

INTERAGENCY AUTISM COORDINATING
COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, JULY 26, 2017

The full Interagency Autism Coordinating Committee (IACC) convened in Bethesda, Maryland, at the National Institutes of Health, (NIH), 31 Center Drive, Building 31, C Wing, 6th Floor, Conference Room 6 at 9:00 a.m., Joshua Gordon, M.D., Ph.D., Chair presiding.

PRESENT:

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

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

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

JAMES BALL, Ed.D., B.C.B.A.-D, JB Autism Consulting; Chair, Autism Society Board of Directors

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

PRESENT: (continued)

LINDA BIRNBAUM, Ph.D., D.A.B.T., A.T.S.,
National Institute of Environmental Health,
Sciences and National Toxicology Program,
National Institutes of Health

JOSIE BRIGGS, M.D. (representing Francis
Collins, M.D., Ph.D.,) National Institutes of
Health (NIH)

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

RUTH ETZEL, M.D., Ph.D., Office of
Children's Health Protection, Environmental
Protection Agency (EPA)

TIFFANY FARCHIONE, M.D., Division of
Psychiatry Products, U.S. Food and Drug
Administration (FDA)

LAURA KAVANAGH, M.A., Maternal and Child
Health Bureau, Health Resources and Services
Administration (HRSA)

DAVID MANDELL, Sc.D., Center for Mental
Health Policy and Services Research,
University of Pennsylvania

PRESENT: (continued)

MEGHAN MOTT, Ph.D. (representing Walter Koroshetz, M.D.), National Institute of Neurological Disorders and Stroke, (NINDS) National Institutes of Health (NIH)

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

EDLYN PENA, Ph.D., California Lutheran University

LAURA PINCOCK, Pharm.D., MPH, Agency for Healthcare Research and Quality, (AHRQ)

LOUIS REICHARDT, Ph.D., Simons Foundation Autism Research Initiative

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

JOHN ELDER ROBISON, College of William and Mary

MARCELLA RONYAK, Ph.D., LCSW, CDP
Indian Health Service (IHS) Headquarters

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

MELISSA SPENCER, Office of Disability Policy, Social Security Administration (SSA)

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

PRESENT: (continued)

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

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

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PROCEEDINGS

DR. JOSHUA GORDON: So, welcome to the summer meeting of the Interagency Autism Coordinating Committee. Those of you who don't know me or are watching on the web, I am Joshua Gordon. I am the Director of the NIMH and the chair of the IACC. It is my pleasure to welcome you all. We are going to have a roll call in a few moments.

Before we do that, I want to introduce two newish members of the committee. First of all, Marcella Ronyak, welcome. Dr. Ronyak is the Deputy Director of the Division of Behavioral Health at the Indian Health Service. Could you just say maybe a few words about your agency?

DR. MARCELLA RONYAK: Yes. Good morning and thank you very much. My name is Marcie Ronyak. I am a member of the Confederated Tribes of the Colville Nation, up in

Washington. So, I literally moved from Washington to Washington. I am the Deputy Director of Indian Health Service, Division of Behavioral Health.

IHS' mission is to raise the physical, spiritual, mental, and social wellbeing of American Indian and Alaska Natives. Part of that is working extremely hard with our partners and in collaborations and looking at various avenues of how we can increase access to services, how we can increase education, training, consultation. We do have our Tele-Behavioral Health Center of Excellence that provides education, training, and consultation to all IHS facilities, tribal and urban facilities, to be able to assist us in meeting that mission.

Thank you and I am very honored to be a part of this.

DR. GORDON: Thank you and welcome. Also Dr. Laura Pincock, a Pharmacist Officer for the Agency for Healthcare Research and Quality, officially joined the IACC in January, but you didn't have a chance to introduce yourself. Why don't you go ahead and do that, please?

DR. LAURA PINCOCK: Good morning, everyone. I work at the Agency for Healthcare Research and Quality. We are a small agency in the Department of Health and Human Services. We focus on healthcare research as well as quality programs, safety initiatives for healthcare systems. I am a program officer in the evidence-based practice center program. Basically, we have a research agenda that works on systematic reviews and evidence reports that we then partner with federal partners and outside organizations to help

inform guidelines and other research program initiatives.

I am a pharmacist and a U.S. Public Health Service officer. That is why I am wearing a uniform. I am very happy to be here. Thank you.

DR. GORDON: Welcome, also. Now, I will turn it over to Susan Daniels for the roll call.

DR. SUSAN DANIELS: All right. So, we are going to have the roll call. Joshua Gordon.

DR. GORDON: Here.

DR. DANIELS: Judith Cooper.

DR. JUDITH COOPER: Present.

DR. DANIELS: Diana Bianchi.

DR. DIANA BIANCHI: Here.

DR. DANIELS: Linda Birnbaum.

DR. LINDA BIRNBAUM: Here.

DR. DANIELS: Josie Briggs.

(No response)

DR. DANIELS: Ruth Etzel.

DR. RUTH ETZEL: I'm here.

DR. DANIELS: Tiffany Farchione.

(No response)

DR. DANIELS: Melissa Harris.

(No response)

DR. DANIELS: Jennifer Johnson.

(No response)

DR. DANIELS: Laura Kavanagh.

MS. LAURA KAVANAGH: Here.

DR. DANIELS: Meghan Mott for Walter
Koroshetz.

DR. MEGHAN MOTT: Here.

DR. DANIELS: Laura Pincock.

DR. PINCOCK: Here.

DR. DANIELS: Marcie Ronyak.

DR. RONYAK: Present.

DR. DANIELS: Stuart Shapira.

DR. STUART SHAPIRA: Here.

DR. DANIELS: Melissa Spencer.

MS. MELISSA SPENCER: Here.

DR. DANIELS: Larry Wexler.

DR. LARRY WEXLER: Here.

DR. DANIELS: Nicole Williams.

DR. NICOLE WILLIAMS: Here, on the phone.

DR. DANIELS: Thanks, Nicole. David

Amaral.

DR. DAVID AMARAL: Here.

DR. DANIELS: Jim Ball.

DR. JIM BALL: Here.

DR. DANIELS: Samantha Crane.

(No response)

DR. DANIELS: Geri Dawson is not going to be here today. Amy Goodman is not going to be here today. David Mandell.

DR. DAVID MANDELL: Here.

DR. DANIELS: Brian Parnell. Kevin Pelphrey I know is on his way. Edlyn Pena.

DR. EDLYN PENA: Here.

DR. DANIELS: Louis Reichardt.

(No response)

DR. DANIELS: Rob Ring.

DR. ROBERT RING: On the phone.

DR. DANIELS: Hi, Rob.

DR. RING: Morning.

DR. DANIELS: John Robison.

MR. JOHN ROBISON: Yes. Here.

DR. DANIELS: Allison Singer is not going to be with us. This is her first missed meeting in all of her time on the IACC over many years. Julie Taylor.

DR. JULIE TAYLOR: Here.

DR. DANIELS: Great. So, we are done with the roll call unless I missed anyone. All right.

DR. GORDON: Should we do the minutes?

DR. DANIELS: Yes. So, you have in your packets the minutes from the last meeting that took place in April. Did anyone have comments on the minutes? Any corrections? All

right. Can we have a motion on the floor to accept the minutes if there are no comments?

DR. BALL: So moved.

DR. WEXLER: Second.

DR. DANIELS: All in favor of accepting the minutes as written? Any opposed? Any abstaining? So, the motion carries to accept the minutes. We will get them posted on the web as soon as possible after the meeting. Thanks.

DR. GORDON: Thank you all. Just a quick reminder to please when you speak, speak into the microphones because this meeting is webcast to the public. That makes sure that your remarks and questions will be heard by all.

We have a busy schedule for the day, as usual. We are going to hear from the National Autism Association, from the Interactive Autism Network on mortality and risk in

wandering. We are going to complete some committee business, in terms of getting the strategic plan hopefully finalized and approved. We will see. Then we will have a public comment session. Then we will hear from the Madison House Autism Foundation. Then we will have our discussion of the summary of advances and a round robin around the table.

A quick note - I apologize in advance I have to run off for a meeting at three o'clock, myself, with some higher ups in HHS. So, I am going to be leaving at 2:45 or so and coming back whenever that meeting is over for the final round robin. Susan will lead the meeting in my stead. I wanted to announce that in advance in case I have to run out during the talk that precedes the 4 o'clock hour.

We were to have an update from the Deputy Assistant Secretary for Health, Thomas Novotny, but Dr. Novotny must be running late so we will move right along. We will go ahead and get started if we are ready with the first presentation. We will slot in Dr. Novotny later.

It is my pleasure to introduce Ms. Lori McIlwain, the co-Founder and Board Chair for the National Autism Association, who is going to be speaking to the committee about her organization's work on the issue of wandering and elopement, followed by Dr. Lipkin, the Director of the Interactive Autism Network, who will also be speaking about recent research addressing the issue of wandering. This is an important issue with considerable morbidity and mortality. It is important that we consider this as a committee. Ms.

McIlwain, if you will go ahead and take the podium and go right into it.

MS. MCILWAIN: Thank you. Thanks to the committee for inviting me here today. I believe this is NAA's fourth update on missing children and adults on the autism spectrum as it relates to wandering and elopement.

For those not familiar with us, the National Autism Association is a parent-run organization. And the issues we focus on are often the same challenges our own children have faced or are facing.

In accordance with our mission, we work to address the most urgent needs of our community, which often center on tougher topics that impact the lifespan of our loved ones, looking at the lethal and higher risk outcomes first and then working backwards to determining contributing factors leading up

those outcomes for the sake of prevention. These factors can range from mistreatment to comorbidities, communication challenges, anxiety, stress response, sensory challenges, insomnia, GI issues, pain, epilepsy, et cetera.

We have various programs dedicated to education and training and direct assistance and since 2011 have shipped close to 40,000 big red safety boxes to autism families across the US in an effort to prevent wandering.

We also work with the National Center for Missing and Exploited Children and notify them of minor children with autism missing. We have helped them intake almost 400 cases.

NAA began collecting data on wandering-related lethal outcomes in 2009 and then all ASD missing person cases in 2011. What I will share with you today is the results from our

data collection from 2011 to 2016 as well as an update on the 2017 cases.

We collected data on 800 ASD missing person cases and found missing cases that occurred in the US over a six-year timeframe. Found missing cases are those involving children and adults who were not reported missing, but were rather found lost or wandering as with happened with my son almost a decade ago when he left the school yard and was found by a motorist.

Cases were collected through reliable media and agency channels in real time. And existing case information was utilized to collect outcome retrospectively. This is certainly an underrepresentation of what is really happening out there, but these are the cases that were serious enough to be reported to the media.

Missing cases were identified and reviewed to identify diagnosis, US location, age, gender, race, time of year, time of day, search response and interaction and outcome and other relevant information.

Of 808 cases included in the sample, 139 resulted in death, 105 required medical attention, 309 were close calls, which includes those rescued from water traffic, roof tops, other high-risk locations and situations. The NamUs database was used to determine that five individuals with ASD were still missing, one of whom has since been found deceased. Two hundred fifty cases demonstrated minimal risk or the information was unclear.

Of 139 deaths, 71 percent, mostly children, died from accidental drowning. This replaces our older statistic that we based on a three-year sample of 91 percent. Eighteen

percent died as the result of being struck by a vehicle. Six individuals, mostly children, died after being struck by a train. Two children died from heat stroke and two adults died from hypothermia. Two individuals died after falling from a dangerous height. That was one teen and one child. Two adults died after mistaken home invasions, one from a gunshot wound, and one from asphyxiation. One adult with autism died as the result of people restraint and one adult death was ruled a suicide.

Looking at higher-risk categories that resulted in death or injury, the highest threat was water followed by traffic. The close calls in blue correlate with IAN's survey results and the pediatrics data where parents reported a higher amount of close calls with traffic over water. But on the

lethal side, water is certainly the higher threat.

Other risk categories known include eight cases of post-elopement abduction or predator involvement. Six missing person cases noted suicide ideations or completed suicide, which is something we were not seeing early on. The use of Tasers, physical restraint or other police involvement were noted in several cases, including the use of a Taser on an 11-year-old girl with severe autism. Physical restraint, as I just mentioned, on an adult with autism that resulted in death. And the use of gun fire reportedly intended for an adult male with autism who left his group home, which instead struck his aide.

DR. GORDON: Sorry Lori. The numbers on the bottom. They are numbers of cases?

MS. MCILWAIN: Yes, but those are just the identified. This is actually a paired down version of the higher risk category.

Children 5 to 9 had the highest number of deaths while children under 5 face the highest lethal risk with cases ending in death nearly 60 percent of the time. The lethal risk dropped beyond age 14, slightly increased in adults 25 to 29. Also, I do not have a slide for this, but the lethal risk among females with ASD was higher, which is similar to our previous reports and other reports out there.

The average age per year stayed relatively consistent among non-lethal cases, but we did see an increase in average age. For lethal outcomes and most used of this sample period, I believe a previous update to the committee and NAA President Wendy

Fournier had mentioned that we were seeing an increase in age.

Drowning deaths tend to occur in younger children, especially females. The traffic injury deaths were more likely to occur in older children, teens and adults, mainly males.

This is the first time we looked at ethnicity for lethal outcomes. We are seeing a disproportionate risk among black individuals with ASD when compared to general population numbers.

When looking at cases by 2012, it was an unusual year. We initially attributed that to the warmer temperatures that year. Things kind of leveled out after that, but the last twos, the case went back up. And about half of the lethal outcomes in this sample happened in the last two years alone and 2017

so far has been similar to the past two years.

Risk of death was highest during summer and spring months. Overall activity was higher in September, but the lethal risk was lower. That is likely due to school transitioning.

We looked at time of day and other factors that may have contributed to elopement and of those identified, nearly 40 percent occurred during a transition. School bus and classroom transitions came up a lot in that data. Other times were during commotion or stress, which includes cases where the individual was frustrated or agitated. We saw multiple cases where an upset individual walked, jumped, or ran straight into traffic. About a third of cases occurred between 9 p.m. and 9 a.m. where caregivers were more likely to be sleeping.

There were a couple of arrests of parents whose children went missing overnight.

Thirteen percent occurred while playing outside. This includes school recess. The lethal risk for those who eloped from an unfamiliar setting or from a family gathering was notably high. Reported cases that occurred from a family gathering ended in death nearly 70 percent of the time.

For identified search times, most lethal outcomes occurred within an hour, indicating that quick research time is pretty essential.

These are the top places from where individual left and where they were found. Relative's homes, hotels and vacation homes posed the highest lethal risk. Again, those unfamiliar settings. Water and train tracks also posed the highest lethal risk. Most individuals seemed to be seeking out quiet,

low sensory locations more so than special topics.

What increased risks? Setting types seemed to have more of an impact on risk than supervision type. Residential settings near water increased risk as did outdoor recreational settings. Times of transition increased risk. Individuals who became quickly agitated or upset seemed to be at higher risk. Caregiver or staff distraction was a factor. This was when mom or dad used the restroom. In one case, there was a father who was winterizing his home while his child played outside, mother planting flowers, staff attending to other children or using the restroom.

Holiday and family gatherings and longer search times also increase risk as well as police not knowing where to look or how to interact.

What decreased risk? The lethal risk was lower and more populated areas like schools and hospitals. That is not to say that this is not happening from schools. We just recently had a death in Arkansas. A little boy, 6 years old, left an elementary school. The school was not fenced because by state law they do not require fencing unless there is a preschool program. That child with autism was found in a nearby pool.

Populated areas not in proximity to water seemed to decrease risk. Quicker response time was also key as well as tools like silver alerts, tracking and Reverse 911, which prompted more public involvement, which we saw a lot of. We are hoping all states with silver alerts expand their criteria if they have not done so already to include individuals with autism and other disabilities regardless of their age.

IDs also help decreased risk, especially once the individual was found. Police familiarity and training were also key factors in positive outcomes.

Currently, we are seeing about 20 ASD missing person cases per month, seriously enough to be reported to the media. About three to four deaths per month.

Here are some of the headlines from this month. This is out of Naples, Florida on July 3, July 5 out of Pawtucket, Rhode Island, July 6 out of California. This individual left his group home. He left through a window. He was severely impacted. He was told by police to stay put. He could not comply with those instructions and he was killed by multiple vehicles. This same individual in January went to the same highway and was found safe.

July 7 out of Indiana. This is a little boy who was visiting from Louisville. This is one of those cases when we report this to the National Center for Missing and Exploit Children, we flag cases like his because we see that he is an unfamiliar setting and we know that these children are at high risk. On July 8, unfortunately, his body was found in a nearby pond.

This is July 9 out of Florida. July 10, another case out of Pawtucket, Rhode Island, found safe. This is July 11 out of Albany, Georgia. This was a multi-agency search overnight. Another July 11 case in a different Albany, Albany, Oregon. And this boy's body was found in a pond on July 12.

There is good news. There is more awareness, more rescues we are seeing, more understanding to search water first. But we are also seeing an increase in cases and

deaths. Awareness, police training and resources are not widespread. I recently did training in Arkansas. I spoke to about 150 police officers. I was asking them about certain tools and technology to see if they have heard of it. One person raised their hand. We are not reaching a lot of our Southern states, Southwestern states, specific Northwest states with this information.

There is also a disproportionate risk among African American individuals with autism.

Here is an example of an agency that likely has not had training. A young boy with autism was reported missing this year. They searched the home multiple times because as this lieutenant says, in some cases, missing children are often found hiding in their own homes. That might be the case with

neurotypical kids, but children with autism are more likely to go to water. That is exactly where this child was found.

The Alzheimer's community faces similar challenges. Many missing person cases, more than our community, not as many deaths as far as my data goes, which could be the result of national models like this one from the International Association of Chiefs of Police, which has about 30,000 members. They provide training, train the trainer sessions, lots of good stuff, including mail pieces like this one to help first responders recognize the signs of Alzheimer's and do's and don'ts of interaction and that sort of thing.

The program was initially federally funded in part through the Missing Alzheimer's Disease Patient Initiative program along with a radiofrequency tracking

initiative. Radiofrequency tracking is very different from GPS. It is low tech. It does not store data. It does not listen in. It works under water. It does not require a Smartphone, which many families cannot afford. It also runs through local law enforcement. They must have training, which is how they learn about autism. Great program. It has been around for a long time.

Here is one case this year involving a person with autism who was found via the same radio frequency tracking technology. Another case out of California. Because radio frequency tracking requires a monthly battery change, this tends to help build familiarity and trust between the individual and members of the agency. That is what helped in this case. The water was not deep, but it was February. It was frigid. They were worried about hypothermia. Instead of having to go in

and forcefully get him out, they were able to talk him into coming out because that volunteer knew the teen.

Last year Kevin and Avonte's Law was introduced and would have reauthorized that same program and expanded it to include people with developmental disabilities who may wander or elope from safe settings. We believe that this is a critical piece of this, certainly not the whole piece, but would be extremely beneficial for our community and preventing elopement, reducing risk of injury and death as well as risks that may arise during interaction. The training piece alone is critical.

A lot of focus has gone on the tracking component of this bill. But we are keeping our eye on something like the IACP model, tailored for our community. It would be ideal to provide a good foundation for building

relationships between law enforcement and individuals with autism.

Another key concern is really for the search volunteers and the good Samaritans who intervene and first responders. What are not included in this data are those who died or were injured during a search and rescue. One individual, just a Good Samaritan, accidentally drowned trying to save a child with autism. Another died after discovering a deceased child with autism in his pool.

The effect of these cases goes well beyond our community. This is something we need to recognize as well. We hope that the reintroduction of Kevin and Avonte's Law will happen soon. I think it is supposed to happen any day now. I know the language is being worked on. We thank Senators Grassley and Klobuchar for their support, of course, Senator Chuck Schumer, who originally

introduced the bill early on, and Congressman Chris Smith who has fought for this bill and Congresswoman Maxine Waters as well for their continued support on this.

Here is what would help. We keep coming back to this. The need for more involvement from our pediatric community. They are in a position to warn caregivers. We are doing the best that we can to try to reach caregivers. We could use some help on the ground. These children are diagnosed. Obviously, somebody is seeing them and can make recommendations. We know holidays and family gatherings pose significant risks. We know these children will go straight to water. There is no reason why every caregiver shouldn't be warned of the specific risks like this about prevention strategies and to be encouraged to enroll their children in swimming lessons.

Widespread training, also essential federal initiatives would help families and first responders in our other states. Lots of training and tools, especially in the Eastern states, not so much in other states. And having access to life-saving information and resources should not depend on where an individual with autism lives.

Also I am wondering if our Department of Justice can become more involved with this committee.

The disproportionate risk among African American children with ASD needs our immediate involvement. Outreach, awareness, and resources are needed. I would be interested in hearing your thoughts on that and things that we can do to help address that.

As I mentioned earlier, we are seeing some crossover between elopement and

suicidality and ideation sometimes in very young children with autism. This is not something we were seeing early on. As I mentioned, one adult died by suicide. That happened late last year. It is the first time we had seen a missing person case like that since we began collecting data on these cases. I can tell you that in 2017, there has already been two. NAA spoke about suicidality recently in the UK. Dr. Lipkin was there as well.

Elopement behaviors and heightened stress response may evolve into other forms of exit seeking in some individuals. Study and discussion is needed on the topic of self-harm and suicidality and ASD here in the US. It would be great to see Dr. Lipkin, Dr. Cassidy from Coventry, and Dr. Rogers from New Castle at IACC to report on this critical topic.

Last November, Christian, a young man with Asperger's was reported missing from his grandmother's home. His death was ruled a suicide. This person's family has been devastated. I can tell you that his very brilliant and loving young sister, Hannah, will go on to be a wonderful advocate for our community.

I would like to end this presentation with words from Christian's mother. When you think of Christian, you find yourself guilty of being selfish. In our family, Christian was the guy you wanted to have around to help make yourself feel better. He was silly, spontaneous, thoughtful, loving and his smile swept through the room like wildfire.

Having been diagnosed in his teen years with early onset schizophrenia and Asperger's syndrome, those amazing qualities were only visible to those closest to him as Christian

struggled connecting with a world that was eager not to take the time to understand him.

