them, yes, we could, but they need to initiate that process if they want to join.

MS. SINGER: Can I respond to that?

DR. GORDON: Alison, please.

MS. SINGER: Thank you, David, for bringing that up. I just wanted to clarify that there is nothing in Congress standing in the way of the Appropriation. The issue was just the timing and that the bill passed in March. The 2018 Appropriation process was pretty much over. Rather than wait until 2019 Appropriations, this was an act of expedience to see if there might be existing funds and specific department as Department of Justice.

I agree. Again, this is something that this committee can do. I am not sure if the federal members can participate in a letter like this, but in the past, the public members have gotten together and written letters to agencies requesting specific items like this.

I would certainly be willing to take the lead in drafting something that I could circulate to the public members as well as to the federal members so that they could have input if they so desired.

The wandering issue is one that this body has been focused on for years. We have made really important progress as a committee on the wandering issue. This is the final last step of actually getting appropriations to fund programs to help first responders understand programs to prevent wandering and to develop opportunities for tracking technologies, and to again support law enforcement, as Geri was describing earlier. I am happy to take the lead on that.

DR. GORDON: It would be great if you would. We are not allowed to lobby Congress for an appropriation.

MS. SINGER: But this is not Congress.

DR. GORDON: This is not Congress. We will look into how much we are or are not able to ask DOJ to do something versus ask them if they have plans to doing something, versus not participate in the letter.

We will look into that from the federal standpoint, but if you want to take the lead and start drafting some language, Susan can help share that with the committee and then we can figure out – depending upon which kind of language you include, whether and how our federal partners can sign on to the letter or send it from the committee itself. I don’t have any whispering or yelling in my ear that I just screwed up, so hopefully that is okay.

Walter is nodding. That means I have Walter's consent. He thinks we can do this.

First, let me just ask if there is anyone else either on the phone or here, that has to leave early that would like to make to – Geri. Let us start with Geri.

DR. DAWSON: Just real briefly, two round robin items. One is I just wanted to talk about the event that I was able to attend at the UN this year. I attended the luncheon, the Autism Advantage. It was just phenomenal the number of businesses that were there. As I said, the person beside me was the senior VP of Talent Acquisition for the entire nation for Wells Fargo. It was really I think heartening to see how many businesses are interested and getting engaged in this area.

The second thing though is I just wanted to mention that the International Society for Autism Research meeting will be held soon. It is going to be in Rotterdam this year. It is a bit of a distance, but it is May 9 through 12. A lot of the research that NIH funds will be discussed there. I encourage you to keep track of that.

All the abstracts are posted on the website of INSAR and also the keynotes are recorded. Even if you cannot travel, it is a good way to really keep up with the literature that may not be out in publication yet, but is in improving and advancing science.

DR. GORDON: Thank you, Geri. Stuart, I believe you pre-registered a request.

DR. SHAPIRA: Thank you very much. I am Stuart Shapira from CDC. There has been a lot of interest in CDC's report on the Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years in 11 communities in the United States. There have been some questions to me here at the meeting about it and where is that report.

I am announcing that CDC strives to publish this report in the MMWR early during the Autism Awareness Month every other year. That is the goal to do it early, but it is a complex report. It is a comprehensive publication. This time around has required a lot of expert involvement in the publication.

But I am very pleased to report today that it will be published during Autism Awareness Month. I am pleased to share with you that the report will be released next

Thursday, April 26 by the MMWR. That is the Morbidity and Mortality Weekly Report. It will be officially published on Friday, the 27th. The information will be available at that time.

Then I have just a couple of other quick announcements and updates since we last met. CDC has a new director. Dr. Robert Redfield was appointed as the new CDC director and he joined CDC from the University of Maryland School of Medicine. He has been a public health leader. He has been actively engaged for more than 30 years in clinical research and clinical care of chronic human viral infections and infectious diseases particularly HIV. We look forward to briefing Dr. Redfield about the work that goes on here at the committee regarding ASD.

And then a couple of other quick announcements. We presented on the Study to Explore Early Development or SEED last October and during the fall meeting. We discussed at that time the plans for SEED Teen, which is a follow up study of children from the first phase of SEED who are going to be young teenagers, 13 to 15 years of age. We plan to launch SEED Teen this May. That will get going very soon.

And then I also talk about our "Learn the Signs. Act Early." program, which is early identification and previously talked about a mobile app for parents to monitor the development of their children. This app has been developed now in Spanish. We hope that it will be launched this summer.

DR. GORDON: Thank you. No sneak-peak for us on the prevalence issues.

DR. SHAPIRA: Unfortunately, no sneak-peak. But 1 p.m. on the 26th, it will be no longer under embargo.

DR. GORDON: We will set an alarm on our iPhones. Julie.