Christian clung to the safety and familiarity of his family, but yearned to receive more from this world in which he could never completely find his footing. The difficulties he found in navigating everyday social aspects of human interaction often left him exhausted, frustrated, and on the worst of days, in tears. He sought love and purpose of being, but in the end, this world proved too gruesome to withstand. Christian took his last breath in the coldness of dark and alone, which is perfectly attuned with how he viewed his place in the world.

Thank you to Christian's family for those words and thank you once again to the committee for your time and your consideration. If you are a parent looking for wandering prevention materials, we have

those at AWAARE.org, which is aware with two A's in the middle, and NationalAutismAssociation.org. We would also encourage caregivers to download our first responder toolkits or our Meet the Police toolkits. We are really encouraging them to introduce themselves to their local members of law enforcement. Thank you so much.

(Applause)

DR. GORDON: Thank you for that compelling and eloquent presentation. Again, we will have questions and opportunities for discussions after the next presentation by Dr. Lipkin of the Interactive Autism Network.

DR. LIPKIN: Thank you all for asking me to speak today and particularly Drs. Gordon, Daniels, and Novotny. I would like to thank Lori for her really very important presentation.

We, at the Interactive Autism Network, have done some more recent work on this. It is that data that I would like to present to you today. This is, as far as I am concerned, a major issue where we have seen action, but we have seen a little change and the questions come up about what we need to do to try to decrease the issues of morbidity and mortality for children and adults with autism.

For those of you who did not participate in the IACC process in previous years, this whole story began in 2010 thanks to the work of Lori, the National Autism Association, people in Autism Speaks, and other important advocacy organizations when parents were speaking up and describing their problems that they were seeing and the major problems with morbidity and mortality of children and young adults at that time.

I think there was in some ways really quite impressive action taken in a very short period of time. From October 2010, the issue was brought up at one of these meetings. Within a month, a Safety Subcommittee was convened by the Interagency Coordinating Council. Funding was obtained from Autism Speaks, National Autism Association. I apologize for not knowing offhand several other autism associations to try to do what would be the first deep dive into looking at what the prevalence of the kind of problems that we are seeing.

We, at the Interactive Autism Network, launched a survey soon thereafter in March and a report was in hand to the council by April. It took essentially six months from a concern to where we had really important information, which was then published in the literature one year later.

I will just briefly review what that initial study was all about. At that time, we surveyed parents who were registered within the Interactive Autism Network. About a thousand surveys were completed from families all throughout the United States, reporting on wandering and elopement behaviors in their children. This was the first set of data that clearly showed the very high rates of wandering among children and teens with autism with an overall wandering rate of 49 percent. Essentially, half of children with autism had wandering at some point in their lives. You can see that it peaks in early childhood, but did not disappear and rose as children became older into adolescents. The blue line above is the children with autism. The red line below is their siblings. While wandering is a problem amongst all children particularly preschoolers, we could see that

in children and teens with autism that the rates are much higher and really quite high.

At that time, the data showed that parent report that of all those who attempted, 53 percent succeeded and were missing long enough to cause concern about their safety. Police were called 31 percent of the time. Two-thirds report a close call with the traffic injury and 24 percent report a close call with drowning. Lori reported to us today on those and who unfortunately the fatalities we were seeing.

At that time, we saw the higher functioning children with what was then called Asperger's disorder were attending to escape because of anxiety. And those with lower functioning problems were more likely to simply run for purposes of exploration or heading to a favorite place.

What was apparent at that time was this is a very common condition and was a major concern to families and that more supports were needed. The ICD 9 coding was then extended from Alzheimer's into autism. There was some action there on the part of the coding system. But clearly, other areas of research were being called for.

There have really been only three papers since that 2012 publication that have looked at this. Again, these are using different sources of data. Two of them are from the pathway survey from the Centers for Disease Control, National Center for Health Statistics. They essentially verified the same types of findings. Our data is always a bit skewed by people who volunteer to participate and is skewed towards higher socioeconomic group. But the CDC data really showed that a third of kids were wandering

and of course of the prior year from home, from someone else's home, from daycare, from public places. They verified that this remains a huge issue across survey modalities. That paper was by Cathy Rice and group.

And this paper was by Kiely et al. It took a look at what kind of measure were reported through that survey. And parents clearly veered towards using physical barriers, electronic measures in small frequencies of about 3 percent. Any type of prevention strategy was being used by about a third of parents who report the child who have ASD only. But for those who have autism spectrum disorder and intellectual disabilities, about more than half of them were needing to use prevention strategies for children who they knew were wandering.

Allan Andersen is a child psychiatrist who worked with us over the course of a year from Johns Hopkins and Kennedy Krieger Institute and was really interested in extending this data further to see what more we could learn about wandering. Through Allan's work with our group, we put together a survey, looking at elopement patterns and caregiver strategies. That is what I will be reporting on now.

The aim of this project was to report on the strategies that were being employed by caregivers for individuals with ASD in order to prevent elopement behavior, their perceived effectiveness, burden of use, and cost. What I will be reporting today are the perceptions of the caregivers and the activities that they are employing at this point to prevent elopement.

This survey was launched a year ago between March and September of 2016. Only parents of children below the age of 18 were surveyed so we do not have data on those 18 and above. This was typical of our ASD cohort who all have their autism spectrum disorder verified through multiple modalities.

The elopement behavior questionnaire was centered around the basic question. Does your child try to leave safe spaces and/or the supervision of caregivers? With that as the fundamental question, we looked at what the children's diagnoses were, what their patterns of elopement were, what the consequences were, how the parents responded, what preventive interventions were being used including medications, how they perceived the effectiveness, the burden of use of these strategies and what their estimated costs were.

We had 867 people who completed these studies. I should say that this data has previously been presented at the American Academy of Child and Adolescent Psychiatry and at the International Meeting for Autism Research. This is the third time that this data is being presented. In a recent re-analysis - I am presenting a recent re-analysis, a deeper analysis of this data that we have done more recently for this presentation.

There were 867 families who completed the survey. Of those 867, 526 said that they had ongoing preventive interventions or their child was having elopement behavior. And it is those 526 that I will be reporting on to you right now. Their children average about 11 years of age. It was clearly predominantly male that they were reporting on. It was predominantly a white population and non-

Hispanic population. This was consistent with those who were represented within the Interactive Autism Network.

The autism severity was on the higher side with a mean social responsive scale T-score of 90. Parents reported that 16 percent of their children had intellectual disability, 31 percent had some sort of language disorder. High rates of ADHD and anxiety disorders were also reported as well. Twenty percent of the children had problems with aggression and 24 percent or one of every four had problems with self-injury.

Of these 526 parents, this gave us some sense of the frequency. We asked them how often these problems were occurring. And 22 percent of them said that in the past two years their child had no attempts, but 49 percent or nearly half said that their children have had an attempt within the past

one to two years. In fact, a third of them or 29 percent report that their children were having at least one attempt per week. Very high rates there.

The children were eloping as other stories like Lori have told already of predominantly from home, but they had problems in public places such as stores. Even in the classrooms, 41 percent elopement rate. And also transitions from one place to another children were running away.

They felt that these were occurring of a bunch of different situations. Forty-three percent were escaping an anxious situation, 40 percent of stressful environment, 24 percent escaped when there was a conflict that they wanted to escape from. Thirty-eight percent reported sensory problems, particularly noise standing in their way or some other uncomfortable sensory experience.

Sometimes it was purely out of interest about what was going on. Twenty-seven percent were pursue because they had some special interest in doing something such as reaching or playing for a toy, reaching a favorite food. And then there were some children who were felt to do it on the basis of impulsivity where they were under-stimulated or centered in a boring environment.

Ninety-six percent of them were using at least one intervention to try to prevent their children from wandering further. Overwhelmingly people were doing what I have categorized as using environmental strategies. Half of them had dead bolts installed in their house so the child cannot leave. Half had special latches put on their doorways. And more than a third were putting up special gates to try to prevent the child from escaping.

Many were also employing other types of services such as behavioral psychology, assistance, use of social story modalities or having a one-on-one aide to try to prevent their child from eloping or wandering away.

A smaller number, but significant number is using different types of tracking devices. Nineteen percent reported that they did have some sort of GPS tracker. And those who did not use electronic devices - many were still using IDs such as bracelet, shot tags, Medic Alert bracelets. Parents are trying many different ways to try to keep their children safe.

How effective are these? We wanted to get parent's perception about these strategies and how well they were working. Overall, they felt that there was good or very good effectiveness of about 75 percent. In those families though who had high rates

of elopement, they only reported effectiveness of about 61 percent. Despite their best efforts, they were still having major challenges.

The mean number of interventions that they tried was six, but standard deviation quite wide. Parents were trying many things to try to keep their children safe. And of course, the higher rates of elopement of their children, the more they would try. But even those who did not have high rates were still using at least five different interventions because of their concerns and their worries about their child eloping.

We were concerned about the financial burden for these families. You could see that families of children who have rates of elopement of at least once a week were spending more than \$5000 out of their pocket to try to keep their children safe. And

obviously there is a very high sense of burden that all of these families are feeling and worry around this. This is a crisis for families. It takes a tremendous amount of their time and energy and concern as Lori so well highlighted today.

The question is what did they feel was the most useful to them and what were the burdens attached to them. We have categorized them into four different categories. Those that were felt to be good as well as cost effective were putting up window bars, fending, and project lifesaver bracelets. They found that to be good and cost effective.

There were some limited access modalities that people liked, but unfortunately access was limited. Home behavioral specialists were felt to be effective, but that tends to be limited

because it tends to be costly and families need to be able to access that through insurance that they may have, health insurances or other insurances.

School aides also were felt to be really quite effective with minimal burdens. And of course, there is no direct cost to families around that, but it is limited because the school has to agree to provide that for the families.

Service animals were interestingly found to be quite effective, but the burden was felt to be fairly high in bringing a pet and dealing with a pet in the home.

Ones that people are quick to think of because they are cool and they are high tech are security cameras and GPS trackers. The effectiveness was not clearly as - they were not felt to be clearly as effective as these

lower tech devices. And of course, they have significant costs attached to them.

From the medical sphere, the question is is medication important and does that play a role. Again, this is parent perception. Half of the parents were describing their children as taking some sort of psychiatric medication. And 16 percent said that they were specifically taking it because of their child tendency towards wandering and elopement.

You can see the categories are across the board of the types of medications that children are being treated with the highest rates of being what we see highest in children with autism. That is antipsychotic medications, ADHD medications, and antidepressants. Those were felt to be most effective where you see labeled here. Lorazepam and Diazepam actually were reported

as the most effective. The stimulant medications were less effective for the elopement behavior.

In conclusion, we felt that simple environmental and behavioral interventions are generally rated by caregivers as cost effective and much more effective than medications in reducing elopement. Medications are generally perceived as ineffective with high rates of side effects.

Questions that remain at this point are that for interventions that are rated as highly effective but are less commonly used, what are the obstacles to implementation? Maybe we need to look at these. There things like cost. Fencing is a tremendous cost burden for many families or for school systems for that matter. Availability is a problem in terms of having personal aides in school or at home and similarly with

behavioral specialists. And then things like door alarms and others that represent a major burden and hassle for families.

We also do not know if there are subtypes of elopement that will require different prevention strategies. We hope to get to that with our data. We do not yet have that.

At Susan's invitation, Dr. Daniels' invitation, I am going to bring up one other important issue to us because for me, I am a developmental pediatrician. For me, wandering and elopement is really a health crisis. We are talking about children who are getting ill, children who are dying and really quite limited attention from the health care establishment around this. But similarly, I think we are seeing the same in terms of suicidality in autism. There is a big untold

story here that I think also needs to be considered as we go forward.

I will tell that there is very little research on suicidality and autism. There are really just two key papers, one out of the UK by Dr. Cassidy and group where they looked at adults with Asperger's syndrome. And two-thirds of those adults were contemplating suicide compared to 17 percent of the general population. A third had actually planned or attempted suicide. These were adults with Asperger's disorder.

In contrast to other things that we see in the autism population, the risk was greatest in women with Asperger's disorder, which is actually just the opposite of suicide behaviors in the general population.

In Sweden, they took a look at their massive data samples between 1987 and 2009. In adults, they also found that suicide was

the leading cause of premature death in populations of children with autism spectrum disorder. If this is not a health issue then what is?

There is really no current published data from the United States on this. My colleague, Roma Vasa, and some others at Kennedy Krieger and Johns Hopkins recently looked at data from the pediatric emergency department at Johns Hopkins where there was active suicide screening going on in all pediatric patients coming to the emergency room. They just looked at children who had a diagnosis of autism spectrum disorder.

Of the 104 children who had autism spectrum disorder being screened in the emergency department, 31 of them screened positive as being at suicide risk. One out of every three children coming into the emergency room with autism was at some sort

of suicide risk. Two-thirds of them without the screening process would not have been identified as having any sorts of suicidal ideation. Of that group of 104, there were 12 suicide attempts. I am not going to go through the causes of suicide, but it is a wide range of things that we see in all populations. Again, this is a major health crisis from my particular perspective.

We have just launched in April, National Autism Awareness Month, what we call Mental Health and Suicidal Behavior Questionnaire. Just as the parents were informative to us around elopement and wandering, we have launched a survey looking suicidal behaviors and other mental health issues to establish a clear understanding. This survey is actively ongoing at this point in time.

We are, again, just looking at children because of issues of limitations on

investigations with adults. But we are also having to survey parents who have a dependent adult as well. We right now have about 55,000 participants in IAN. This was distributed online to families. The questionnaires are laid out as you see here. We wanted to find out generally not just suicide, but what is the mental health history that their children or dependent adult are experiencing. What kind of major family life events are occurring? What are the life events that are occurring for the individual with autism? What are the suicidal behaviors that that person is exhibiting?

We also want to find more about who these children and dependent adults are. The lead question around suicide is has this person ever expressed any thoughts or feelings about wanting to die or not wanting to live anymore. Have they ever expressed any

thoughts or feelings about wanting to end his or her life? Has he or she ever indicated that he or she had a plan to end his or her life? Have they ever actually tried to end their life? This is a very sensitive survey. There are multiple warnings that we provide to families as they fill this out, but we think this is important information that we do not know in the United States and really is important to the autism community.

What I cannot share with you by slides, but I can share with you by word is that we so far - we will be running this survey through the end of September. We have had 680 responses to date. We did a preliminary analysis of this in May for a suicidality and autism summit that Lori and I attended in England.

As our reports in May, there was passive suicidal ideation reported in 42 percent of

the children or dependent adults, active ideation in 23 percent. Almost 10 percent had some sort of suicidal plan and 4 percent had suicidal attempts.

Really quite fascinating is we asked when they first had their suicidal ideation because we were thinking about this as a problem in teens and young adults. In fact, the first signs of passive or active ideation were occurring as young as 8 and the median age was 10 years of age that children are starting to show worry about self-worth and possible ending their life.

The median age for having a suicidal plan was 12, again, beginning as early at 8. And the median age for an actual attempt was 14 and with the earliest attempt being reported as 9. We will be collecting this data again through the end of September. We think this is going to be very important data

to inform certainly the committee as well as the United States policymakers, advocates, and researchers. But this is getting attention worldwide at this point and I think it is a next step that I think we all need to take.

I think we have done really some great work here in terms of exposing the problems around wandering and elopement. The problems are still out there and I think we need to do the same around suicide because I think others - probably nothing more important from my perception as a physician around issues of health and life around children and adults with autism spectrum disorder. Thank you.

(Applause)

DR. GORDON: Thank you for another compelling presentation both on wandering and on suicide. We have had presentations here on the risk of premature death and autism. And

adding suicide to the list of possible concerns is important.

We can now open it up for questions or comments from the committee. They can be addressed at either of the presenters.

MR. ROBISON: I think that it is clear from these presentations that suicide is a major problem in the community. And when we look at that in combination with the elopement and wandering, one thing that I take away from this is to be blunt. There is a lot of bullshit in wishful thinking in the way we are putting this research together. Because if I read those slides right, we have the statements of what they described as the Asperger people who can articulate I guess why they ran away, saying that they mostly ran away to escape stressful situations. And then again if I read this correctly, the autistic people who presumably cannot

articulate for themselves, their parents said he ran away because he was curious. For Christ sakes folks, do we truly believe that? Do we truly believe that the people who are articulate ran away because it was stressful and everyone else ran away because they were smiling and curious? I think when we have that kind of thinking, it is no wonder we don't solve this problem.

I look at those slides and what I saw time again was stressful situations cause autistic children to flee. I think about myself as an adult. I think about all of you. How many times have you, my fellow committee members, said I have to get out of here? But we are adults so we are not eloping. We are going somewhere else.

Every autistic person I know says with some regularity I need to go into a quiet space. I need to cool down. I need some time

for myself. Again, it is ordinary. But for these children, somehow it is elopement. It is a special, unique condition.

I think we have to recognize that this is an ordinary thing. We create stressful situations and kids who have no other coping mechanism respond by running away. We are putting our heads in the sand until we face that.

I listened to the extreme seriousness of the situation. So many autistic people die. We are not facing what is to me an obvious truth. Am I nuts here? What do you folks think?

DR. GORDON: One thing that did astound me and that is why I asked the question in the moment about the numbers in the bottom of the slide was that the pure number of cases. Obviously, it is probably not comprehensive.

It is a best attempt, but it is a lot of individuals who are dying.

I wonder if we might have a response from either of the presenters first specifically about what the research says in terms of stress as an inducer of elopement and/or suicide and/or the protective measures that one might take in that context to try to reduce it and then we will have some more comments from the committee.

MR. ROBISON: This is the rule, not the exception, Josh. I have been suicidal. Almost every autistic person I know.

DR. LIPKIN: It is quite clear that anxiety and stress are really key components here that are driving many people to action.

MR. ROBISON: (inaudible comments)

DR. LIPKIN: Again, this is a parent report. It was the way the question was framed. I think one has to be cautious about

that. This is all the information we have. This is all the data. I would like to spur other researchers to really dig deeper in the kind of questions that you are asking, John, because we know it is a problem. We really do not quite really understand the depths of what the issues are that are driving it.

MS. MCILWAIN: I can give you some examples. We had a 13-year-old girl who was on the Staten Island Freeway. She did not want to go to her father's house. She leapt from the SUV into oncoming traffic. She jumped from the car.

Another case like that was a teenager who got into an argument with his foster parent. Walked out of the car and walked straight into traffic.

I was reading a spectrum.org article about suicidality a couple of years ago. It is a story of Bianca, a 15-year-old girl, who

did not get the chicken dinner that she loves. This disappointed her greatly and she spoke of - please, if you could just kill me now, we can just both get this over with. She said that to her mother.

Fast forward two years, a 17-year-old boy just in February left his home because he did not get the spaghetti dinner he wanted.

These seem like really small triggers to us. They are huge triggers to these individuals. The 17 year old who left his home - he was struck by a car. He could not talk like Bianca according to reports.

If you are looking at both cases, they are leaving because of some type of acute stress. They are responding in a way in either they impulsively want to harm themselves or may not understand and not care about what threats come along such as traffic. That is something that we have to

look at and decipher especially in the nonverbal kids who are going straight to threats.

DR. GORDON: John, if it is okay, I want to make sure we get other people from the committee. I have Laura, David, Judy, David, and Samantha.

DR. PENA: Thank you both for the presentations. I wanted to quickly say to Lori. I am a parent of a 9 year old with autism. We are recipients of the big red safety box. That has actually prevented my son from wandering. He just started a couple of months ago. This presentation is very timely in my personal life. The door alarm in particular is jarring, but for good reason. Thank you for that free resource that you provided to hundreds of families.

My question to follow up on John's point to Dr. Lipkin is is there a way to

disaggregate your data in terms of whether the child has complex communication challenges or limited speech so that we can attribute causes that the parents report to those children or individuals who may not be able to articulate the reasons why and then we can maybe have some more information to fill in the gap.

DR. LIPKIN: One of the strengths of the Interactive Autism Network's data is also one of its weaknesses or what it has been criticized for. It is purely parental report information that we have. We do not have clinic data except by parents reported.

What we do have is their report where the child had intellectual disabilities, where the child had language disorders. We probably cannot disaggregate that, but it is parental report. It is not based upon clinical information.

DR. AMARAL: I wanted to agree with John that I think it is clear that stress and anxiety is under appreciated particularly in younger individuals with autism who have intellectual disabilities or who have lack of language.

John, I think to speak to your issue, we have been really focusing on trying to differentiate anxiety from the symptoms of autism for the last few years. One of the things that has impressed me is that once our clinicians determine that a particularly young child has severe anxiety, often times when they go to the parents and say do you know your child has anxiety. The parents say I had no idea. A lot of the symptoms that our clinicians determine are actually an anxiety disorder and have been assumed by the parents to be just part of the autism.

I think that there has to be an increased awareness particularly in subsets of the autistic population about what anxiety really is and then maybe those charts. Again, this is parent report. I suspect a lot of our parents who we finally say your child has anxiety had no clue. They just maybe misinterpreting why the children are eloping. I agree with you. It really is an underlying anxiety disorder and severe stress that just was not appreciated.

DR. GORDON: I suspect the answer may be no given your previous answers, Paul. You showed data that the efficacious medications were predominantly benzodiazepines and that might also speak to this anxiety issue. Do you know if that was the reason why? The thing that popped into my head when you were showing - benzodiazepines - make them go to sleep, but perhaps there are actually

treating an underlying anxiety disorder, reducing that acute stress response.

DR. LIPKIN: We do not have that granularity. Basically, we asked what kind of things were they using for their child's elopement behavior. We provided a list of medications. They just checked off which ones that they had. We do not quite know.

I was surprised that the benzodiazepines came out so high. They are not that widely prescribed in general. But I think it is telling that medications that are more widely used whether it be the stimulants for ADHD, whether it be the anxiety medications, families were not finding those more commonly used medications as effective.

DR. GORDON: Right, particularly the antipsychotics, which you might think might be prescribed for that reason.

MS. CRANE: I have a few comments. I am just going to apologize in advance for having a few things to say. One thing that really struck out at me in the first presentation was the elevated risk to the African American community. We are working on our own safety surveys as well. And what we are finding is that because African American individuals are at higher risk of police violence, there is a real sense in the community that we need more alternatives, more ways that we can get help for a missing child, but do not involve deploying armed police to the scene.

We have definitely high profile cases like Arnaldo Rios Soto, who went missing from his group home. He was not really missing because his aide was right there, but he was not where he was supposed to be and a police officer shot at him and traumatized him. Now,

he is institutionalized because he could not go back to his group home after that trauma.

I think that it is really important when we talk about training police that we also start looking at interventions that do not involve police at all. That can be another reason why tracking devices or other things that might involve getting police to the scene might be an issue.

We also need to worry about training that is not the right training. There was a case a few years ago in which an experienced hiker who also was autistic was lost in the Arizona Desert. He was found near a creek. And when asked about how did you find this person. The police officer said I knew that autistic people were drawn to water so I looked at the water. A normal person would say he was lost in a freaking desert. If he is still alive three days later after he went

missing, he is probably near some water. I do not know what other people look for when they are lost in the deserts. Maybe that is something we should consider. You should definitely look near water when someone is missing, but I would say that that is because if any child is missing, you should look near water because if they are near water, they might be drowned in one or two minutes so you better look at the water as fast as you can. Then you start looking at other places. That is common sense.

They do not know that, but I think we need to make sure that we are not perpetuating a myth of autistic people that are human dowsing rods that just immediately go to the water. Yes, you should look near water, but I feel like we need to make sure that are messaging that right.

MS. MCILWAIN: To your point, I think that we have to not minimize what is happening out there with the water. This is really just to help first responders understand exactly where to go as quickly as possible and not just them, but also parents.

MS. CRANE: What worries me is - accidental drowning is a leading cause of death for all children. This is not an autism-specific thing. And frankly, your study, while it is absolutely showing a huge pattern of drowning deaths in autistic children, we did not look at non-autistic children wandering and what their cause of death is. We just need to be very precise when we message about this that water is dangerous to all children. It is not because we are necessarily drawn to water, but because water is a very fast killer. I have children too. We are paranoid about them

around water because drowning is a fast and silent killer. We need to make sure that that message gets out.

With respect to suicide, I really want to quickly get to suicide. I am worried and I think I agree with John here that conflating suicidality and wandering could be a real problem. We know that people in the autism spectrum have been dying from suicide for a very long time. It is not new. If we are seeing more of it in media accounts of wandering, it is probably because media is treating all autistic missing persons cases as wandering because of the heightened awareness of wandering.

People who are suicidal are not lost. The solutions are probably not the same. Having a door alarm or having a tracking device is not going to stop someone from being suicidal. It might stop someone from

accidentally going to a dangerous place. But it is not going to prevent suicide. I am not sure that that is going to help when we think we need to make sure that we are talking about these issues separately.

With the investigation of the suicidality survey, I am really concerned that the survey is asking parents about suicidality and not asking the actual autistic people about suicidality. Sometimes a parent has to be there to answer because they kid literally cannot. But if we are not asking the actual autistic person, it is like what David mentioned. Sometimes parents do not know that their kid is anxious. Sometimes parents do not know they are suicidal. I do not know if we would have a study on teenage suicidality that does not ask the teenagers if they have felt suicidal. This might have

some IRB hurdles. But if we want good data, we really need to do that.

DR. GORDON: Thank you. Any more comments or questions?

DR. MANDELL: I was wondering if either of you two knew or anyone on the committee knew about whether safety planning, which is a rigorously tested intervention for reducing suicide among suicidal people has been adapted or applied to people with autism or people with developmental disabilities. It seems like a very logical fit. I do not know if it is something that perhaps the committee would want to recommend as a fertile area for exploration.

DR. GORDON: Anybody aware? I am not aware of it. We do have ongoing studies at NIMH in using the screener actually that Paul discussed, the ASQ, and adapting it specifically for autism individuals. It is

undergoing testing right now in two different sites, an inpatient site and an outpatient sites, but that is just screening. That is not actually - then what do you do if they - as you can see, they are going to screen positive at high rates. And then if you follow up, actually two-thirds of them will have significant --

DR. MANDELL: Sometimes when the rates are really high especially if you could identify subpopulations where the rates are really high, maybe you do not need to screen. Maybe we ought to be talking about safety planning, which is a relatively light touch with everyone or with certain groups of people with autism who are at high risk.

DR. GORDON: I would say the point that Paul raised was that if you do not screen, you will not identify the folks at risk

because two-thirds of them are not going to otherwise have evidence that ideation.

DR. RONYAK: Thank you. I am also a parent of a child that is high functioning on the autism spectrum. He just turned 8 last weekend. I wanted to say two things. I apologize for taking some time.

One is I do want to come back to the co-occurring. My child was also diagnosed with ADHD. Clearly, he is taking ADHD medication, which has taken some time to get him acclimated to. He also takes melatonin in the evening because the anxiety and the lack of sleep - we love to have sleep in our house. Having a child go to sleep before 1 a.m. and getting up at 3 is extremely helpful. However, you have to think about on co-occurring if it is not managed, if the sleep is not managed. How does that influx into the anxiety that is going on in school. When he

was in kindergarten, it was our first episode of him literally leaving a teacher that he absolutely adored and the principal found him out on the street on the curb because he was upset about something.

You have to tease it out. Is that anxiety? Is it ADHD? Is it frustration? Is it a social skill piece? But at that point in time, he was not diagnosed. We did not know.

I know that we had some concerns and he does go to Montgomery County, which I have to say has phenomenal services for students. I just think that is one thing that maybe we need to think about as we are looking at research.

Coming back to Samantha's point and when she was talking about asking the child or the young person. For the very first time I think it was in May, my son finally said what if I ran away from home and I never came back

because I could not. We did not know what that meant so we asked him. It was the first time he talked about death. It was over Legos. You sit here and you go something that simplistic. How does he know about death? How does he know about running away? At this point in time, he was 7. We never spoke about him not being in our home or running home. You do wonder. Is that pieces he picks up at school? As we all know, they are around other children who we do not know what those conversations are about. But to know that you can be that young and be 7 years old and have the concept that you can run away to try to find safety because you cannot deal with the emotion of whatever is occurring at home or your Lego time was being cut off because it is time to go to bed. Those kinds of things.

It makes me wonder if Samantha brings up a good point of yes, we might have some IRB

challenges. But if we are speaking to the individual themselves, we may have completely different answers than what my husband and I would fill out on a questionnaire. Thank you.

DR. GORDON: Direct follow up?

DR. PENA: I am wanted to follow up on the fact that black families are disproportionately affected by wandering. I am wondering if you know of any research or even practitioners who are focusing on investigating more about that because that seems to be a big issue and yet I recall the survey had 88 percent white participants in one of the studies that was reported. How do we reach the black and African American community?

MS. MCILWAIN: That is a good point. I am looking for guidance from you. We know that the participation among the African American community is not there. For survey like IAN

and other research studies and initiatives, outreach is needed. These are the outcomes though. Media reports. We were able to go in and look at that.

It is important that we can focus some of our efforts on that type of outreach. They are not hearing from us. We need to figure out ways to reach them with this information before Thanksgiving, before Easter, before every holiday. We put out warnings. We prepare and don't scare. We put out warnings to caregivers that this is - your child. Their wandering tendencies may increase and here is what you can do. In every holiday, there is always that one kid, that one family that we missed or maybe more. We need to find ways to reach them.

If we do not have programs through law enforcement and fire fighters. Fire fighters are great. I saw lots of enthusiasm from them

when searching for our kids and helping out. If we have programs in place then we can reach more on the ground. Pediatric developmental physicians can reach more people on the ground. There is just not enough happening in the pediatric community on this issue.

Where are the ideas on what to do for that and for programs for our African American communities and other communities that may be underserved?

DR. GORDON: Larry and then Linda. That will be it. We have to give Dr. Novotny a chance to give his report.

DR. WEXLER: Dr. Lipkin, how did you identify the recipients of your survey?

DR. LIPKIN: These are families who electively on their own choose to register to participate in our network and to take calls

for research. They are all people who are consented to be invited to participate.

DR. WEXLER: I just want to reiterate something I have said here for years. That would be on the lower bound of your survey in terms of age, you are undoubtedly getting parents of kids with much more significant autism because they are identified that early typically. Your 3, 4, 5 year olds are within the school environment, preschool environment, typically identified as developmentally delayed, speech language. That is just how it is. That is how the data reads.

I think it is important when you represent - I know you are shaking your head, but I maintain the data for six million kids with disabilities in the United States. I can tell you. We track the identification ages. We have some idea of why. And parents are

specifically given the option to have their child identified as developmentally delayed when they are younger because that is how they want them identified or speech language. I think it is important when you talk about those 3, 4, 5, 6 year olds even that you might want to have a caveat that these are in fact self-identified and typically and maybe more severely involved in terms of the children that is within the typical population.

DR. LIPKIN: It is important that you bring it up. We always make a point of saying that these are self-identified families and the level of severity is spelled out in the data.

But what I will say in terms of the skew in age is we have been around for ten years at this point in time. Actually the mean age of the children registered in our survey is

about 13 to 15 right now. We are not representing a younger cohort. We are actually representing an older cohort that lines up with the history of our network.

As you know better than I, every large population based survey has specific strengths and specific weaknesses. We do not pretend to be anything in the voice of parents here. I think that is really quite critical.

DR. GORDON: Thanks. I am going to ask that Linda be very brief.

DR. BIRNBAUM: I just wanted to respond to Edlyn's question and Lori's response related to the lack of participation or the lack of numbers of the African American community. There is also a lack related to the Hispanic community in the data that we had in the Native American community.

But the only way that you are going to get those communities involved is by working with the communities. You absolutely need some kind of community-based engagement, not so much outreach, but engagement.

DR. GORDON: Thank you very much to both the presenters.

(Applause)

DR. GORDON: Now, it is my pleasure to introduce Dr. Thomas Novotny.

DR. NOVOTNY: Thanks Josh and Susan and everybody. I am very sorry that I am so late this morning, but I have been sitting out in the gate waiting to get cleared. I guess wearing a suit and having an ID does not really count. Usually it is a very smooth process and Susan takes care of all the details. Somehow, some dots did not get connected. I am very sorry to be late.

But I just wanted to give you a couple of updates and let you know that on Friday, we completed the final interagency review of our autism report to Congress on the transition of youth to adults with ASD. All I can tell you is that this has been a very thorough process of clearance. I think what we have come up with is a very well-researched exploration of all of the issues, all the equities on autism spectrum disorder in the transition phase in the government and with the input of also some of the stakeholders as well as the GAO report, which I think you are very familiar with right now.

That means that we had to send this around not just to HHS, but to the Department of Defense, Department of Labor, Department of Transportation, Social Security Administration, and everybody else. That takes times.

It looks like we will be able to get this - in this last review was minimal comments and I think we are in pretty good shape right now. I want to thank Labor and Education especially for their - and Social Security Administration for very substantive comments towards the end.

I think what we will be able to do is have a bit of public roll out for this I am assuming in a couple of weeks or so. I cannot promise you the exact time, but I am pretty sure that there are no hang ups right now. The report gets looked at one more time by the policy team, which is the political team that is in HHS just to make sure that they are all happy with it. But they have seen it a couple of times already anyway. I do not think it is a problem.

At any rate, we are expecting to do a bit of a roll out on that. We will have some

help from NIMH for printing and production. We will have we hope a journal article that comes out in accompanying this with some of the recommendations that gets made and a few other things. Not too big a deal, but at least something that makes it publicly accessible.

I just want to say that I think it has been a really useful process even though it has been almost a year overdue to Congress, but we can do with resources that we have.

It is certainly educational for all of the members of the interagency working group that were on this. I think that is one of the biggest accomplishments is that we actually have established much more communication and some of these things have benefited, I think, the IACC as well in the process. We have established a very great communication and partnership with Susan and her office and

many of the other folks that have been contributors.

That part, I think, actually answers one of the suggestions or requests from the GAO report, which is do something about collaboration and improve that and I think we have. It is something I think will continue.

And then we benefited from some recognition from Secretary Price. I put out a blog post at the beginning of autism awareness month in April and then he also put one out at the end of the month, which was good. It means he was paying attention and the policy team is paying attention as well. That is a good sign, I think.

On the second thing that the GAO recommended is that we interact and connect up with something called the Federal Partners in Transition. This was an ongoing quasi-formal interagency activity involving the

Social Security Administration, Labor, Education, and HHS to a fairly limited degree. That group deals with transition in general. That is for all youth transition to adulthood and the social services and the medical needs as well for the general population. But now, I think we have established a good rapport. We have actually participated in some of the interagency activities of that group to make sure that autism is looked at as another piece of responsibility and at least awareness.

I think that we have answered what the GAO has requested of us. I think we will hopefully continue with the interagency work that has been started. It has been, again, a great educational process for all of the members I think on the committee. I want to thank them. There are several in the room here. I just want to make sure that we

continue that - that was not the end point. That was actually the stimulant rather than end point.

I would be happy to answer any questions. I do not really want to blow the cover of all of the things that are in there yet until it is actually cleared out of the policy office.

In the October meeting, I believe, I will have a little bit more time to go through what the details were and we can discuss it in more detail then.

DR. GORDON: Are we going to be able to have the full report when it is posted to the IACC site?

DR. DANIELS: Yes, it will be posted on the IACC site so once the final production is done. And we will share the copies here at the meeting on October 24.

DR. GORDON: Are there any questions for Dr. Novotny who is the national autism coordinator and the deputy assistant secretary for health?

Thank you very much. Dr. Novotny. The reason why we interrupted the discussion, which we can now resume, is that Dr. Novotny has to leave a little bit before the break.

If there are any other questions or comments about the discussion on elopement or suicide, we can resume that. I apologize because we were in the midst of it, but I had to interrupt.

MR. ROBISON: I just would like to remind the committee that this childhood is only a quarter of the lifespan and one of the things I think we and IACC need to keep in mind is we need to keep pressing researchers to take the more difficult path and track down autistic adults. I understand autistic adults

are much harder to find than children who are in ready supply in clinics. I understand we do not have parents to bring us in, but that is most of the population. I think it is scary as what we have just heard. The true numbers of suicide are likely three, four times higher because that is the whole population. I just would like everyone to keep that in mind.

DR. GORDON: I believe, Paul, that you did have some adults in the suicide study as I recall. Can you remind us?

DR. LIPKIN: This is only what I described as dependent adults. The report is still a parent or a caregiver. We do not have a primary report from adults.

I will say that the English have been doing some research around that, but there is nothing like this in the United States yet.

DR. REICHARDT: I just wanted to say, John, and I think you know this that the SPARK study has recruited several thousand both dependent and independent adults.

DR. LIPKIN: I will just build on that. IAN is active partners with SPARK in this. Together we probably represent - IAN right now has about 2500 adults who have registered. Interestingly over the past year, we have had a lot of adults who have electively chosen to register on their own and SPARK is finding the same.

DR. TAYLOR: I think it will also be important in the US studies and I know that this is happening internationally to make sure that we are thinking about embedding suicidality and mental health questions and studies that are not necessarily about suicidality and mental health because I think we always have to worry that if we are

getting samples that are responding to surveys about that that we may be inflating the numbers, not to suggest that this is not a big problem, but I think we have to be careful about that. If parents get an invitation to respond to a survey about your child's suicidality, are all families going to respond to that or the families who may have some concerns about this? I think we do not know.

To embed these questions into larger surveys and I know that we have to think carefully about this from IRB perspectives that are not necessarily about these issues and families are not necessarily responding our adults for these issues specifically. It may give us another look. It may be more accurate or maybe not about what the scope of this problem in adults and children in the US in particular.

DR. LIPKIN: Can I make a comment on that? I agree of course. The research community - this is an area that the research community is very nervous about entering. It is easier to avoid it. It has been avoided for a long time. These are very difficult things to ask families. They are very difficult things to research. The solution has been to be avoided. There probably needs to be calls to action in a research community to look at these issues in many ways. I will say the same goes with wandering as well. This is not easy research to be done and it is easier to look at other things.

I will come back to my other point. These are life and death issues. And organizations like the National Institutes of Health, the CDC. This needs to be perceived of as critical as any other health issue.

DR. BIANCHI: Don't go away. I had a question about what is known about the biological research that has been done about the attraction to water. In the non-desert situation, which I agree with Samantha, that would be the logical thing for anybody. So many of these children are found dead in pools. What is known? If we do not know a lot, is that an opportunity to do research to address prevention?

DR. LIPKIN: I cannot answer that and I do not know if anybody at the table can. Lori may have looked into this.

MS. MCILWAIN: There is no research on that. That is the number one question we get. Why do they go to water?

Based on the cases that we see, they are trying to go to a quiet place and a comfortable place.

DR. BIANCHI: You could argue that a cave or something else would be quiet --

MS. MCILWAIN: We had cases where two went to the library outside the library. That sounds like a very safe case. It was not. They were missing for several days. Cemeteries. Garden nurseries. There were two cases for that. They are going to quiet places. I think with our younger kids, again, those cases tend to skew younger. The drowning cases. They go straight to water to find that comfort a lot of times. For a lot of them, that is their special topic too was water.

MS. CRANE: I was going to ask about the suicide survey. What I do not understand is we have suicidality surveys of the general population. There is a robust effort to screen a general population for suicidality. We have that data up on the NIMH website. The

CDC tracks it. Is there an extra hurdle that is preventing us from tracking this in the autistic population?

One of the things that I am concerned about is I have heard from some researchers who are telling me that when they look for IRB approval, they are being told by the IRB that autistic adults cannot consent to this kind of study even though non-autistic adults can. That is alarming. It interferes with our ability to do research. I am wondering if that is one of the reasons or if there is some other reason why it is extra hard to survey autistic people on suicidality.

DR. LIPKIN: I think in terms of why this is getting attention in the general population, but not in autism. I think there has been a lack of awareness on this issue just like there was with wandering and

elopement. What we are hoping to do is to bring further awareness to this.

Are there problems in researching this in adults? I would maintain that there might be some obstacles, but they are readily crossed. I think the obstacles at this point just have to do with limitations and the limited funding for such research and the limited number of researchers in the field. I think if we bring greater awareness to it and perhaps support around doing such research, we can get there.

DR. GORDON: I would just point out that the CDC tracking of suicides in the general population is made off of death certificates, which obviously for many reasons would not normally have a diagnosis of autism on there. The comorbidity with autism is not going to come easily from that. You are going to need more in-depth stuff.

MS. CRANE: I thought there was tracking of attempts as well.

DR. GORDON: That I am not sure about. You might be right. But even then the attempts are going to come from emergency wards, et cetera, and not from in-depth surveys that would reveal diagnoses like autism.

We are going to go ahead then and take a break as scheduled. We will resume here at 11 o'clock for committee business.

(Whereupon, the Committee members took a brief break starting at 10:47 a.m. and reconvened at 11:02 a.m.)

DR. GORDON: If everyone can take their seats, we can get started. We are just about ready. As I mentioned, we are going to resume the meeting with committee business. I am going to turn it over to Susan Daniels.

DR. DANIELS: Thank you. I have some updates to share with you and then we will dive right into business. Just acknowledging the OARC staff in the work that they have done.

First up is we wanted to introduce the OARC newsletter. I think that most members of the committee should have received this if you are on our mailing list. But this is a new effort from the office to try to keep people informed of the work of the IACC and partner organizations for us to be able to share updates on new publications. We hope in the future we will be doing some exclusive new features such as videos and interviews with people from the community. We are trying to keep it brief, but hopefully filled with information that is useful and interesting to the community. We welcome your feedback. Hope that you enjoy the newsletter and let us know

if you have any suggestions or if you want to have something that you are doing be featured in it.

Next, I just wanted to share with you that we have an upcoming event in the fall. We are going to have a seminar on autism in girls and women. This is going to be a joint seminar sponsored by our office, the OARC, and the NIMH Office of Research on Disparities and Global Mental Health.

The tentative date that we have set is September 19. It is going to be in the NIMH Neuroscience Center in Rockville.

The panel for this seminar will be Dr. Kevin Pelphrey, who is a member of our committee, Dr. Pam Ventola from Yale, and Ms. Zoe Gross, who is from the Autistic Self Advocacy Network, talking about different aspects of this issue. It should be really interesting. We are going to have it as a

live seminar where people can come in and see us as well as on the webcast. Be looking out for that. We will feature it in our email updates in the future and it will be on the website.

This is committee business. I just wanted to give you an update on what is happening with portfolio analysis in our office. Our office is in the process of preparing the 2014 and 2015 IACC ASD Research Portfolio Analysis Report. I have already been publicly sharing the data from the report, but we are going to have the final report hopefully in your hands at the October meeting.

We are in the process of preparing the data call for the 2016 data set, which will use the new objectives from this new strategic plan.

I have a request for you. I would like to have three to four IACC members who would be willing to serve as volunteer consultants for our team in terms of issues that we may have trying to determine if we should be adding new funders to the portfolio analysis or if we have any other questions we are trying to set definitions or anything like that. We wanted to have a little bit of help from members of the committee. Give that some thought. If you are willing to be a volunteer, it would not be taking up too much of your time, but it would be good to have some people who are willing to give us some advice in those areas.

Then we are going to be moving right into the strategic plan. This is just the background, which you all know about the strategic plan. That the new plan is covering both services and research issues. And the

working groups have been working over the last several months to prepare the drafts. You saw them first in April and now they have been edited. This is just the list of some of the steps we have gone through.

At this point, the OARC staff has edited the seven chapters and prepared all the other sections of the strategic plan. Today's goal is for the IACC to review and hopefully approve the 2016-2017 IACC strategic plan, but we will want to hear your comments and thoughts about anything else that might have been omitted or needs correction where we would be able to approve.

There are 13 sections to the new strategic plan, including an introduction, a statement on the vision, mission, and core values, an overview of ASD research funding progress that is based on the portfolio analysis work of the OARC for the IACC, and

then chapters for questions one through seven, talking about the different areas that the strategic plan covers, a section on duplication of effort, which was approved back in January, but we have provided here again for your consideration and is required as a part of the Autism CARES Act to be a part of the strategic plan, and a budget recommendation. There was a working group that looked at the budget recommendation. We will be presenting that information to you here so that you can, as a committee, make a decision about how you would like to do that budget recommendation and then the conclusion section.