DR. TAYLOR: Just briefly. We have had a lot of conversations over the past years that I have been on the committee about interventions for transition to adulthood. Partially or mostly because of the work on the committee, there have been a number of RFAs that have come out over the last couple of years for pilot interventions for transition age and adult work. Tomorrow the grantees from those different grants will be getting together for a working group to really think about what we are testing and what we are learning and what are some of the roadblocks to doing larger scale research.

Denise Juliano-Bult at NIMH is organizing that and I have been helping her out a little bit with that.

I am excited that hopefully getting people together to talk about what they are doing will help speed up our progress in terms of understanding how better to serve this population and we can help really move our small-scale interventions to large-scale interventions sooner rather than later. More to come on that, but I just wanted to let everybody know that this – is a direct outcome of the work that the committee has been doing over the last few years.

DR. GORDON: Thanks Julie. Walter, any updates from NINDS?

DR. KOROSHETZ: I think we’re still going on with the trial I mentioned in aggression regression and another one in Fragile X.

DR. GORDON: Samantha.

MS. CRANE: I wanted to talk for a little bit about ASAN's activities around Autism Acceptance Month this year. One of the things that we are really concerned about is that the Food and Drug Administration has yet to finalize a proposed rule that it issued that would ban the use of electric skin shock devices on autistic and other kids with developmental and psychosocial disabilities in Massachusetts.

This is a serious human rights concern and a serious malpractice concern. The FDA in 2014 convened an expert panel that heard all of the evidence both for and against the use of these devices and the panel recommend that the devices be banned as unduly risky to causing an undue risk to health and safety.

The FDA issued a proposed rule in 2016, but still has not finalized it. We just wanted to raise everyone's awareness of this and if anyone wants to talk to us about our campaign to finalize that rule, we will be happy to talk after --

DR. GORDON: Allison, we missed the chance to introduce you, but Allison Cruz is one of our newer members. Welcome. Do you have anything to add? Why don't you introduce yourself and then let us know if you have any programs to talk about?

DR. CRUZ: Good afternoon. My name is Allison Cruz and I am here on behalf of Jennifer Johnson from the Administration on Disabilities. I would like to thank all the presentations that were here this afternoon. It was great being here and observing what goes on. I foresee Jennifer to be back for the next meeting, but if not then I will probably talk with her about giving me the opportunity to be here. Thank you very much.

I do not have any updates on behalf of AOD. Thank you.

DR. GORDON: Thank you. Laura.

MS. KAVANAGH: Just briefly, we will have data from our National Survey of Children's Health available to report to you at our next meeting, which now will be October I guess, as well as results of several of our grant competitions both around interdisciplinary training, our developmental behavioral pediatrics training program as well as some of our autism intervention research as well.

DR. GORDON: Alice.

DR. KAU: I do have one piece of information from NICHD to share with you. We awarded supplemental funding to the Autism

Centers of Excellence at Duke University to address some of the research gaps identified by the US Preventive Services Task Force to address the research gaps identified by the US Preventive Services Task Force and specifically the supplemental project where we are examining the potential burden and emotional harm of ASD screening when no previous concerns were identified by parents or professional staff.

DR. GORDON: Thank you. Nicole.

DR. WILLIAMS: Sure. We have just completed our FY17 program for the Autism Research Program under the Department of Defense. We are in the process of making 11 awards and that kind of covers everything from basic science to smaller clinical trials.

We did receive a seven and a half million dollar appropriation for FY18, which is great news. Our solicitations we are working on right now and should have those out probably in the next couple of weeks.

DR. GORDON: Tiffany.

(No response)

DR. GORDON: Alison.

MS. SINGER: At the Autism Science Foundation this month, we announced our spring pre-doctoral and postdoctoral grants. There is about a quarter of a million dollars in funding for that we just put out. We also are funding for undergraduate summer research fellowships and our efforts to get the best and the brightest before they even know what autism is and encourage them to study autism. We are preparing them with experienced mentors and really hoping that this will help them to build a career in autism.

We also held our annual Autism TED Talks earlier this month. All of those videos will be available online at the end of the month. We had some great presentations on potential use of medical marijuana for a treatment in autism, on the role of diet, on studying the pain response in individuals with autism and also looking at sleep issues. I hope everyone will take a look at the videos.

DR. GORDON: Larry.

DR. WEXLER: No.

DR. GORDON: I have one update from NIMH and that is that I just wrote my director's message on the Autism Awareness Month. It is live as of about an hour ago. You are welcome to go check that out. If you do not know where that it is, go to my Twitter feed and eventually I will tweet that it is out.

DR. DANIELS: And we will be putting it up on the IACC website, too.

DR. GORDON: Anything from the IACC? Thank you everyone, for I think, what is another wonderful meeting, and particularly thought provoking and compelling today. I think nicely it did really cover the spectrum that we need to think about from lots of different perspectives. I appreciate it.

(Whereupon, at 4:34 p.m. the meeting adjourned.)