We are going to try to go through all of these. I know that you have the documents in front of you and hopefully many of you have had at least a chance to skim through if not

fully read the chapters that you have received and we will take your comments.

I am going to start with the introduction and ask if anyone has any comments about anything that you think needs to be added to it or any other types of comments.

DR. REICHARDT: I just wanted to say that I read the introduction. I thought it was quite good.

DR. DANIELS: I should have acknowledged that John did the first draft and then the OARC has worked on it as well. We have put together a collaborate effort on the introduction.

MR. ROBISON: I was just going to say, Susan, I think that you did a really good job of weaving a lot of maybe disjointed ideas that I sent you folks into a coherent whole here. My comments on it really are limited to

just to details of it that I will email you.
I am pretty happy with what you all achieved.

DR. DANIELS: Thank you. You are welcome to send small edits and those kinds of things after the meeting. We would like to receive everything by August 4. That is for the entire strategic plan.

MR. ROBISON: I do not think I have anything that needs to be actually discussed here. Just little stuff.

DR. DANIELS: Great. It looks like there are no more comments on the introduction. Let's move forward to the vision, mission, and core value statement. The OARC went back through the previous vision, mission, and core value statement. We took comments the last time and tried to incorporate them. The vision statement and the mission statement are on this slide. Does anyone have any comments on it? We tried to incorporate a

couple of ideas that came through in the new plan to give it a little bit of a refresh. But there is anything there that needs to be updated?

DR. BIANCHI: The use of the term consumer. Is that required? To me, that sounds odd. In consumer, you are either a person with autism and part of the community.

DR. DANIELS: We could change that wording. That is from the original group that put together the first strategic plan. They always talked about consumer-based questions. We could absolutely change that if the committee likes that. I think they did not want to use the word patient because they did not - not everyone with autism or a family member would consider themselves a patient. Community member or community focus would be fine. What do other people think about that?

MS. CRANE: I do not want to say community in a way that omits the requirement that we focus on the actual autistic individual as well because that happens in the autistic community. There are autistic individuals and there are family members. I think both are important, but I think we need to call out both specifically.

DR. BIANCHI: How about if we say individual and family focused. It is just that consumer to me means that you are buying something.

MS. CRANE: It is a very common - we are using the mental health consumer community. That is probably where it came from.

DR. DANIELS: I think that they were at the time thinking about making sure that the plan is going to help bring value to people. I think maybe that is where they came up with the word consumer. I think individual and

family member would be fine. Is that agreeable to people at the table?

DR. GORDON: Please speak up if it is not. There is a reason the word was there. I do not want to exclude any contrary opinions.

MR. ROBISON: A couple of small points on this. In the spirit of collaboration, I think it has been a sore point with autistic people. I think we should specify that we will treat autistic people, we will listen to autistic views. I do think that you are right though in what you have written that we want to listen to diverse views from all people. But somehow, I think we should weave in there specifically autistic views without eliminating the others.

Another small change that I would suggest is that in the sense of urgency, this of course is what I have pushed for all along. We will focus on what steps we can

take to rapidly and efficiently address the needs of people living with ASD. But Louis has always thoughtfully reminded me of the need to not lose sight of the long-term game. That we still need basic scientific research. I think that deserves a sentence in urgency too even though I thank you for putting our community needs first.

In the ethics or equity portion, I just would say that you had quality of life and human rights and so forth. I would just put quality of life as the first thing, not the third thing.

DR. GORDON: I want to make sure we get all those things, but I also want to make sure we come back to this consumer focus. Because the idea is that we want to have the language approved by this committee especially for this that we get these details right. There was a proposal to change

consumer to community and then if you will a counter proposal to change consumer to individual and family focus. Let's do that first and then we will go to the other issues that John raised.

Are there any thoughts about those two possible substitutions for the word consumer?

DR. BIRNBAUM: I do not think we want to lose the word community. I would think we might want to say individual family and community.

DR. GORDON: Samantha, I believe you brought up that you wanted to maintain the focus on the individual. Is it enough if it would say community focus that the rest of that description says we will focus and make a difference in the lives of people affected by ASD or do you need it in the - let's get it up there.

Consumer focus. The idea would be community focus. We will focus on making a difference in the lives of people affected by ASD.

MS. CRANE: Can you tell me which paragraph it is in?

DR. GORDON: It is the top paragraph, the very top paragraph.

MS. CRANE: I think that is fine.

DR. GORDON: Are there any objections to that? We will have community focus. Later on, we will have a formal motion to approve the whole document. That is why I want to make sure we get the words right for this part especially.

The second part of that - Susan, the spirit of collaboration. What was John's point there?

DR. DANIELS: Just incorporating something about the importance of listening

to the views of autistic people and making that a priority.

DR. GORDON: Does anyone have proposed wording for that? This is the final paragraph there, spirit of collaboration.

DR. BIANCHI: How about if we have we will treat individuals with autism and others with respect, listen to diverse views with open minds?

DR. DANIELS: I think when John spoke about it, you were talking about listening to the actual views from people with autism. You could say listen to views from people on the autism spectrum as well as the - something along those lines.

DR. GORDON: The third clause "thoughtfully consider public input" covers everyone else. If we have listen to views of individuals with autism with open minds and

thoughtfully consider public input, is that inclusive enough?

DR. DANIELS: Would you need to add family members as well?

MR. ROBISON: Individuals with autism and their families. That is fair.

DR. GORDON: Listen to individuals with autism and their families with open minds, thoughtfully consider public input. That gets everybody else. Any objections to that language?

The next issue that John raised, Susan.

DR. DANIELS: In the sense of urgency, he mentioned adding something about the science to the urgency. Although in the excellence section, we do have some wording about ensuring that we pursue scientific research with the highest quality.

MR. ROBISON: Then maybe to address that, we could just say we will focus on responding

rapidly and efficiently to the needs and challenges of the community. Just shorten that first sentence and then if we move right into excellence, maybe then we cover the long-term aim in the excellence paragraph.

DR. GORDON: The proposal is we will focus - for everyone, this is the top paragraph on the slide. Sense of urgency. We will focus on responding rapidly and efficiently to the needs and challenges of the community affected by ASD.

MR. ROBISON: Needs and challenges of autistic individuals and their families. We will focus on responding rapidly and efficiently to the needs and challenges of autistic individuals and their families.

DR. GORDON: I do not have an objection to that, but I want to make sure that we recognize that we are changing the language to be autistic individuals instead of

individuals with ASD. I want to make sure that no one thinks that excludes anyone.

MR. ROBISON: I just hate the idea of being disordered, Josh. I just do not like it.

DR. GORDON: I respect that. I just want to make sure that there are not contrary opinions in the group.

DR. DANIELS: Commonly in the strategic plan, we refer to people as people on the autism spectrum. That has been a fairly acceptable term. We could use that unless you prefer autistic individuals.

DR. GORDON: Then it would be and challenges of people on the autism spectrum and their families.

MR. ROBISON: It is okay by me. What do you think, Sam?

MS. CRANE: People on the autism spectrum and their families are fine.

DR. GORDON: I am going to repeat now. Again, we are talking about the top paragraph. Sense of urgency. I believe I will get this right. We will see. We will focus on responding rapidly and efficiently to the needs and challenges of people on the autism spectrum and their families. That allows a more quick and ready access to the next paragraph that points to science. Any objections to that language?

Were there other issues that John raised? Are there any other issues with regard to the core values and mission?

DR. KAVANAUGH: Could you just read back the spirit of collaboration one more time? We will treat others with respect, listen to diverse views from individuals with autism and their families -

DR. GORDON: I believe it was just listen to the views. I want to make sure we get it right.

DR. DANIELS: Listen to the views of individuals on the autism spectrum and their families with open minds, thoughtfully consider public input, and foster discussions where participants can comfortably offer opposing opinions.

DR. KAVANAUGH: Is there any issue with just leaving diverse views --

DR. GORDON: We can do that.

DR. DANIELS: Would you prefer to stay with diverse views or the views of people on the autism spectrum and their families?

DR. GORDON: Spirit of collaboration. We will treat others with respect, listen to diverse views of people on the autism spectrum and their families with open minds. Actually, we should move that "with open

minds" to listen with open minds to the diverse views; otherwise, we are now separating it out. I do not know. There is some grammatical thing wrong there.

I am going to repeat it so we make sure our note takers get it right. Spirit of collaboration. We will treat others with respect, listen with open minds to the diverse views of people on the autism spectrum and their families, thoughtfully consider public input, and foster discussions where participants can comfortably offer opposing opinions.

DR. FARCHIONE: I just have a question about that because one of the things that we do here is we listen to folks who are doing research - stuff like that. It strikes me that if we - on the one hand, we are saying individuals with autism and their families and all that. By doing that, it takes out

that academic piece that we also do. I feel like just saying diverse views is sort of all-encompassing and maybe does not need to be qualified. I do not know.

DR. GORDON: The feeling was that we wanted to ensure that this paragraph included specifically listening to individuals with autism and their families and that the public input would encompass all other input. But you are suggesting perhaps that we might need to remind that this input would include that from scientists or are there other constituencies as well that might not be covered by public input?

DR. FARCHIONE: I guess it is more just -
- I feel like the sentence gets really clunky with adding all that extra verbiage. I just do not know that it is necessary if the phrase diverse views are encompassing enough. If the folks who are on the spectrum feel

like it is not encompassing enough then that is problematic. It feels clunky.

DR. DANIELS: I have a proposal here. We could say we will treat others with respect, listen to diverse views with open minds, thoughtfully consider - something about the views of people on the autism spectrum and their families and the general community or something that combines all three of those and foster discussion. We would put all of those in another clause, but we would diverse views that would capture everything and say that we are going to thoughtfully consider the views of all these particular people.

DR. GORDON: Are there thoughts from - I cannot remember if it was John or Samantha who suggested the original insertion. It can be challenging to do this without it written up on the board. Do we have something we can

write on or can we change the language on the slide?

DR. DANIELS: The slides are PDFs. They cannot be changed.

DR. GORDON: Let me try to repeat it. Samantha and John, let me know if you are having trouble following it. Spirit of collaboration. We will treat others with respect, listen to diverse views with open minds, thoughtfully consider input from people on the autism spectrum and their families as well as the general community and foster discussions where participants can comfortably offer opposing opinions.

I think what you lose in there is the notion that you are trying to include diverse views and perspectives of the individuals with autism and what they bring to the table. I think that is what the comments were before.

As a scientist, I am happy being considered part of the public, but I do not mean to push the issue that way if there are other ways.

DR. FARCHIONE: I understand that point. Obviously, we need to consider a diverse range of use from folks on the spectrum because that is a diverse population. It just probably needs some wordsmithing that I do not know that we would be able to accomplish in here.

MR. ROBISON: Is what we have settled on then we will focus on responding rapidly and efficiently to the needs and challenges of individuals on the autism spectrum and their families?

DR. GORDON: That is correct.

MR. ROBISON: Is that what we agree upon then?

DR. GORDON: Yes. For the sense of urgency, I think that was fine.

DR. BIRNBAUM: I do not want to forget community. Autism and members on --

DR. GORDON: Community is another aspect of the mission. The next slide has --

DR. BIRNBAUM: Community is important all the time. Community is an inclusive word. It includes individuals. It includes families.

MS. CRANE: We mentioned individuals and -- we are saying individuals and families in there.

DR. BIRNBAUM: But we are not saying community.

MR. ROBISON: Autistic individuals and families.

DR. BIRNBAUM: I guess, John, I might say that we have communities of people who are important to be involved, to care as well as the autistic individuals and their families.

We are never going to be where we want to be if you do not involve the community.

MR. ROBISON: I think the community is an - part of this thing - has been marginalized all our lives. It is the autistic people.

DR. GORDON: I think that the community is included. Maybe we have to make sure it is in the spirit of collaboration. The focus is now actually community focus. I think that we handle well enough. That should cover it.

Let's move back though to this issue that we still have not resolved, which is the spirit of collaboration. It may be tricky, but again this is the upfront language. I would be much more comfortable having this committee approve a final version today than having to edit it. We really want to get this approved today.

I am going to try and read it. Spirit of collaboration. We will treat others with

respect, listen to the diverse views of people on the autism spectrum and their families, thoughtfully consider - why don't we say thoughtfully consider community input and that, I think, would include the scientists, but maybe not - community input and foster discussions where participants can comfortably offer opposing opinions.

I am going to repeat that because it was a little stilted. We will treat others with respect, listen to the diverse views of people on the autism spectrum and their families, thoughtfully consider community input, and foster discussions where participants can comfortably offer opposing opinions.

I will repeat it. Spirit of collaboration. We will treat others with respect, listen to the diverse views of people on the autism spectrum and their

families, thoughtfully consider public input, and foster discussions where participants can comfortably offer opposing opinions.

DR. TAYLOR: Is it helpful? Do we need to have listening to and thoughtfully considering as separate? Can we simplify it down and say thoughtfully consider the diverse views of people on the autism spectrum, their families, and the community? Do we lose something when we do that?

DR. GORDON: I think we do. Again, I am coming back to the point that was raised by Samantha. If not, it was John. Maybe both of you raised it. We want to include the notion that there are multiple perspectives coming from the lived experience of being on the spectrum and also the lived experience of being a family member. That is separate and distinct from community input.

MR. ROBISON: I like the way you read it, Josh.

DR. GORDON: We will go with that language. Any other comments on any of the other points?

DR. DANIELS: Next, we are going to move to the section of the overview of ASD research funding progress. This was a section prepared by the OARC based on the portfolio data that was discussed with the committee and the working groups.

Do you have any comments on this section? It was basically a summary of what we have learned from the portfolio where we still see gaps where some of the gaps have been filled under the last strategic plan?

DR. AMARAL: First, I did try and read most of these sections. I just want to congratulate you and thank you and OARC for doing really a good job.

DR. GORDON: I want to make sure the public could hear that. You are not quite speaking into the mike. It is on, but you are not speaking into it.

DR. AMARAL: OARC did a great job, very clearly. I did send you some minor edits. You can incorporate those later. But I did think that at the end of this section, there needs to be a point made that increased funding in the gap areas should not come at the cost of reducing funding for the areas that have already made progress because there are very few questions in autism where we know absolutely the answer. It's not a zero sum game I guess. I do not have the exact text, but something to that - should go in there.

DR. DANIELS: I think we can do that. We do have the budget section as well where we could reiterate that same point, which I will be going over with you in a little while.

Any other comments here before we move on to the next section?

DR. GORDON: Let me just ask the committee if they are comfortable with the notion that we would draft language. I want to be specific about changes like this. We will draft a sentence or two to that effect and that will be part of the approved document that we are going to vote on later. Any discomfort with that?

DR. DANIELS: That was the plan if we were going to wordsmith the entire document. I do not think we will be done today. Then we will be re-meeting in October to talk about this again. Hopefully on things like the mission and vision, they are very specific language. But hopefully, we can take suggestions from you and if there are omissions or gaps here and there that we

could fill them in and be able to still generally approve the document today.

Let's move on to Question 1, which is on screening and diagnosis. The new question is how can I recognize the signs of ASD, and why is early detection so important. I have on the slides the revised objectives. They have been streamlined to be in a consistent format and also to try to take care of any redundancies between objectives to make them all distinct. Do you have any comments on the objectives themselves or any part of the text there? Anything that was missing? Things that need to be corrected or any other kinds of comments on this chapter?

DR. KAVANAUGH: Susan, I had two minor changes that I will just email to you where HRSA was also involved in some activities that are outlined --

DR. DANIELS: Great. That sounds fine. Do you want me to actually read you the objectives and go through them one by one or are you fine with just looking at them on the slides?

Any other comments about Question 1?

DR. MANDELL: I was wondering if someone who was involved in writing it could help me understand how the second bullet under Objective 1 fits there.

DR. DANIELS: That was a part of what the working group put together. They were thinking about disparities issues in ensuring that there is evidence that these interventions work in diverse populations. That is one of the parts of the USPSTF recommendation.

DR. MANDELL: That is fine. This is sort of a value statement, but it does not tell me what to do. I wonder if similar to the way

that the bullets under the other objectives tell me what I am supposed to do as a researcher or a policymaker. It could be reframed.

DR. DANIELS: Do you have a suggestion about that? Does anyone here have a suggestion on how that can be done?

DR. KOROSHETZ: I thought from the wording that it was research needed to develop early detection methods validated in these populations, girls and intellectually delayed individuals.

DR. MANDELL: That would be a reasonable thing to say, but I am not sure how that strengthens the evidence base for the benefits of early detection. It sounds like a disparities issue.

DR. DANIELS: Some of the other objectives and then there is a new objective I am going to be introducing to you about

girls. We do have other disparities issues in some of the other objectives as in your chapter, Question 5.

DR. MANDELL: I may be over thinking this. Feel free to tell me to shut up. I want this to get the attention that it deserves. If we think that girls are not detected as early as they should be or that people with intellectual disabilities are not detected as early as they should be because we do not have the right tools or because the workforce is not as attuned to their needs or because there is some statistical discrimination that goes on that is institutionalized in our health care system, I would want to call that out in the right place. This just does not seem to call that out.

DR. DANIELS: We have the chairs of the working group here in the room. I do not know if they might want to make some comments on

that or if they have suggestions on how it could be modified. We have Ann Wagner and Alice Kau back here. Do you want to make any comments?

DR. WAGNER: I do not know if I can add to what the intent is. The intent is exactly what you are saying. I think if there are suggestions for how to word that differently, that would be great.

DR. PELPHREY: David, your point is partially the wording that mostly the location. It does not actually strengthen the evidence base, the benefits of early detection even if we ran 10,000 studies.

DR. WAGNER: Is it a matter of researching whether the screening - whether the methods we have for early detection work equally in all these populations? Is that the question?

DR. MANDELL: That is a great question. It would just mean that it would go under reducing disparities in early detection.

DR. GORDON: I disagree because it is not -- reducing disparities mean you have disparities that you need to reduce. What we do not know is whether we have disparities to reduce or not although maybe we do know it. I apologize if we know it, but maybe that is why it is in Objective 1.

DR. MANDELL: If that is the case then it would be to ensure that the benefit of universal screening is equal among subgroups with perhaps particular attention to girls and people with intellectual disability. But the way this is written is to improve early detection and that there are these two groups where detection is not as good as it should be.

DR. PELPHREY: You want the disparities issue or I think we want the disparities issue to be highlighted elsewhere, but there is a scientific question here that we do not want to be lost, maybe two of them. One is we need tools for early detection of ASD in girls that do a better job because many of us believe that we are missing a population. We want research directed at that.

And then we also want to test the question of whether there are differences in outcomes as a result of that early detection, which interfaces with the idea of with early detection comes early intervention which reflects back into the basic underlying biology. Are there different sensitive periods in boys and girls that might offer better or worse opportunities for intervention? There are three or four interrelated scientific questions.

DR. MANDELL: All those are awesome questions. When we think about at the end of the year as we are looking at what was funded and the extent to which it fit with the objectives. I think we should be calling out things that - with that in mind. What is the goal? How are we meeting that goal? Those are all three great questions. You just articulated how this could fit in Objective 1, 2 or 3. I think we just figure out where it belongs.

DR. WAGNER: I think that for this one I think the intent was for the second bullet to be a follow on to the first one, which is asking for developing methods. I thought that the second bullet was just meant to say in doing that, we want to make sure we are taking into account the differences in these special populations such as girls.

DR. MANDELL: That is great, but Objective 1 is not about improving early detection. Objective 1 is in direct response, I think, to the preventive task for saying we have to show that there is a real benefit to early detection to early detection leading to treatment, leading to improved outcomes. Are we saying in the second bullet that we need make sure that that pathway is clear for a lot of different groups, especially girls and people with intellectual --

DR. WAGNER: The taskforce specifically talks about disparities.

DR. GORDON: I think if we just put these designs must pay attention to special autism populations such as girls and intellectually delayed individuals, would that be good?

DR. MANDELL: If that is the intent then that makes perfect sense.

DR. WAGNER: I think that is the intent. There is a big working group. If somebody remembers it differently, please speak up. But I think that was the intent for this. But if you are raising something that is missing from the whole thing then that would be good to hear.

DR. DANIELS: With that type of a language change, do you think that would solve that issue? You have not seen all the rest of the objectives as yet either. There are places where disparities and girls are prominent in other objectives as well.

MS. CRANE: Can I just interject and get to a more simple thing? I am not sure why we are saying intellectually delayed individuals. I think probably the more accepted language is individuals with intellectual disability. Is there a strong feeling in favor of intellectually delayed?

DR. DANIELS: That is fine. That is actually the language we use throughout the rest of the plan. It is individuals with intellectual disabilities.

MS. CRANE: I get very distracted by that. It is hard to talk about the rest of it because it is leaping out at me.

DR. REICHARDT: I just wanted to say that I have some concerns about the way this is going. I think you guys generally did an excellent job in editing. But I think that either there should be another set of conference calls with the committee members and perhaps both of these, a subgroup, perhaps the chairs of the committees just discuss this because I have equal discontent with many of the other sections. I can see the way the clock is running. I am just not sure it is as close you think. I think it

might benefit from another round of discussion.

DR. GORDON: Can you be more explicit? I am not exactly sure -- I want to know more about why you feel it is not ready.

DR. REICHARDT: It is an excellent review, for example, but there are issues that I think are quite important that are not brought out, not specific to this section. I thought the section differences discussion was quite inadequate frankly in terms of what we know about various possible mechanisms.

I think there are issues like the ups and downs of various animal models, which are simply not discussed.

There are a number of issues about the importance of various genetic efforts, for example, GWAS, whole-genome sequencing versus exome where the big bucks are and where the

opportunities are. I did not see that in the sections that I read.

I think the text reads terrifically I should say. I think, Susan, you and your colleagues have done a great job in cleaning up our poor use of English and grammar and so on. I think at the end of it, it would still - after you did this, there was no effort to go back to the committees and I do not mean that as a criticism. That is really on Walter's and my responsibility, not yours, but I suspect that is true of everything.

I also thought that - my personal opinion is some small subgroup should probably just be charged with taking a look at the whole thing because we all know that the larger the number of people that are involved, the less responsibility each member of that committee feels. That is actually the reality of life, which is why people say you

do not want advisory boards that are more than five or ten. We clearly are a much larger board. I am not advocating that this committee as a whole not finally have the opportunity to review or accept things, but I think there are some procedures that might make this a better document.

DR. DANIELS: Under FACA rules, of course, the entire committee must be involved in the approval. I have put out a time for comments until August 4, which I do not know if you would want to extend that more. We could take more extensive written comments, do another revision, and then send it back out to the committee to review again or to have just the chairs look at it again and then bring it back for October or we could try to approve on the phone. We could do that, but we would have to have a quorum of

the committee on the phone ready to do that work.

DR. REICHARDT: Personally, I would be more comfortable with October. I think what I would personally urge is a two-step process where you have another set of conference calls that you had with each of the committees on the questions because I think very few of the members on the committee have taken a seriously look at this after you guys cleaned it up and then perhaps some subgroup, but then with final approval in October.

DR. DANIELS: This has not gone back out to working groups. The working groups were originally set to be completed and done with their part of the process and it was going to be in the committee's hand from here forward. But if we need to, we could reconvene the working groups.

I feel though that among the committee members, you probably have the resources within the committee to complete this without going through a whole new set of committee working group calls.

MR. ROBISON: I think even recognizing valid concerns of Louis and the others, I just think that you guys have done a good job pulling this together. We already six months late. We have faced delays from the election and changes in the committee and all these things. My vote is to just get it done. Let's do it with what you have here and now.

DR. DANIELS: This document is setting priorities research and services that are important. Until they are done, they really cannot be advising anyone. That is part of the urgency. I would have liked to have sent back the revised version for people to review at more length. But given the urgency of

trying to get the document done, we were not able to do that. But I am happy to add more procedures if you like.

MR. ROBISON: Just remember folks, it is only a few more months and we are going to be doing this again.

DR. GORDON: I would suggest that we continue with the review of the chapter by chapter efficiently. And then we consider the question of whether to accept this document despite any deficiencies that Louis or others might recognize with it. We will take a vote of the committee at that point as to whether we need to revise it more significantly and approve in October or do so now.

DR. DANIELS: It sounds good. Question 1, were there any other substantive comments on the content, major areas that have been missed, or anything that was controversial? I am not seeing anything around the table. It

looks like really it was just that second bullet of Objective 1, which we could continue work on a little bit.

Then I am going to move to Question 2, which is about the underlying biology of ASD. In this question, we have three objectives. I would like to also share with you something that OARC put together. We proposed a cross-cutting objective that does not necessarily - it could sit in Question 2, but pay attention to the word cross cutting. We noticed that as we read the entire strategic plan from cover to cover that the committee and the working groups had highly prioritized research on women and girls throughout the strategic plan, but there was no single objective that called this out. And the objectives are what is used by the agencies to help with their priorities. We wanted to propose to you potentially putting the ideas of the full

committee together in an objective that would focus on these issues.

We put together some language here that you can review, but it would be to support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls and women on the spectrum, and develop strategies for meeting the needs of this population with a few bullets. But we thought that captured much of what was said throughout the strategic plan.

The idea here would be why we have called it cross cutting is that we could still code individual projects that were on these diverse topics to their question in the portfolio analysis. It would not be that all the dollars would be counted under Question 2. They would be counted where they should be

counted, but we wanted to coalesce the idea of doing research on girls, research and improving services for girls and women into one place. I wanted to see what the committee thought about that.

DR. REICHARDT: I am very supportive of that concept.

DR. MANDELL: I like it too.

DR. TAYLOR: I do too. Why is it under Question 2 and not --

DR. DANIELS: We could put it anywhere. It really does not have to sit anywhere. I just arbitrarily put it at the end of Question 2. It could be at the beginning. I did not want it to fall off the end and not be seen by anyone. I thought throwing it in the middle might be a good thing. We could put it at the end of Question 1. It has a component of each of these questions in it.

If you have a better suggestion, I am open to that. I just did not want it to get lost.

DR. PELPHREY: Obviously, I love it. I would suggest just in terms of serial position. The beginning and the end would be great, but certainly the beginning probably so it is clear to the reader that it belongs in each of the areas.

DR. GORDON: Separately before Chapter 1 -- before Question 1. Before Question 1.

DR. DANIELS: We will figure something out in terms of how to do that. It sounds like we have some support for adding this cross-cutting objective. I just wanted to point that out so that we will be focusing research in that area to that objective. And the other objectives here again have been revised just to make the language a little bit more standardized, trying to show action like what is needed in each of these areas.

Were there any comments on the content of Question 2? Any areas that you felt had been missed or needed more explanation?

DR. KOROSHETZ: -- most of the edits you guys did were taking things out. We analyzed pretty carefully. MEGHAN did. I guess we were kind of comfortable that the stuff that was taken out was referenced in the shorter form. If you have objections to taking things out, the question to you is do you take things out because of space. Is that the issue?

DR. DANIELS: We were trying to get each of the questions to be sort of uniform length. We did not want one question that is three times as long as another question. There was some of that and plus readers just have a hard time the longer it gets. We tried to move anything that could be put into a reference rather than having to be explained in very great detail. Also, just being lay

friendly and not getting into too much extreme detail about molecular function and so forth.

DR. KOROSHETZ: Of the things that you feel were taking out that you could argue to put back in --

DR. DANIELS: If there are certain things that you think because of the edits have been missed in some way, you could send us some comments.

DR. KOROSHETZ: -- some things that are incredibly diminished.

DR. REICHARDT: I read the new document, but I did not compare it to the old. I probably should not say anything at this point.

DR. GORDON: Just to reiterate three areas, I think two of them pertain to Chapter 2 and the third to - Question 2 and Question 3. Sex differences may hit on this.

DR. REICHARDT: Sex differences - I think there is a chance to work on. I should say there are certain issues, which were not really discussed. You point out that it is very unclear which animal models are appropriate - this is a big - I consider this a very big issue. I consider what types of risk analyses should be done particularly with regard to genetics where I think the questions are pretty clear. It is a very significant issue where the biggest bang for the bucks is. We are charged with spending money efficiently. And the sex differences, as I said, I think those are the three things that I was just not happy with as I read through. It did not seem to me that is reflected a current knowledge of the bases of sex differences --

DR. GORDON: To bring up the point that Walter was making, were those sections that were taken out --

DR. DANIELS: No entire sections were taken out. It is just that the language was edited down. If there is a point that you think was really important that got edited out, you could send us a comment and let us know to try to put it back in.

DR. REICHARDT: With the exception of the sex differences, which I think --

DR. DANIELS: Did you read the question through sex differences information? There was a comment you made at the last meeting that we did not actually understand. Maybe you could follow up.

DR. AMARAL: I just wanted to say that some of this is covered in Section 3. I think risk assessment is in there.

I thought the animal models actually in Section 2 were actually quite good. It laid out the ambiguity of certain animals not being appropriate for some studies, but highlighting potentially. As a forward-looking document, the potential of using non-human primates, for example. That is still in there. I thought that was actually very good.

DR. REICHARDT: Maybe I am too much in the weeds, but I thought, for example, the challenges of adequate numbers with primates - there are issues like this. The challenges of level of development and reproducibility. Many brands or IPS - these were certain - one should be clear about what limitations are major caveats to approaches as well as - otherwise, we are just not being critical. Anyway, that is a personal -

DR. KOROSHETZ: Maybe you and I can just sit down at lunch and try and go through it.

DR. DANIELS: You can always send things to us after the meeting.

DR. BIANCHI: I just wanted to raise a point about Objective 3 under Question 2, which says support the creation of large cohorts, characterized both phenotypically and genetically with complete health records from early embryogenesis through adulthood. Your records when you were an embryo are in your mother's health record.

First of all, you probably want some pre-conceptual genetic screening as well, but I can envision within the next five years that there will be specific genes identified that may come as part of a pre-conceptual genetic screen that the mother and the father get and it might be interesting to know particularly variance.

But we somehow have to get at the issue that you want the complete health records of

the pregnancy as well as the individual. You want the mother's records.

DR. GORDON: It does not specify. It just says complete health records. It does not say who.

DR. BIANCHI: Yes, but I think you are talking about an individual. I do not know. To me, it seems imprecise, but that is the world I live in. The mother and the child.

DR. DANIELS: If we added something that said something about including pre-conceptual genetic screening data or something like that.

DR. BIANCHI: -- conceptual screening data as well as prenatal records or something like that.

MS. CRANE: I am sorry. This is Sam. I am kind of alarmed by the prospect of pre-conceptual screening data. I think that a lot of people on the autism spectrum are a little

alarmed by that too. I do not oppose genetic research, but I think that people are going to read that as a gesture towards trying to move towards universal pre-conceptual screening for autism and that is going to be politically charged. If we could avoid making that implication somehow that would be helpful.

DR. BIRNBAUM: I think the science is beginning to move that fathers matter. We are spending a lot of time focusing on what happens before birth, for example, in utero where you focus both on the mother and on the developing embryo fetus, but in fact there is more and more data showing that both for the mother and the father that it is not only their genetics. It is also their environmental exposures and defined broadly, may make a big difference. That is true for everything.

DR. GORDON: I would argue though in support of the notion that the language read by the community writ large matters. Again, I will point to complete health records. Complete health records to me mean all of that. It means the age of the father. This is an objective to support research. It is not described in the details of that research, which could be defined by the research funders. The point that Samantha is raising is putting that language into here unnecessarily raises issues and that just complete health records or maybe with some minor things added defines what we are talking about.

DR. BIANCHI: I appreciate your sensitivity. What I am just trying to get at is the capacity to be able to collect information if it is available. Maybe we could revise this to phenotypically and

genetically with complete health records from pre-conception through adulthood. Pre-conception means everything, whether you took prenatal vitamins before you got pregnant, not saying pre-conceptual genetic screening. To me, what I reacted to was early embryogenesis. Who has the records on early embryogenesis? If we just say complete health records from pre-conception through adulthood, that would be my proposal.

MS. CRANE: I would like to finesse that a little bit still. Maybe even just saying health records of the child and parents might help. When we say pre-conception, I know that a lot of people in the autism community when they are hear that, they are going to think it has started. They are going to try and prevent us - this is a eugenic campaign. I know our community and I know that that is going to happen.

DR. KOROSHETZ: (inaudible comments)

MS. CRANE: We could talk about parental health. That could be a way of mentioning things that are - parental health is relevant. It will not necessarily be read in the same way.

DR. KOROSHETZ: -- phenotypically and genetically complete health records of parents and the child from early embryogenesis through adulthood.

DR. BIANCHI: The embryo is in the mother's record. It is confusing. We do not really know a lot about the embryo unless you have pre-implantation genetic testing. You might know about the fetus through ultrasound.

I think it is cleaner the way Samantha suggested that. Complete health records from the child and his or her parents. That is what you want.

DR. GORDON: Strike the time period.
Complete health records from the child and
parents.

DR. KOROSHETZ: -- the medical record is
not the most important part - the most
important part was longitudinal
phenotypic/genotypic studies.

DR. BIANCHI: Right. You want to capture
the pregnancy. You also want to capture the
father's exposures.

DR. KOROSHETZ: But just to note, medical
record was a minor component of this.
Phenotype/genotype medical records.

DR. DANIELS: All right. Any other
comments on Question 2? We are running short
on time probably because we are already into
our lunch break.

DR. GORDON: Susan and I will look at the
afternoon schedule and figure out where we
can continue this because I think there have

been comments at each chapter. Although we are trying to get this done this time, maybe we will not be able to. But it is apparent that we need to spend more time on it than just the hour we allotted. Susan and I will figure out what we can do this afternoon. We will break now for lunch and resume here at 1 o'clock.

(Whereupon, the Committee recessed for lunch at 12:05 p.m. and reconvened at 1:10 p.m.)

DR. GORDON: Good afternoon. We are going to get started. Just a quick organizational note regarding timing. We are going to proceed with the public comment session from now until 2:15. At 2:15, we are going to have the presentation by the Madison House Autism Foundation. We had 45 minutes for the presentation and a half an hour for discussion. But in the interest of resuming

the discussion on the strategic plan, we are going to cut that short a little bit to one hour total. That will end at 3:00. We want to go 2:15 to 3 o'clock. We had initially an hour and we are cutting it to 45 minutes.

At 3 o'clock, we are going to take our afternoon break and we will resume at 3:15 with the strategic plan discussion, which we hope to be able to finish in an hour. That will be 4:15. We will have then an abbreviated discussion of the summary of advances, 3:15 to 3:30. We can always push off discussion if we do not conclude until next time because that is really an annual thing that ends in January.

And then from 4:30 to 5, we will have an abbreviated round robin. That is how we will finish. Hopefully, the strategic discussion, but I did not want to cut into the public comment session especially after last time.

We had fruitful discussions in the light of the public comments.

We are going to go ahead and get started. We have four oral comments and then we will have a summary of the written comments. We are going to start with the oral comments. We have allotted a total of five minutes for each of the presentations. And then in the spirit of last time, if the committee would like to discuss in between the public oral comments, we will take a few minutes to discuss each one. If nothing comes up immediately then we will wait until after the written comments where we will continue to have discussion. There will be opportunities in between the oral comments for urgent discussion as necessary and then at the end of the written comments for discussion of the public comments.

The first oral commenter is Thomas Frazier, Dr. Thomas Frazier.

DR. FRAZIER: Thank you, Josh. Thank you and thank you to the committee for the opportunity to provide comment. For those of you who do not know me, I am Tom Frazier. I am the chief science officer at Autism Speaks. I am very grateful for this chance.

I also want to acknowledge Geri Dawson and Rob Ring for their prior leadership at Autism Speaks Science. I would also like to thank Louis and the Simons Foundation as well as Alison Singer and Alycia Halladay at Autism Science Foundation and the Simons Foundation because they both reached out and offered to figure out ways to be complementary and collaborative as we move through and try to develop a strategic plan for science.

I am going to spend a few minutes giving an update on the science portfolio at Autism Speaks. I am going to start off by mentioning our MSSNG, which is a whole genome sequencing project. It is also open science. We are trying to get as many people interested in using the data as possible with the ultimate goal of getting up to 10,000 genome sequences. It is a public/private partnership between Google, SickKids and Autism Speaks. And the data are fully available for folks to access.

We expect the database five release in the fall, which will include up to 8000 whole genome sequences available on the Google Cloud. Currently, 5000 are available.

As I said, we are trying to get as many folks to access and we are seeing access increasing over time with more than 100 investigators currently.

The MSSNG community portal will be launching hopefully in the September/October timeframe. That portal is really designed around trying to allow individuals and parents to connect with other individuals around their genetic sequence data as well as to access advice in genetic counseling.

The Nature Neuroscience paper by Steve Scherer's group is a good example of the power of this kind of approach. The paper talks about identifying 61 risk genes associated with autism, including 18 that previously did not have high confidence for their association.

More importantly even than that is that many of these genes are clustering into distinct biological pathways. We think this is exciting because several of these genes and pathways have pharmacological targets already identified.

Before I move on, I just want to mention that there are a number of exome sequencing efforts out there. We really see MSSNG as being an opportunity to complement those efforts and allow us to look at non-coding variation in addition to what is already being done.

The Autism Treatment Network, as many of you know, has 13 sites in academic medical centers around the US and Canada. It is co-funded by HRSA and I want to acknowledge that it is really a dual network with the AIR-P network, Autism Intervention Research Network on Physical Health. There have been a number of milestones over the last year that has been achieved. I am not going to be able to go through all of them, but I want to highlight a couple here.

One is more than 320,000 downloads of health care toolkits, which we think is

exciting because it means that this knowledge is getting disseminated to providers and to the community.

We also want to acknowledge the substantial training efforts of the network to train medical providers and also to provide care coordination for families.

I would be remiss if I did not talk about our Weatherstone Predoctoral Fellowship. These fellowships have been around since 2009. They fill a very important hole in the space for these predoctoral-level individuals. We want to attract really innovative folks, people who are dedicated and will become dedicated to autism science. We have eight additional fellows that were approved yesterday. We will have a full class for 2017. And a number of these fellows provide blogs and information on our website

that I think folks should access if you have a chance.

We started the strategic planning process and part of that process is our survey. Some of you have may already participated in that survey. We are trying to get as many people to participate, including a full range of autism stakeholders. We have had a Medical and Science Advisory Committee meeting last week that was very productive and moved this forward on our strategic plan.

As I mentioned, we really want to be as complementary as possible to other funding sources. We are going to be presenting that plan to the board in October 2017.

The survey. We have more than 5000 responses to date. A number of moms have responded although we do have good numbers in other categories in relationship to autism. I

am just going to review a couple of things here.

First, there is no slide on this, but we did look at basic versus applied science and we see that both of them are being rated in the important range, which I think is encouraging. It shows that at least on the basic science side, people are becoming more aware of the value of this, the potential value of this for our autism.

We do see some variability across specific topics. Some of that may be due to the way that we frame the question. I think, in general, the positive here is that many people are seeing these areas as being important or very important to the future of Autism Speaks Science.

We are going to be collecting additional responses and analyzing them by the role and

relationship of the individual to autism, and we hope to disseminate that information soon.

And then I am going to end by just mentioning that we see our role as changing slightly. Our new role is going to be to see novel projects. We still want to cover the full space from discovery to solutions where we know that we need to be more targeted. And we also know that we might have a unique role in funding very practical, more immediate projects that can bring relief and help and increase quality of life to individuals and families.

We have also talked about transitioning our Autism Treatment Network to a Learning Health Network with the clinical trials' capacity. We, of course, want to include advocates both self and family advocates in our review process and we have been doing

that including through our most recent Weatherstone Fellowships.

I will just end by saying that we see a unique role for us in connecting the community to research findings and research findings to the community. Thank you.

DR. GORDON: Thank you, Dr. Frazier. The next oral commenter is Carol Weinman. If you would go ahead and go up to the podium. Let me just ask while she does so if there are any urgent questions or comments from the committee; otherwise, we will proceed. Again, we will have a chance to discuss at the end.

MS. WEINMAN: Good afternoon. I am honored to be here. For those of you who do not know me, I am an attorney. I have been a criminal attorney for over 25 plus some years. I started as a prosecutor and then became an expert in the area of autism. I have a son on the spectrum. I then became

certified as an autism specialist. I have brought the two together.

I am here to speak to you about today - my biggest challenge is going to be keeping this to five minutes. Because of my passion about this issue of crime in autism.

What I see in my practice - I represent offenders who are on the spectrum. We hear a lot about victimization, which is a big area and certainly an important one. Then we see a lot about wandering. But what a lot of people are not aware of is how many of these individuals are becoming criminal defendants and offenders.

The reason for that is many. Many of them, which I speak about often, are the characteristics that are unique to this population. They tend to bring their attention to police officers and law enforcement.

They often do not understand the consequences or the behavior that they are doing and that it is considered criminal. They are finding themselves being arrested, processed, and then - we have them from the front end. We have the ones that are getting arrested. Then we are dealing with them all the way through the criminal justice system to then the issues that come up with being interviewed by the police and then in the court room if they make it to trial. The issues come before us about them being put on the witness stand and some of the concerns with that.

The greatest way to approach this, as is many of the things in this area, are training and education. There needs to be a heightened awareness of this issue and then how to deal with it.

In terms of how to deal with it, number one, at the front end are the police training, which I know was mentioned here in terms of elopement. It is about how we train the police so that when they see this, they maybe know that it is a person with autism. The person is identified. They treat them differently. Maybe they will not take me through this system. I have had cases where they are not getting processed.

And then we have to train the prosecutors so that they understand why it should not be handled and charged the same way as any other criminal defendant. That is what I deal with very much in my work and it has been very challenging, but also very rewarding.

But we need to do it on a much bigger scale in terms of training them to understand that this is not what it looks like. That is

what I deal very much with prosecutors and the judges are that they just do not have any understanding of autism. Once they can be made to understand it better and to see that there is no criminal intent to commit a crime.

And what they really want to know is will this person offend again. In my experience, very few offend a second time. And the reason for that is because once we teach these offenders from the other side what they did was wrong and take steps to prevent it from happening again and more so for them to understand that it is considered criminal, they do not do it again. A lot of it is that they did not even know that what they did was wrong or socially inappropriate.

I see a lot of sex-related crimes. And reasons for this are obvious because they do not have enough education in that area

either. Many of them take to the Internet. What is happening with that is that once they take to the Internet out of curiosity, they are on the Internet and all of a sudden before they know it, they pushed a button and they are downloading child pornography.

Even though the percentage of individuals and in my experience, mostly males, that are getting arrested for these kinds of crimes maybe much less than individuals on the spectrum that you are seeing in other areas or arenas we are talking about. But the consequences are so severe that even though the percentage may be less, it is a really serious issue.

Once they get into the federal system, many of them are getting convicted or doing pleas for child pornography and having to be registered as sex offenders. There needs to be some changes in the law there too, but

that is probably going to be down the road in terms of the registry issue.

But more importantly, you have this vulnerable population. They have already got so many challenges that they are facing up against and then on top of that, we are going to give them a criminal record, which changes their entire course of their life.

My job has been to prevent them from even getting a criminal record, but it is also raising awareness, training, understanding. That is my five-minute mark. Thank you.

DR. GORDON: Thank you very much for raising this important issue before us. It is very helpful to hear those comments.

Our next oral commenter is Mary Jo Lang. Dr. Lang, if you would move to the podium. Let me just ask if there are any comments or

questions, committee members, regarding that last comment while Dr. Lang takes the podium.

DR. KOROSHETZ: I guess the question that comes to mind is is there data out there - are there publications in law journals that we should be looking at that would help us move to the next step?

DR. GORDON: Are there folks who are aware of data regarding involvement with the justice system and individuals with autism.

DR. DANIELS: There is some published research, but I do not have it with us right now.

DR. GORDON: That is something for us to follow up in future meetings.

MR. ROBISON: I would just offer something for committee members to think about. Some of you know that I also serve the judiciary branch of government as an expert in autism in criminal cases. You just asked

are there studies, for example, in journals that we could turn to. One real problem in unraveling the issue of autism or other psychiatric conditions in serious crime is that very often the records of autism or any psychiatric condition are sealed. A person who is an expert working on the legal case may know about that. Such a person may have worked on other cases, as I have and know about those things, but we cannot speak about them or publish on them. It is a very difficult situation because it is a thing that really concerns me. I agree. She is right to be bringing this up, but I could not, for example, tell you of my own experiences on that. I do not know how to get around that problem other than maybe some governmental answer in the future.

DR. GORDON: Good point. Thank you. Dr. Lang, if you would go ahead.

DR. LANG: I want to thank this prestigious audience for having me speak for a few minutes, but I am also very honored to follow a defense attorney as I have been expert witness and I know what that is like.

But I want to speak about antecedent management before the student gets such a situation where they need to be incarcerated. I am changing my initial remarks with something a little different.

First of all, one of the problems in autism is just the teachers are not prepared. I have a school that I started. We are now up to 100 students. We have everything that you can imagine. They have art, music, and all that stuff. The problem is the teachers who come from the universities may have had a course. A course does not make you understand and apply your knowledge to a very complicated situation. It is not only the

student, but it is the parent, the parents who are grieving, who come in just storming and raging. It is all your fault and why my child isn't cured. I am just yelling yes. What you say is they are just angry.

There is limited mental health resources for parents who learn to deal with this. Many of them are impoverished. Even those that have resources do not fare well when they have a child with autism or a disability.

By the time you have dealt the child - I will tell you how bad it is. The school I started serves children that are moderate to severe. Do you think the school district sends me students who are Asperger's and are on a diploma track? Absolutely not. I get the student that have been tied up and handcuffed in the back of a public school classroom or have been abused or a student who has broken the speech therapist's arm in speech therapy.

Then they call up and say Dr. Lang. We are in an emergency. You have to do something. I have to work with these. I call myself the emergency room for the school districts.

If this happens at a very young age, you can imagine by the time the child becomes an adolescent and you are ready to transition to the workplace, you have a very difficult situation in educating the public. If you do not know about autism by now, you have not listened to the news. But they do not really want to necessarily integrate them into their office. They do not understand what it will take, how much of their resources. There is a whole host of community involvement and activities that are necessary and education that has to take place.

To support my attorney friend even more because I have spoken on the issue of sexuality and presented at the INSAR

organization when they had it in Spain. I did the research so I could go to Spain. The issue is nobody addresses it. If anything is going to keep you out of the workplace and accessing public benefits whatever they are, parks, it is sexuality and the inappropriateness because they do not understand it and neither do the parents. The parents do not talk.

How many neurotypical parents speak to their neurotypical children about how many times they are going to masturbate during the day? I had to get over that and saying those kinds of words. But they are normal behaviors and you have to teach it in an appropriate way. That is one thing that will keep them out of jobs and being productive citizens and having a quality of life that they should well deserve. Thank you.

DR. GORDON: Thank you very much. That was really wonderful and compelling description of the importance of working in the schools.

While our next commenter, Margaret Gautier, comes to the podium, I will just ask if there are any responses or comments from the committee.

We will go ahead with the written comments and if the oral commenter comes in before we move on then we will have her comment then. She might be on campus somewhere. Hopefully, she will show up later.

Now, we will have the description of the written comments by Karen Mowrer. Dr. Mowrer is a science policy analyst in the Office of Autism Research Coordination at NIMH.

DR. MOWRER: Thanks. Hi everybody. Since the April meeting, the IACC received written public comments from 17 commenters. For the

purposes of this presentation, we have organized these under six broad topics and the committee has been provided all of the comments in full, but I will be summarizing them briefly here.

The first topic was autism research priorities. We had nine comments on that topic. Ms. Noelle Aloe, Ms. Caryn Harb, Ms. Joni Iqal, Ms. Lauren Harb, Ms. Gina Jaber and Mr. Marc Spilo asked the NIH to fund research on the use of an existing anti-parasitic drug called suramin as a potential treatment for autism.

Dr. Stelios Georgiades provided links to his recent publication and additional information on the topic of autism heterogeneity over time. He offered to keep the IACC updated on his research.

Dr. Eileen Nicole Simon asked the IACC to discuss her comments, describing potential

links between autism, disruptions in language development and complications resulting in brain injury such as umbilical cord clamping and asphyxia at birth.

The Autistic Self Advocacy Network asked the IACC to prioritize ASD research on lifespan outcomes, co-occurring conditions, support and services, assistive technology, diagnostic disparities, and the prevalence of autism in adults. ASAN also urged the IACC to promote the involvement of autistic adults in the research process.

The second topic was the role of the IACC. We had five individuals comment on this topic. Ms. Marian Dar thanked the IACC for screening the film *As One: The Autism Project* in recognition of autism awareness month. Mr. Nathan Olson thanked the IACC for the positive experience he had when he presented an oral comment during the April 2016 IACC

meeting. Mr. John Best expressed general frustration about the IACC.

Dr. Eileen Nicole Simon would like her comments discussed rather than only summarized. She requested that more time be scheduled for the discussion of public comments, that the IACC be required to discuss all of the written comments, and that the discussions be moderated by IACC members familiar with each topic.

Mr. Dwight Zahringer feels his comments from previous meetings have not been addressed. He also recommended that the IACC facilitate a survey of parents of autistic children.

The third topic is transitioned to adulthood and adult services. We had two comments on this topic. Ms. Helen Zhang wanted to make the IACC aware of mBot, an educational kit designed to teach computer

programming skills to individuals with autism.

ASAN expressed concern that according to the 2013 IACC portfolio analysis report, only about 2 percent of federal autism research funding went to research on service effectiveness and access, but only about 1 percent went to research on lifespan issues.

The fourth topic was autism resources and support. We had two comments on this topic. Mr. Kellen Smith wanted to make the IACC aware of an online resource available at www.tuck.com, which provides sleep management information for individuals with ASD. Ms. Jamie Juarez wanted to make the IACC aware of her book titled Hope for Autism.

And the fifth topic is vaccines in autism. We had two comments on this topic. An anonymous commenter believes autism is caused by mercury in vaccines and expressed

frustration that the issue is not being addressed by the IACC.

Mr. Dwight Zahringer asked the IACC to investigate how glyphosate maybe affecting children with ASD versus those without ASD. He also asked the IACC to request that congress investigate the CDC whistleblower issue and to provide a full debrief of the study on autism and the MMR vaccine.

And the last topic is the IACC strategic plan for autism spectrum disorder. We had one comment on this topic and it was from ASAN. They continue to have concerns about the IACC strategic plan questions. ASAN believes that the questions should not suggest that autism should be cured or prevented. They also asked that lifespan issues be prioritized in the plan.

That concludes the summary and we thank everyone again who submitted written comments.

DR. GORDON: Thank you, Karen. We now actually have some time to discuss. The discussion can be about the written comments or the oral comments. I would encourage you especially since several of the written commenters asked that their comments be discussed. That if you feel like you have something to add, answer, or contradict the written comments that you feel free to do so at this time.

MR. ROBISON: I think I have raised this issue before, but is there any way that we could do some kind of roundtable discussion where we could address some of our constituents' concerns at greater length than the few minutes we have for a comment session in here? I would volunteer to come to

Washington for another day if we could because I just see how important it is to these people who write into us and come to us.

DR. GORDON: For that purpose, we have actually extended the public comment period for this meeting to an hour and 15 minutes. That means we actually have about 40 minutes to discuss any of the topics that you would like now. I apologize if you were not prepared to do so, but I feel like we have the opportunity to do that now if there are specific items that you have noticed or if you want to take a few moments to look through and look at some of them, that would be wonderful.

MR. ROBISON: One thing I will ask because it speaks to several of the comments today is how do my fellow committee members feel about us making a coherent committee

statement about what the tradeoff of accommodation, acceptance and cure means to us. For example, I know cures are a very charged topic. Some people interpret it as cure is ridding the world of people like me. I do not think any of you believe that people like me, Sam, or any other autistic person should be got rid of, but I understand how people feel that way.

Some of you have said things to me like if my autistic child could speak for himself the way your or Sam could, I could consider my child cured. I do not consider myself cured of autism because I am able to advocate for myself or others here in this forum, but I understand that feeling in parent's part.

Might we try and develop a statement on what this means to us and what our objective is because when I receive letters from people and they say I cannot believe that IACC is in

the hands of you neurodiversity people and I want my autism cured. I hate my autism. It is hard for me to really answer that. I do not oppose the development of any therapy to help such a person. If you feel like you are in pain from your autism, if you cannot do something, I absolutely support developing therapies to help with that and I think all of you do. I wonder can we as a group answer that.

What do some of the others of you think about that topic?

DR. GORDON: Let your comment sit for a little bit. I think that people will have something to say if you give them a moment.

DR. DANIELS: John, this is a topic that is in the strategic plan and could always be enhanced or expanded a little bit if the committee felt it was important to highlight it in a bigger way. We could take what is in

the plan now or in the introduction of the plan even and try to enhance that so that it captures some of that.

MR. ROBISON: Would you like me to write something and send it to you?

DR. GORDON: I would actually like in the spirit of your challenge to take this up as a discussion item amongst the committee. I am wondering if there are other comments or points of view.

DR. BIANCHI: I will take an attempt at this. My research is in prenatal treatment of Down syndrome. This has come up extensively in the Down syndrome community as we query the ethics of trying to approach a neurodevelopmental disorder. Working with ethicists, I have been very struck by the fact that prospective parents make a distinction between an unborn child that has no personality and a person who has been born

and experiences a life and has a personality. We never use the word cure either. We use the word treatment or encouraging brain growth because with Down syndrome, one of the big problems is there is microcephaly.

Treatment is a complicated issue. That is all I am saying. There may be different points getting back to the lifespan where we are looking at early embryogenesis through adulthood. There may be certain points of the lifespan where it may be more appropriate to think about treatment as opposed to later on. You have lived a life. You are who you are. It is very difficult to think about changing who you are and your personality, which is so intrinsic to you. I would say that for anybody in the room. I do not know if I am being articulate.

But my main point is that there may be certain points in the lifespan where

treatment is more ethically acceptable and appropriate in the context of helping individuals function independently in the world.

MR. ROBISON: Do you see treatment as cure?

DR. BIANCHI: Not use the word cure.

MS. CRANE: Whenever we talk about ethicists and about what parents think versus fetuses versus individuals who have already been born, I would say that if we do have this conversation, we need to make sure that we are not just hearing from parents and ethicists, but from actual autistic people and that includes people on the autism spectrum who are non-speaking people who have serious communication difficulties, people with intellectual difficulties. When people say, John, let's keep John the way he is. We are just going to go and change these other

people. A lot of the time that other group of people also has opinions on this that can be ascertained. Those opinions need to be taken into account.

MR. ROBISON: It is absolutely important to recognize that for every one of you - for everyone who says John or Sam does not need a cure because they can do this, you are going to find a John and a Sam who say I do not think that I am free of disability. Here is what I cannot do.

MS. CRANE: I do not think I am free of disability. I am pretty disabled actually.

DR. GORDON: You both have indirectly raised a point that I think - actually all three that we need to make explicit. In the normal adult, doctor-patient relationship, the patient makes the decision about what treatment he or she will pursue provided the patient is competent. For most medical

decisions, the doctor provides advice. It might be very strongly worded advice, but advice nonetheless and the patient retains a decision-making capacity.

There are ethically more straightforward situations like the one that, Diana, you described where an individual like - there are conditions where the treatment decision is being made by someone other than who is getting the treatment where it is clear that has to be where an individual or patient cannot make the decisions for them. And ethicists have made it very clear that other people should act in the best interest of that patient and then make the medical decision for them.

What is tricky about thinking and talking about cure with autism or prevention with autism is that it is parents making that decision potentially very early in life. But

I do not think you would get very much argument with ethicists that parents do not have the right to make that decision.

MS. CRANE: But that is not really the question. I actually think Judith would have - we were just talking about the deaf community and parallels with the deaf community. There is a very live debate in the deaf community about cochlear implants on infants. And absolutely from a medical ethics point of view, parents can decide whether or not to put a cochlear implant into their child. But when we are talking about what does the community feel about this, deaf adults have very strong opinions on whether or not they would have wanted a cochlear implant as a child. That is obviously a very important thing to be taken into account. That has parallels to what we are seeing here.

DR. MANDELL: We are talking about this within the context of treatments or cures. But I wonder if, John, the larger question you raised is what are the underlying assumptions that guide both spoken and unspoken that guide the decisions that we, as a body, make because our strategic plan is a set of decisions. This is what we prioritize and this is what we think should be funded or the research that should be done. Understanding those assumptions, some of which relate to treatment and cure, some of which relate to other things, is probably pretty important.

One question is how important is it that we have consensus on what those assumptions are versus that we have robust discussion of what they are. In going through the statements about the IACC this morning was our respect for diversity of opinions and

diversity of views on many of the issues that we are talking about now. I would be very open to discussion of these things and to make sure that we all know where we stand as individuals. I am not sure that it is either incumbent on us or healthy for us to come to consensus about what all those underlying assumptions are.

DR. PELPHREY: I think that you beautifully articulated a very important point. I can only add to that. The diversity of opinions is important and then when one considers what our objective might be, which is to obtain funding for our community's interest in order to fund research and services. That requires putting forward a concise, clear statement about what we want funded. That is the only time that we all need to stand in unison.

In the year that I have been in DC, I have learned in talking with professional politicians that they love the autism community largely because they can say they love children. They are supportive of autism and autism research and mind you on both sides of the aisle and would love to do something to help and then are very familiar with the different factions and the different arguments and the different views. They quickly point those out whenever you begin to talk about what you would like to see done.

As I have gotten to know some of them better, they point out very frankly that one of the reasons your community is so loved is that you are not presenting a coherent set of asks. Therefore, lip service is free. There is plenty of that in town. Until the community presents that set, which you could think of the strategic plan being that, we

are not going to get anything. If we spend time trying to build consensus without keeping that end goal in mind then I fear that it will be a waste of time, not a waste of time in terms of existential waste, but rather in terms of getting that product done because it sounds like we are in broad strokes agreement about most things if not the most important thing for a committee, which is the general respect for each other's points of views and wishes and therefore can develop a set of asks.

I am speaking as a parent of a child that is fairly heavily affected by her autism and epilepsy and would be one of those parents that would say I hope she turns out a lot like Sam. Then I am also very well aware of the then what. I can see both sides of it very clearly.

MR. ROBISON: I think that is a good point. We do not have to maybe all agree with everything that we want. But when I engage the people who challenge the idea of neurodiversity people, you are opposed to cure and I want a cure. And I say what specifically would you change about yourself or what would you change about your child. Mostly what I hear is I would fix this thing, this disability. Maybe that is cannot talk. Maybe it is cognitive functioning or whatever. Clearly, Sam and me, your child - we have different challenges because of autism and each of us would say maybe I would change this thing or maybe now at my age I would just live with this thing in me.

But I am not opposed to anyone who says I want to fix this thing in me. I want to make myself better. My question then is if we all agree with that, we should agree with the

general statement that I want to develop the tools with government funding. I think it is the job of government to provide this kit of tools and therapies that can assure the best quality of life for every autistic person. That means maybe you need to speech help, maybe you need GI help, maybe you need cognitive help. I think that is a job of government to do that research and provide those things. If you agree, you should join us in that quest and we should put aside a fight over semantics. I feel like the fight over semantics is significantly harmful to us as a group because we cannot mount a coherent effort to get what we want.

DR. GORDON: John, actually, I think that is a wonderful point and that crystallizes actually what is really in our vision statement. Our vision statement is the strategic plan will accelerate and inspire

research that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan. It is a great step.

I still admire your attempt to bring it back to this issue, which I think is more than semantics, but perhaps not consentable. That is not a word. But I am glad we are having this discussion. I think it is a discussion we need to have every now and then to remind ourselves of the different perspectives around the table.

DR. AMARAL: John, I think Question 3, the way it has come out, is that research is fostered to try and preempt and prevent disabilities associated with autism broadly speaking. But we agree that that is the goal is all I am saying.

I think it is going to be impossible. I agree with Kevin and the whole tenor of this

discussion to say anything more than that. I do agree with you. Many parents say we want to cure our child. What they are really saying is that they want to eliminate the gastrointestinal problem or they want them to sleep normally or they do not want to have profound anxiety. Those are all components of autism. I think our research agenda is trying to attack those issues.

For different people, it is going to be different issues. I think we all agree. I do not think there is any disagreement. For different people, for different personalities, we are going to have to address different aspects of their concerns.

For you, it is the issues that bother you. We should be developing a research agenda that helps people in your situation. For an individual who does not sleep at

night, there is a whole new agenda of trying to understand sleep disturbances in autism.

I guess I am sympathetic with what you are saying, but I do not think we disagree. I think this is what the strategic plan is trying to get at.

MR. ROBISON: It sounds like we do have that consensus and maybe we just need to articulate it in words in our written plan.

DR. GORDON: Actually, I think it is there. I think it is there in the vision statement. It is there in Chapter 3. Nonetheless, I am glad we had this time to discuss it.

I would like to ask if there are other - now that we have had perhaps a chance to look at some of the written comments and consider the oral comments if there are other topics that individuals brought up that members of the committee would like to discuss.

MS. CRANE: Can I bring something up?

There is definitely some of conversation about services in the comments. Because of the deadline, I do not think commenters had the opportunity to raise this issue, but I feel like I have to anyway. Those services are potentially going to be impacted by policies that are being debated in the Senate right now.

We know that almost all of the home and community-based services for people on the autism spectrum, all of the supportive housing services, all of the job services or nearly all of the job services, quite a lot of special education services. These are all funded by Medicaid. We are looking at a significant cut in Medicaid. If that cut happens, those services -- and I know many of the other members of this committee have been

speaking out on it. Many of those services are at risk.

I also wanted to bring up that today is the 27th anniversary of the passage of the Americans with Disabilities Act. It is kind of coincidental that we are meeting on the exact anniversary. That law has done so much to move us out from institutions and into the community and into real jobs and into integrated employment and education. When people talk about Olmstead, moving people out from institutions into the community, that decision by the Supreme Court was based on the Americans with Disabilities Act. It is a very important day for us as a result of that.

Again, when people do Olmstead work, when they try and move services from the institutional settings to the community, Medicaid is almost always the main funder for

those services. I just wanted to remind that of everyone.

There is a limited amount that I can say as an IACC member. But I really hope that people are taking that awareness into the rest of their professional lives and working to educate the community on that. Thank you.

(Applause)

DR. AMARAL: I just wanted to comment on one of the written summaries from Dr. Eileen Nicole Simon, who has actually been here and presented. She was actually one of the people who said why don't we talk more about it. I feel bad that we do not have enough time to address some of the issues.

In the particular case of Dr. Simon, she has for a number of years had a theory about what brain regions might be most damaged leading to autism and has actually talked

about childhood asphyxia during delivery and things like that.

I just want to put on the record that I think that these are all interesting ideas. She has done a huge amount of research over tens of years. Our problem is we do not have the material in terms of postmortem brain material and other raw material to prove some of her theories.

I think in this case, it is not so much that she may be wrong. She is proposing very interesting, provocative ideas. It is just that we do not have the wherewithal at this point in time to actually prove her theories. I just want to make sure that people know that we are not paying attention to these things. In time, perhaps we can come back and see --

DR. GORDON: Let me actually underscore your statement. You might want to add

something of your own with regard to the need to continue the development of brain banks so that we can do these kinds of postmortem studies. NIMH has a brain bank, which includes autism. I encourage anyone who is listening out there to go and visit the NIMH website and do a quick search for the brain bank. You can learn about how to donate brains of course after you die. We do not take them from you when you are alive. David, I know that you have an effort that you might want to also publicize.

DR. AMARAL: I will just say a quick word. From the Simons Foundation, we have initiated Autism BrainNet. If anybody is interested in getting more information, they can go to TakesBrains.org and actually sign up for a registry. You will get a quarterly newsletter. You are making no commitment whatsoever. We actually had our hundredth

donation to Autism BrainNet. We thank the community for considering this obviously very important donation. But we want to get more and more involved. We appreciate their participation.

DR. GORDON: I have just been informed that our final oral commenter is here. Margaret Gautier. Why don't you go ahead and take the podium? You have five minutes for your comments.

MS. GAUTIER: Hello. How are you doing today? I am sorry I am late. It was a lot of fun getting here. That was a lot of circling and leaving and coming back. Thank you for being patient with me.

Part of me being here is to share my perspective as a parent and someone who has a child in the public school system where part of the problem that I have noticed, I am not a scientist or anything, but I have dedicated

12 years of my life, he is 12 too, trying to understand this and educate a mentor and really advocate for the cause.

Part of the issue that I have encountered is that we do not have a functional academic curriculum for autistic kids. In the public school system, there really is not a way to identify the levels in which children are functioning at and we need to be able to find a way to pull that information from all the specialists and the teachers and all of these tests that they have our kids doing and be able to try to come up with a way to educate our kids.

My story deals with - my child essentially lost a year of instructional learning because his teacher did not know how to teach him. She did not know how to progress him academically. And part of the problem is because the State of Virginia

where I live does not have an actual functional academic curriculum. They have something called the SOL and then they have these sub-categories for what they teach that still goes with the SOL. But the teacher is also responsible for coming up with their own curriculum that coincides with the SOL. Sometimes these teachers do not know really what to do. They do not have the tools or templates to really educate our kids and be able to put them on a path of success. There was a lot of inconsistency in the public school system regarding how our kids are educated.

For some of us where I live in Virginia unfortunately some resources are not available because of where we are. We do not have centers. We do not have a place where teachers can actually come together and be able to try to come up with a way of how we

can actually instruct the kids. It has been very difficult for not only myself, but I am sure for other people in trying to ensure that the services are administered fairly and properly and that they meet the needs of our kids. Sometimes you have these teachers that are just so burnt out that they really do not have the energy or the drive to stay dedicated to the cause that they went into to begin with.

Another thing also is technology. I do see the benefits of having more technology in a classroom with kids that have autism. My son is a technology guy. He is a computer freak. He can navigate through anything on the computer that he wants to. That is a wonderful thing. That is something that I encourage at home, but it is not always the same thing at the school system. With the school system, they give him a tablet and to

play with, but there actually is not anything that they may be learning. I know there are a lot of tools and a lot of resources out there for them to use, but unfortunately I do find that the level of education in the public school system is very inconsistent.

I should be able to take my kid to one school on this part of the county and be able to get the same type of education in another school in a different part of the county, but that is not the case. It is really based on the teacher and their ability to really be patient, to learn to educate themselves. There is training and all these things available, but a lot of it is not mandated. It is not required.

I think that we really need to - I think the government needs to help more with trying to come up with a way to standardize autism as a service and somehow find a way if there

is not something already in the works to make it a specialty amongst the medical field, amongst the teachers and the academic field and within that community so that we can all try to build upon what we already have, what we know and help our kids just transition easily to help them learn and grow in a different kind of way.

My kid is not really like most autistic kids are not really big on human interaction. But the way that he can learn and interact is through the computer or through technology because he does not have to figure out other people's emotions, their body language, what they are feeling, and the energy that they are giving off. It is a lot easier for him to get instruction off the computer.

I have asked my public school system to - I have heard of Melo. I have read about it. I heard that it was great and a wonderful

thing. I am telling these teachers, why don't we have this in the classroom. Maybe this can help facilitate learning for them for some of the kids that have a hard time dealing with people and interacting with the teachers or other students.

Funding is always a problem or they just do not have interest in it because they do not know the technology themselves and they are not willing to learn. I even talked to the director of special education for my school district, which is Prince William County schools. Some people kind of get it, but a lot of them don't. As someone who is in a leadership position, I do not feel that they really fully understand what our kids need in order for them to really be taught in a less than conventional way.

That is why I am here to just kind of spread that out because I have grown to be

very frustrated with the fact that my tax dollars, 42 percent of them, go to funding the school system, but yet we do not have enough technology, enough resources, enough training, enough information available for these professionals who are supposed to be certified, degreed, and educated all throughout whatever specialty that they are in and my kid is sitting in a classroom and not be taught anything and then he has unfortunately regressed as a result of that.

Communication is an issue. Some teachers do not community very well. We need to have some more oversight in the public school system. I do not think that we can really allow the states to figure it out for themselves. I think that they need to hear from a higher authority that this is what we need to do in order to make sure that we have a certain level of consistency across the

board. If I move to Iowa, my kid probably has no chance there because there are certain things that they do not have. We need to try to standardize things as much as possible, pull data, pull information and collect it in one of several places so that we can try to figure out how are we going to teach these kids in a public school system. That is pretty much it. Thank you.

DR. GORDON: Thank you very much. Sorry for the inconvenience of having it in a difficult place to get to, but we really appreciate you coming and giving such clear and compelling testimony.

Are there comments?

DR. MANDELL: I wish Ms. Gautier had written the services chapter for the IACC report because I think she really eloquently hit on exactly the problems we are trying to address in that chapter. I just want to

reiterate some things that I thought were really important first and that were said by some other presenters as well.

The complete inadequacy of preservice training. What we want is to make teachers who are expert in working with kids with autism and what we have is a model in which they are allowed to dip their toe in the water before they are thrown into the pool to work with these kids, leading to tremendous amount of burnout, which we found the turnover rate in the Philadelphia School District among special education teachers working with kids with autism is 25 percent a year. They have no in-service consultation or support. Even as they find problems, they are not able to implement what they want to implement or the field changes. We do not have a good way other than to as we like to call it, train and pray. We send them for a

one-day workshop on something that we want them to be expert in and we send them back to the classroom.

There is a panoply of programs that we, as a community, have not said these are the fundamentals that should be in every classroom. As a result, we have warehouses filled with curricula and programs that somebody thought were a good idea last year because they got a flier about it or went to a training that are no longer being used. We have wasted a tremendous amount of money. This is particularly true in districts that are under resourced primarily because education funding is tied to property taxes because Congress has never fully appropriated all the funds for special education that they said they would probably about 17 to 19 percent. That this is driving a lot of the disparities that we say we want to address in

our strategic plan and we should keep in mind that when we are talking about race, we are often talking about place when it comes to these kinds of disparities.

I would love to make sure that everything about that that has been said today is really foremost in our mind as we think about what the research agenda should be and what the practice agenda should be. We already know a lot of things we should be doing and we are not doing them. We could do all the research we want, but if it does not make it into practice and if we have not developed a policy system and a service system that allows that to happen then the research is not good for anything.

DR. GORDON: Thank you, David. Are there other comments about the oral commenter or any of the other commenters or the written comments? Thank you very much and thanks to

all the commenters, oral and written, for those of you here and for those of you who are listening in. We really appreciate it. We apologize that we do not get to discuss every single one, but we do look at them and we do - I, myself, have marked several of these that I want to follow up on in terms of trying to figure out whether we should include them in the NIMH agenda. I assure you that even if we did not get the chance to discuss them individually today, we do consider them important.

We will go ahead and move on to the next item on our agenda, which is the discussion of autism after 21. To lead us off in that, we are going to have a presentation by the Madison House Autism Foundation. I welcome JaLynn Prince, Adrienne McBride, and Desiree Kameka, who are going to have a presentation. Afterwards, we will have time to discuss.

MS. PRINCE: Thank you very much for the invitation to be here. We are grateful to the fine leadership that we have been seeing with IACC. I am very impressed with a number of people that I have had the opportunity to get to know that are sitting around this table.

We wanted to tell you a little bit about what we have been doing for the last several years. We started Madison House officially ten years ago though we started research 13 years ago. My husband was a research scientist and I had a background in many different things, in PR in science in broadcasting and in the arts. We decided that we wanted to move forward to do something in the field of autism. As we moved forward, we did a marketing survey. As we did our research both locally, statewide, and nationally, we saw that there was a great need in the adult arena. In fact, the space

was wide open for good or for ill. We want to talk to you a little bit about what we have been doing over the last while.

Let me tell you a brief story about why we are in this. This illustrates something. We were on our way to a family event. We had a nose count of how many people were going to be there, how many adults and how many children. My husband did not realize that we had the nose count and as we were in our van as many people do going on to a family function, he was saying do we have the right count. Do we have Madison? I turned to him and I said Madison does not count, thinking that he had already been accounted for. A moment later we heard a little voice in the back seat saying one, two, three, four, five. Madison counts. Yes, Madison counted at the age of 11 as he made that statement. He is now 27 years of age and he still counts.

He has been termed often as the tidal wave or the tsunami of autism. He has been able to benefit from a number of things, but we are seeing that in the adult arena, there are few things that exist to help Madison and the many other Madison's around the country.

Madison House Autism Foundation is not a government-funded organization. It is not part of a university. We are not providers although we work with each one of these entities.

We started the foundation, but now it is time for this foundation and the work that it is doing to be taken over by the rest of the country to do very important things in every community in this nation.

One of the things that we had toyed with in the very beginning was to have a roundtable and I bring this up because you were talking about something of a similar

nature. One of our original goals had been to have the financing to pull together voices from around the country both in government, the private industry, and universities to put out a plan for autism and especially for the portion of autism that takes up as someone wisely said three-fourths of one's life.

Let me give you an idea of what Madison House has been doing. We have a few videos here for you. Let's start with this.

(Video Shown)

MS. PRINCE: That describes in a nutshell the things that we are working on.

Part of those statistics -- in that particular video. In the darker portion there, I want you to look at the last line. There was something that my husband found in his research in looking at some work that had been done at UC Davis Medical School in California. Look at that number on that. Each

year by the cost for direct services, indirect services, and the lack of productivity it costs our nation \$300 billion. That is a staggering sum. They estimate that by 2025 that that will almost double. Can we afford not to do things? We are hoping that organizations like ours and other not for profits and the government and private industry can come together to examine what we can do to reduce that cost to our country.

This is a type of funding that we have right now. This happens to be information from IACC. We see that there is 2 percent of the research dollars that go toward adults. Again, remember that three-quarters of one's life is spent in adulthood. I think those statistics are a bit problematic.

We have come a long way with societal expectations, focusing on person-centered

planning and moving away from institutionalizing individuals or institutional programs for individuals, but to make certain people can be involved in community.

Madison House identified areas that you saw on that video. We have seen that there is - and we have had these four things. There are so many things that we could be working on. These are our four core things. The lack of appropriate and affordable housing so people have various options and that they can have the supports in communities that they desire.

We see that there is excessive unemployment. It is estimated by Drexel around 80 percent un- or under employment.

We have also seen too that we have needed more university programs, more vocational programs. One of the things that

we started very early on was a conversation with a university that had had the challenge to grow. In April, we were fortunate enough to have the ribbon cutting for a new place of learning that can help those navigate college that are college bound so they can have a successful experience and move on hopefully for employment. Many of these things are plans that need to be into play many years before they are realized.

We have also seen that there is a lack of medical care. I am not saying necessarily treating autism itself, not necessarily the gut issues or different types of things. Those are all important. But we have very few physicians that are trained to work with individuals on the spectrum for typical medical situations.

There are ways - we have had a member of our board who put together a wonderful video

about how you can have effective encounters with physicians and that individuals on the spectrum and others and feel comfortable in going back to physicians. Is that going to eliminate some of the costs that we have in society if we had people that are healthy and that we have appropriate medical care?

This is something that still absolutely astounds us. Many of us have heard this phrase before. Autistic children grow up to become autistic adults. There is not a week that goes past that I do not encounter someone that is a very well-informed individual of the community that says I had never given it any thought. I had no idea there were autistic adults. I have heard a lot about children being helped, but what about adults? It is astounding to me the lack of awareness. I hate to use that term. Because the thing that we are very interested

in is bringing a consciousness about having these individuals in our community. But how in the world can we create solutions if people have no idea that there is a need or that there is people that exist that need help?

We have selected the word consciousness because we have felt that we have needed in some ways to step backwards a little bit because we have been proceeding with our work. But when we find that corporations and individuals do not know that we have adults on the spectrum, how can we expect their participation? Something that I will be explaining in a moment will seem like it is a very simplistic approach on something, but I hope it will be a key to something very important.

We have come up with called Autism After 21 Day. We are going into our third year with

this. We want to challenge the nation that during the month of April on the 21st, this signifies the time when most services and for most adults, sometimes it does at age 18 in some states and in some situations that we can bring to the consciousness of communities around the country an understanding that we have individuals that can contribute to our nation, to our communities. We try to emphasize the talents, abilities, and yes, the challenges because they all go together.

Autism After 21 Day has been a very interesting thing to be working with. We have had something that we have felt has been very successful. I want to give you just an overview of one of them. There have been other states that have been doing this.

We are challenging people in each state to go to their legislators to have Autism After 21 Day declared. That sounds like a

simple thing and maybe a rather fluffy thing to do, but au contraire. If we can step into the halls of government on a nonpartisan basis and challenge people to come together to make a declaration of yes, we want to help adults that are on the autism spectrum, what does that mean during the rest of the year if we do have issues and we do need to go to our legislators that we need to go to people within our counties or people within our cities to have solutions whether it be educational, whether it be any one of a number of things. That is the first step.

This is a picture of us when we were with the county council here in Montgomery County just prior to doing an event. This was a breakfast that we had for 200 business leaders and individuals and parents. We brought together our congressmen, our county council leaders, business people, and

parents. We had the Secretary of Labor there. We had Dick Marriott speaking. We had David Trone, who is a business leader, who employs individuals on the spectrum. We had people from the media. It was amazing to see the response and to get the feedback going in and coming out of that breakfast.

We had a lot of very interesting things that have come about as a result of that. We know it can work in communities across the country, again, to increase the consciousness.

We also had a young man playing the piano there who was on the spectrum. He also works for a piano company. We had 21 works of art done by people from around the country. Not only did they represent themselves and their art work, but they represented many others because it was a visual connect of the

abilities of many individuals on the spectrum.

There is something that we have included with this that we had made available to various states. These things are made available to you right now. These are mini documentaries about individuals that are on the spectrum. I would like to play one right now.

This is David, who is a cartoonist. Very interesting young fellow.

(Video Shown)

MS. PRINCE: We have one other video that I would like to show you. I think there is a lot of impact with that. May I remind you too that well over a million families have individuals with IDD and autism living with caregivers over the age of 60? Let's go on to our next one.

This next individual is someone who is working on a farm that has been partially gifted to our foundation here in the Maryland countryside. We are offering job training for individuals on the spectrum in agricultural endeavors. This is Adam AJ Jones.

(Video Shown)

MS. PRINCE: I would like someone to stand for just a moment and as a young man in this last movie right here. Adam. Thank you for sharing your story with us.

These are the types of stories that we have talking about and sharing across the country with Autism After 21 Day. To make people real, to tell honest stories, to have voices of families and individuals and those in the community.

With this one particular part of our presentation, we would like to call on everyone to have something of this nature in

your own state and location that we can help provide various aspects of media for it and to have a breakfast on April 21 to start to make more people conscious of the talents and abilities and challenges facing our population.

This is one gentleman from another one of our videos. I want to break the conception that people with autism are unable to do things. They are just as able to do things in their lives as anyone else.

I would now like to turn the time over to Desiree Kameka, who is our national housing coordinator for Madison.

MS. KAMEKA: Thank you for having us. I have been working for the Madison House Autism Foundation since 2009 and made three housing initiatives. The first one is the Autism Housing Platform. It is an online platform where people can bring together the

greatest ideas in housing. I have fliers up here if you would like to take some.

The second program that we run is the Coalition for Community Choice. It is a network of organizations and individuals who are speaking as one voice to be able to increase options and decrease barriers to housing and employment choices.

The third thing that we do is empower local communities by providing consultations and presentations to help inform local communities of all of their options.

Today, I am going to speak about specifically the Autism Housing Network. It is a culmination of many years of research. Our foundation has invested over a half of million dollars into going and doing site visits. I personally have been to over 100 residential opportunities and social

enterprises all around the country and abroad.

It is a direct outgrowth of the 2009 Opening Doors Study, an initiative by Arizona State University and Southwest Autism Resource and Research Center. One of the things that they have called for was to have an interactive database and that is exactly what we have developed with the Autism Housing Network.

We are also growing this database in a housing directory of not just existing opportunities, but also emerging opportunities and opportunities that are in the planning stages in order to help people connect. We host forums and do a lot of consultations to be able to help people. I am just quickly going to walk you through the Autism Housing Network with hopes that it also brings up some potential questions that

can inform research. We really need a lot of information, evidence-based information for housing because we believe that housing is the hub of the wheel. We can put so much effort into employment and developing natural supports and creating social networks. But if someone loses their housing and they are having to move two counties away, all of that energy, effort, and resources have just been lost.

Individuals lose their housing because maybe their group home provider goes out of business, maybe their rent has increased out of their price range, maybe their family member has died, maybe they live in an adult foster care situation and their host home can no longer support them. These are all reasons why people might lose their housing and therefore lose all of that support network that we have worked so hard to build. We

really believe that housing is the hub of the wheel.

This is a shot of our front page. There is also a welcome video on our home page, which will allow you to watch the different functionings of the Autism Housing Network as well.

This is our education page. We help people and give recommendations on how they can explore housing options, create housing opportunities and advocate for housing. We developed information on public funding 101. Here are the basic aspects of where you can get some support, a turning 18 checklist. We have a section that talks about statistics and where you can share statistics about autism in adulthood.

And then we have also developed a virtual tour of housing. This is a video series that is available for free for

individuals. And what we have found is that a lot of families just think that group homes are the only option. They do not realize that there are actually many more options available to them. This video series talks people through the traditional housing and support models, some of the challenges that are being faced with the traditional models and also what are some of the emerging models that not-for-profits and other organizations and family members are coming together to be able to develop, using the tools that we have today.

I think it is really important that we realize that there is no one stop shop that there are benefits and considerations to the multitude of housing models and service delivery systems.

This is a screenshot of our Autism Housing Network, the housing director. This

housing directory can be viewed in the map view, but it can also be viewed in the list view. We have created a set of filters based on our research to help people identify what could be some best practice models. They are filtered by property type, support model, payment options, lifestyles, support levels, and then the primary residence.

Some questions that come to mind. Right now, it is now being filtered for live, work, play communities and planned communities with built-in support services. A lot of individuals on the spectrum may never qualify for Medicaid waivers. They will not qualify for Medicaid long-term support services that they need to have some additional support to be able to live independently.

I was just last week in Florida, visiting a community called the Arc Village of Jacksonville. There are a lot of

individuals that live there. They pay 30 percent of their SSI and they have built-in supports like a community navigator. They have built-in transportation. They have voluntary planned activities where they do not have to try to call friends up to coordinate or figure out rides. It is all done. They just have to decide if they want to go or not. They have a dining option. They have full kitchens with one bedroom or two-bedroom apartments. They have full kitchens. But at the same time they are able to access a dining experience similar to like a college dorm. As well, they have a partnership with a local college so that there is nursing staff there all the time. That is so great too because these are nursing students who are finally getting some face-to-face time with individuals who have autism and other developmental disabilities.

I think that looking at - when we talk about like this morning of suicide rates, if an individual has no choice, but to live with their family, they do not have a job, they are not accessing their community, they are isolated, and how does that influence suicide rates? What if we were to start to look at the suicide rates of individuals who have been able to access residential supports in different types of settings whether that be host homes, group homes, living independently in their own apartment or townhouse, living in a home that their family has bought for them? How are the suicide rates influenced when someone is able to live out on their own?

Additionally, I think something very interesting is the payment options. A lot of people do not realize that there are private paid communities across the country where for

families who are wealthy are able to private pay for their long-term support services for the lifespan of their loved one. They operate typically between \$3000 and \$5000 a month. But when compared to publicly funding options, oftentimes it is less than the publicly funded options in the area.

I wonder because it is private pay, is there a difference in the quality of life of the individuals, their satisfaction with their supports? Is there a difference in the quality of the staff? Is there a difference in abuse rates? Is there a difference in the fiscal responsibility of private pay models in comparison to publicly-funded options? It is worth looking into.

Additionally, I think that looking at property types as well and then lifestyles. There are different lifestyles for different people who are on the autism spectrum are

just as diverse as the neurotypical population in terms of lifestyles.

I was in Ohio just a few weeks ago visiting a community called Safe Haven Farms. It is established by a father who had tried to create an opportunity for his daughter who has high support needs, self-injurious behavior, and elopement struggles. She had lived in a group home. It did not work. She had lived in her own apartment. It did not work. They had created a suite in their basement of their house. It was her own space. It did not work. She was isolated. She was frustrated. She was having behaviors daily.

Finally, they developed a farmstead. It is four homes in a rural community and it is staffed by a provider of their choice, which means that the provider is no longer working for them. They can kick that provider out and

have another provider come in. But it has significantly increased her quality of life. Where she is having bad day she could walk around an area that is comfortable to her where people just expect to be able to support her in certain ways where she can do things that she likes to do. And if she has to walk around in her PJs because we cannot get changed at that particular moment, it is okay. This does not have to be a real community like a farmstead. But I think other campus-based models needs to be looked at and we have to be able to have options for this particular part of the spectrum who oftentimes are unnecessarily institutionalized and medically restrained.

We also have the opportunity for people to be able to submit listings. The opportunities that are on the Autism Housing Network have been submitted by people all

around the country. Please, if you know of an opportunity that you would like to suggest, feel free to recommend it.

We also have a resource directory that you can also submit listings in. Again, it also has a very specific filter opportunity. These objectives include being able to access public support opportunities and resources for developing a home ownership model. Opportunities for managing support services are in this objective field.

In the topics field, this is just an example. We have 21 resources that talk about sensory friendly design and architecture. I believe there are almost 300 resources in the Autism Housing Network right now, but anybody can add to these things.

We also have things like tools for life skills, survey and assessment tools. An area of research that is definitely needed is

right here. Assistive and smart home technology. How can we use this technology? How much money is saved using technology to be able to increase direct support staffing? As well, how is that improving quality of life because someone does not have to have a person inside their apartment? They can have access to on-demand support. How does it change self-direction of an individual to not have someone butting in or interrupting them when they are trying to figure out how to solve a problem? What does it do to abuse rates to have cameras in common areas and to use technology? Right now, the abuse rate of this population is almost 70 percent. That is unbelievable, completely unacceptable.

Another area that I think will be really helpful is right here. Survey and assessment tools. To be able to start tracking what happens to an individual's quality of life as

well as their ADLs, their activities of daily living when they move out of their family's house. Why do we assume that the neurodiverse population does not grow like a neurotypical person when they leave their family home? How much are individuals regressing if they are staying in their family home? Why is government forcing families to keep people in their family home instead of giving them the supports to move out into the community? In the long run, are we saving money by keeping them in their family and making them more and more dependent or would it be a better investment if we were to invest in the individual, give them the supports in the housing that they need so that they can continue to grow in their independent living skills?

We have a discussion forum. We have an area that talks about stories. A lot of the

site visits that I have done - I do interviews with residents where I videotape their responses to questions like what do you like best about where you live and what would you change.

We offer consultations to individuals who are having challenges. We offer consultations to emerging projects. Something that is really important to keep in mind and that haunts me is that a million people who live with a caregiver over the age of 60. Every two weeks I get a consult request where a family member be it a sibling or an uncle or a niece or a nephew says my aunt just died. I do not know what to do with my cousin. Help me. What do I do? These are people who have not had any experience in the system, navigating this maze, and all of a sudden they do not know what to do.

Our next steps are going to be developing a market study with the same leaders who developed that opening door study that the autism network grew out of them. We are combining forces to be with the First Place Arizona Global Leadership Institute to do an actual market survey where we can talk about what are the support models out there. There has been a huge evolution in the way in which people are supported and where they live. There is an emerging niche market that needs to be defined. We are creating a study in order to create that foundational nomenclature so that we can actually talk to the private sector about how do exponentially increase options. What are some of the incentives in policy that can be put into place so that we can create more supportive housing opportunities, more home ownership models? And then trying to develop the

relationships between major entities like a housing and finance authority and Medicaid for them to be able to think more creatively about how are we using our extremely limited dollars.

If you would like to know more about the Autism Housing Network or the market study that we are embarking on, please feel free to come up and speak to one of us. We would be happy to talk to you about it.

(Applause)

MS. PRINCE: Desiree is a rock star. She has been received so well across the country. There have been numerous projects that she has helped begin across the country and changing lives in communities.

We are a national organization. We are also acting locally because we believe that most of these solutions will be developed by people within their own communities that are

informed and that they know what is happening.

To let you know that we do have something else happening with Madison Fields, there was a very interesting attorney that just before he died put us in his will. We inherited the equity in a farm, a 400-acre farm in Dickerson, Maryland. This is to go along with the research because we want to encourage research dollars coming forward to help this population.

We want to provide a place as we are doing job training. We are in the agricultural reserve. We have to confine things to education and employment that we can train people on our farm to go to other farms and work in other parts of the community. But they can have the support and learning what they need to learn by being with others.

The thing that is so unique about this is we are bringing three populations together. First, the neurotypical population. They are participating on our farm. We have former military, some with PTSD. We have some folks from Walter Reed that come out and work with us. They are finding new meaning in life especially when there have been situations where there is survivor guilt. Why am I still here and my buddies are gone? They find that they can work alongside other individuals and have a new meaning in their lives and our individuals are enhanced by their life experience. And then we have those with autism and intellectual disabilities. We want to partner with universities and others doing research because we will have a critical mass there and we want more research being done.

In another 10, 20 years, there will be a lot more information because when we started,

there was very little. We could hardly find out the numbers in Maryland of how many people needed to have services or what waiting lists were even like. We have come a long way, but we have a long way to go.

We have our call for action with our Autism After 21. Look at some of the things that we are doing and we are working with housing. Those are our three take-a-ways today. The idea is not limiting the seats at the table. Everyone needs a seat at the table, and how do we do that? We get a bigger table. That was one of the statements that came out of our Autism After 21 breakfast this year. I would like you to take that with you as you are making decisions here with this auspicious group as we go out into the community and those that are listening to us. Let's empower one another. Let's make certain that we are aware of this very important part

of the population and that we can do something positive and that we can work in partnership to enhance the abilities, talents, and understand the challenges of adults with autism. Thank you.

(Applause)

DR. DANIELS: Thank you, JaLynn, and to all of the Madison House team for your wonderful presentation.

We have a few minutes for questions. We can take questions until 3:10. If you would like to discuss the presentation, please go ahead.

MS. CRANE: I am really surprised that the presentation mentioned that autistic adults are an invisible population and that we have not been addressed until now since the Autistic Self Advocacy Network has existed and has been talking about autistic adults for ten years. There is no one really

better to talk about the needs of autistic adults than autistic adults.

I think that there are a lot of things that Madison House and ASAN have in common and what we want for autistic adults.

Obviously, we all want community participation. We all want integration. We all want people to not be trapped in their parent's houses for their entire adulthood.

But I am really concerned that when we talk about autism and housing, we are just investigating intentional communities here and that is really not what the - that is one choice, but it is not the only choice and it is certainly not the only choice that allows people to move out of their parent's homes.

A lot of people on the autism spectrum who want to live with friends, their solution is they go up to their friend or they have their parents help them go up to their friend

and say let's find an apartment, a three-bedroom apartment. It is you, me, and Joe. We are all going to be living in this three-bedroom apartment. Unfortunately, there is so much less money going into research into how to make that work even though it is what the vast majority of autistic adults who want to move out of their parent's homes are doing. I want to make sure that when we do invest in research on housing projects, we are not just researching one kind of housing project that has a name and a fence around it, but also the full range here.

MS. KAMEKA: Thank you for your comments. I apologize if it came off as if we only support intentional communities. We certainly do not. I think that one size does not fit all and that research money should absolutely be going to the broad range of housing and

service delivery models because we have a broad range of individuals on the spectrum.

DR. MANDELL: As far as I know, there are very few networks of housing opportunities for adults with autism. We have a real paucity of research about the outcomes of different models of housing. Part of the challenge of doing that kind of research is that often looking at the outcomes of a particular setting is hopelessly confounded by the needs and the presentation of the people who live in that particular setting.

I wonder if you think there is enough variability in the different types of setting that are part of your network that might lend itself to some kind of research network that would allow us to look at different kinds of outcomes for people of autism in different settings.

MS. KAMEKA: I think that part of our market survey is trying to define those types of opportunities where we can actually define the service delivery model in general and then define the housing property type and then also define the population based on their support needs so that there can be research done with either one sub-population and one type or to look at the variability. In any way that you can inform how we are developing this market survey, I certainly would like to talk with you further if that would be something that you would be interested in helping us make sure that we are creating those parameters in a way in which you could do your research.

MS. CRANE: Can I just add? I personally live with another autistic person. We have a shared housing model. If the network that we are looking at is just projects that have

signed up to be part of the Autism Housing Network, households like mine are not going to be on it and are not going to be included in market research. That is going to contribute towards a bias towards planned, intentional communities as opposed to what I would call a spontaneous intentional community, which a bunch of people just say let's live together and then they live together and they do not have a name. I want to know how we are going to make sure the full range is included in that study.

MS. KAMEKA: You do not have to sign up for the Autism Housing Network. I think that looking at the providers of individuals who have supports. Consumer-controlled housing and provider-controlled housing are two different types of service delivery models. Provider controlled housing is one service and home are tied together. Consumer

controlled is when an individual secures their housing separate from the service delivery model. I think that when we are looking at the quality of life of individuals, we are probably be having to look at the service providers and therefore the service providers will likely be serving people in a variety of different housing opportunities. I think that that would be one way that we can ensure that housing arrangements like yours, Sam, would be accounted for.

DR. MANDELL: I would love the idea of combining. Part of our challenge is we are always going out and looking for adults with autism to do the kind of work that John was referring to earlier. And that introduces its own kind of bias when you want to study housing. But I think combining some kind of network with some kind of survey of adults

with autism who are living in settings that are not captured in this kind of network could be a very powerful tool to understand and answer some of these questions.

MS. CRANE: I did not mean be negative about the housing network. I am just saying that most people if they choose to live together in a group of three people, they are not going to go ahead and register their house on an Internet database necessarily. They are just living their lives.

DR. AMARAL: Coming from completely out of this whole area as a biologist listening to this, I find it really fascinating. One of the advantages of having a network is that if you are going to do this experimentally, what you would say is we have these several housing models. Let's take a group of individuals with autism across this variability, as David was saying, and you

place them in each of those models, study them for 20 years, and then find out what model works best.

MS. KAMEKA: We do not have 20 years.

DR. AMARAL: I am just being facetious. Having a network where you can try to get a semblance of that I think makes a huge amount of sense.

Beyond that, if you get some data from that network, it is like a lot of the biological studies. We are not encompassing all subjects that have a particular trait. But if we get information about that trait then we can apply it to the broader autism community. In a sense, you do not have to feel left out because you just want to take advantage of something that is established in order to try and get some work done if they need to go on to the next step and try to replicate it.

MS. CRANE: My main point is that certain models are systematically never going to be on this network. That is a concern.

DR. AMARAL: My struggle with this discussion is that you have to pick your battles. I think part of the reason why the percentage of funding going to this kind of research is perhaps so small is because the battles are really difficult and complicated. I think you have to start with doable research and then you expand beyond there. Even animal models. There is probably hundreds of animal models now that have been implicated or that have associated with autism, but really what you want to do is focus on a few of that is going to have the biggest pay offs. I think in this case, you want to come up with a system that may have the biggest pay off.

MS. CRANE: I disagree. I do not think we have any indication that on a broad policy-wide level four people deciding to live together is going to have somehow a less big payoff than four people deciding to live together and calling it an intentional community and putting it on this website. And certain kinds of arrangements are systematically not going to be on the website. They are actually among the most common arrangements and they are going to be left out. There are serious policy implications to this. It is not like we will study this first and then we will study these other things. There are very serious policy implications if we are studying certain kinds of housing and not other kinds of housing that I think we have to think about.

DR. DANIELS: Other comments on this topic?

DR. TAYLOR: I was just going to say - I think that these highly complicated issues that those of us that live in the space on a regular basis grapple with all the time. I think as we talk about it, sometimes it almost feels like - I almost sometimes feel like I want to throw my hands up and say this is so complicated. We should just move forward and do it. I just want to encourage everybody to keep grappling with these issues. Maybe some designs are not the best designs and a study is not a perfect study, but right now we know almost nothing about the effects of housing or the effects of employment or the effects of almost anything when it comes to adult research. Sometimes I think we have to start small and move forward. Any progress is huge progress I would say at this point because we just know so little.

MS. CRANE: The danger is that if one of the biggest sources of housing for autistic adults, which is trying to live with friends, which is a very large group of people who try to do this - if they are invisible then people are going to be diverted away from those models and into other models that we do not know are better. I do not know if I would even necessarily consider that progress if that is what ends up happening and that is what we are really worried about.

MS. KAMEKA: I am not sure when you are saying most people because I will give you an example. I am a host home provider. A young man with autism lives with me. We invited him to live in our house when he had become homeless. We had known for other reasons. He does not have the capacity to connect with other individuals and be able to pay rent. He lived before we got him a job off of his

social security so \$721 a month. For him, he is lucky enough to be able to access services. I think when looking at research purposes, there are certainly two very large differing cohorts, which are individuals who cannot access Medicaid waiver services and then individuals who can access Medicaid waiver services, individuals who can afford housing because they have more than a 20-hour per week job and maybe those who will live off of SSI or SSDI or a little bit more if they are able to access employment, which we know most individuals on the autism spectrum are not accessing employment right now.

I do think that we can try to tease some of the population apart in order to focus on a set of individuals who are not accessing Medicaid services who have a job who are having trouble getting affordable, accessible housing or not. From what I hear, it is a big

problem being able to afford and find housing and roommates that work. And then you have a whole other population of individuals who do not have the capacity to be able to do that who do rely on Medicaid waiver supports and will need to find intentionally affordable housing, not just a housing voucher. A housing voucher - when they say there are housing vouchers for people with disabilities, there is not even waiting lists opened in many places in our country. It is not really an affordable housing solution in any way, shape, or form.

DR. MANDELL: I think Sam's point from a statistical perspective is that if you artificially constrain variance around the housing options that you study, you can only find the relative benefit within the relatively narrow range to which you

constrain. That is how you end up with Charles Murray's bell curve.

I think that we want to be really careful given the policy implications of what we are doing to make sure that that whole range is represented to the greatest extent possible.

Now, in order for that to work though, there has to be enough overlap in the presentation of the individuals living in those different settings for you to be able to draw meaningful conclusions. You have both sets of constraints that you have to be very sensitive to. But I definitely hear what you are saying about the need for the range of housing options to be represented if you want to draw meaningful implications or inferences from what you study.

MS. CRANE: The point that Desiree made about Section 8 vouchers not being available

is another way in which this intersects very intimately with policy advocacy. If we do research on people who are living on SSI, using a Section 8 voucher to live with whoever they want and they are getting self-directed services, yes, there are a lot of people who cannot access that. But if we have data on the outcomes of housing models like that, we can use that to inform policymakers on whether or not these Section 8 vouchers should be made more available and we cannot do that without the data.

MS. MCBRIDE: This discussion what you are saying of how important that the market study that we are proposing to do will build on this body of research to help answer these questions and get the data that we need to answer these questions. If anybody is interested in partnering with the housing study, please see me afterwards so we can

discuss how to move forward and make sure that we do a really excellent study.

MS. PRINCE: Adrienne is an absolutely amazing executive director. I thank her for all the coordination that she does and bringing us here today.

I wanted to remind you of one other thing. During the time that we have been speaking, another four and a half individuals in America have joined the ranks of adults on the autism spectrum. Thank you.

(Applause)

DR. DANIELS: I would like to now move us into our break and for us to be back here at 3:30 to start up again. Thanks.

(Whereupon, the Committee members took a brief break, starting at 3:17 p.m. and reconvened at 3:30 p.m.)

DR. DANIELS: Let's get started on committee business. We want to come back to

this to try to finish the work we were doing on the strategic plan.

We will resume where we left off. We had just finished our discussion of Question 2. I would like to move to Question 3 on risk factors. What causes ASD, and can disabling aspects of ASD be prevented or preempted is the new title for this chapter. You have three objectives that are listed here for you. Does anyone have any comments on Question 3 and the content? Anything that you thought needs to be expanded or if there was some other topic that was omitted.

MR. ROBISON: I would just say the same thing that I think we need to get this done, Susan. We will have plenty of opportunity to make all the changes we want to the 2017 plan in four more months.

DR. DANIELS: We are going to be doing an update in 2018. That sounds far away, but it

is really not that far away. This is the 2016-2017 plan and we want to make sure it gets done in 2017 so we do not have to expand that number. We want to finish this plan this calendar year. I think it is completely doable. You all have come very far with this. I think it is just a few more steps.

Any substantive comments on Question 3, things that you think need to be added.

DR. KOROSHETZ: A point of clarification. They talk about recent survey of autism twin studies find concordance for monozygotics at about 45 percent. I had thought it was higher.

DR. DANIELS: David, do you want to address that?

DR. AMARAL: That is a review paper that came out last year that actually was a meta-analysis of all other - in studies and that is where it landed at around 45 percent.

There is quite significant variation within different studies from this meta-analysis. It was Bourgeron who is the first author of that review.

DR. DANIELS: I know that there are a few papers that have come out in the mean time since this was written. Those are things that in the comment period, as you all review it and send comments, if you want to add a few sentences here and there or references, you can let us know.

DR. REICHARDT: I would just like to say that I wish - there have been a few sentences added at the end of this section on genetics - I was not very happy --

DR. DANIELS: You mentioned something about the evolution of the X and Y chromosome, but that was something that we were not able in the office to be able to write about so if we needed a reference or

something to go with - if you could give us more clarification, I think we could add a few sentences. Evolution of X and Y chromosome.

Anything else topic-wise that needs to be in there?

DR. REICHARDT: (inaudible) -- what is known about evolution - illustrates several - importance of discovering - risk factors - understanding - it has such financial implications --

DR. DANIELS: If you could send us some information and then if we need clarification, we will call you.

Anyone else have comments on this section? We did make the revisions based on the comments at the April meeting to try to capture more broadly the interest in preventing disability, but also ensuring that research is supported for prevention in terms

of environmental factors that may affect early in the process.

MS. CRANE: I mentioned this earlier today with respect to the prenatal language. I think that the language on genetic counseling is probably going to be interpreted by a lot of people in the community as an attempt to say you have an autism gene so do not reproduce or let's screen fetuses for autism before birth and try and prevent people on the autism spectrum from being born. I think that is something that is going to cause a lot of alarm for certain parts of our community. I just do not know if we want to necessarily call that out.

DR. AMARAL: I think that this is really important. I think nobody really has the solution to this yet about exactly what information should be handed out and how it should be handed out. But as we get more and

more into these very comprehensive genetic surveys, not only are there going to be genes implicated in autism, but in long-term diseases, cancer and all kinds of other things. I think people are just now trying to figure out exactly - certainly, there are the implications that you say, but there are also implications for lifetime health that the families have to take into consideration.

I think if we stick our head in the sand and say we are not going to deal with this issue, in the end, families are going to be hurt by that because potentially they are not going to be getting valuable information that will be to the benefit of their children.

DR. REICHARDT: I just wanted to say genes identify targets, which alleviate phenotypes that I think almost everybody would find discomfoting whether it is

gastrointestinal, sleep issues or whatever.

There is a lot of hope from the genetics.

I had one question for David is whether epigenetics was intentionally disappeared.

Did I miss it?

DR. AMARAL: It is in there in a sentence or two.

MS. CRANE: Is there a way that we can word this like gene-targeted therapies or gene-targeted interventions that will make it more clear that that is what we are looking for? Because I agree. I think that genetics - people on the autism spectrum react to medications very predictably. If we can find gene markers for that, that would be great. I do not think anyone in our community would be opposed to that. I just want to make sure that that is what we are clear about.

DR. BIANCHI: The reality is that any fetus with a sonographic abnormality, it is

standard of care that diagnostic testing is recommended, which is usually later gestation would be an amniocentesis. If there is a fetal sonographic abnormality, a chromosomal microarray is considered to be standard of care. Those microarrays routinely identify areas of variation in the genome that are associated with ASD.

Again, I do not think we should stick our head in the sand because part of our responsibility is to help identify an evidence base of accurate information. There is a lot of misinformation out there. By avoiding the issue, you do not want to allow practitioners who do not have accurate information to give inaccurate counseling. That is my concern.

DR. REICHARDT: She is suggested a solution.

MS. CRANE: I cannot even remember what I said anymore. I am sorry. It has been a very long day.

DR. AMARAL: The implications are that some of the mutations that are observed may actually have long-term implications that a family has to be aware of. I think this is trying to emphasize that we need to come up with guidelines about how to present those data. I think everybody is struggling with this.

I really do not think it is intended and I am happy to have it changed to a way that makes it more palatable, but it is not intended as something that would say let's eliminate this individual. It is like how can you inform a family who is not a genetics knowledgeable family of implications of these findings that are going to be coming out.

It is daunting because I know that the best people in the world who are doing this do not really have a solution yet about how to do it.

MS. CRANE: And the question is how are we going to capture that nuance in just this one sentence. I do not know if it is even possible to capture that nuance in this one sentence.

DR. BIANCHI: I think what you want to communicate is the need for an evidence base to provide data on the complexity of ASD risk genes to allow provider education and inform family discussions.

MS. CRANE: I do not think that that is enough. Frankly, we have seen this in a lot of parts of the disability community where simply being accurate about whether or not this is a real risk for ASD or not is not enough to help people make an informed choice

about a pregnancy unless you also inform doctors about lifespan, quality of life, services available, examples of people throughout the lifespan, the full range of what autistic people feel and say. Frankly, this has happened in the Down syndrome community too. This has happened in the deaf community. This has happened in the dwarfism community. It is not enough to just be able to say we are giving people accurate information about whether or not their child will have a disability without getting into a larger discussion about what it means to have a disability. That is not going to be necessarily captured in genetic studies.

If we are talking about this as a specific goal that we want to commit our - I am not saying people should not have information, but if we are talking about one of the things that our community needs most

is resources spent towards identifying these genes so that people can have prenatal counseling then that has implications for whether we value that - I am losing my train of thought. It has implications for what we are saying about people across the lifespan. It is a really sensitive issue. I do not think that we can just boil it down to spend a lot of money, get the science, tell parents and let them make their own decisions. I think it is going to be a lot more nuanced than that.

DR. AMARAL: Just to maybe to cap this off and I take your points. I understand what you are saying. The primary portion of that sentence is understand the causal relationship between identified risk genes and clinical outcomes.

I think the goal is to know if you have a particular gene mutation. What is the

likelihood that you will have a particular outcome, which is really hard to say now? It is almost impossible to say. Until we actually have more clarity on the cause effect relationship, we do not really know how to communicate that to the families. Does that make sense to you? That is where we are aiming for. That may be a decade away. I do not know.

Once we actually have the cause effect relationship established then I think there is a whole other discussion that you are illuminating about does it make sense, does the society want us to actually convey that information. We are not there yet. I think it is really important to actually be able to establish the cause effect relationship if there is one.

DR. BIANCHI: My point was only that it has already happened. I just want you to have

that reality check that it is already happening and it is not necessarily accurate. That is where I am coming from.

MS. CRANE: Amy, I think that one of the things is that we are talking about a goal and we are trying to reach consensus on this goal. What I am hearing is that we do have consensus that we probably want to know what genes do. I do not think anyone is objecting to wanting to know how genes affect people.

We want to educate providers about what genes do so that whatever information we have, they are going to conveying it accurately to individuals and their families. I am not sure that we can come to consensus on wording about genetic counseling in particular that will fully address the concerns of the disability community and the concerns of people who want to improve genetic counseling. I think that we can

probably just include that and say we want accurate information on what genes do and leave it at that.

DR. DANIELS: Kevin and then Linda.

DR. PELPHREY: -- complicated discussion. I was kind of applying the same criteria that David applied to in an earlier one. I thought it was a really good criterion. What does that bullet point tell us to do? It does not tell us much that currently we have the technology to do unless we - with a causal relationship part unless we can experimentally modify the ASD risk gene in a human and look at clinical outcomes. The rest of this discussion can be placed on hold. I think there is a feeling I am getting - see both sides of this where it is - maybe this one is not ready for prime time and the other two do a great job of fleshing out Objective

1 for a year and then this third one just is not there yet.

DR. DANIELS: Perhaps what we could do is we could end after clinical outcomes and the rest of that - maybe if there is a statement about that there is still discussion about what should happen in terms of genetic counseling and put that somewhere in the text and not as a part of the objective.

DR. PELPHREY: And take out causal. Once you start having a clinical effect as pointed out, epigenetics, you start having feedback onto the genetics. I am not sure what causal means there.

MS. CRANE: The final sentence of that thing too. I think that that can stay in understanding parental concerns and attitudes. I think that is important as well.

DR. BIRNBAUM: I was going to make that comment, but I do want to point out the fact

that this is also the objective and risk factors where we talk about the environment. There is beginning to be data that shows that the outcome is going to be very dependent, not only on the genes, but on the exposures that occur. And that is where we will have real opportunities I think in the future rather than actually changing genes, for example.

I think that the suggestion and I think in a sense, Kevin, that you made and, Sam, that you made, which is go back to Objective 1 is just stop after clinical outcomes. I think I am okay with the causal relationship, but then go on to understanding parental concerns when communicating complex information and just leave out the counseling at this point. How do you feel? Because you say people are getting counseling now.

DR. BIANCHI: I think it is fine as long as you are understanding. I think that gets at the issue of developing an evidence base, which is what I am concerned about and then understanding parental concerns appreciate the situation for perspective parents. I think that would be fine. I do not even need the causal.

DR. PELPHREY: Can we change causal to complex because genes do not cause outcomes? Genes cause proteins to be developed, which cause complex --

DR. DANIELS: It sounds like you have come up with some pretty good solutions for this one. I think that we can make those changes. Did you have something to add?

DR. SHAPIRA: Just a comment. I think that this goal, this statement is broader than what has been brought up with regard to prenatal genetic counseling. Most of the time

that a genetic testing is done is the child already exists and is having some symptoms of autism spectrum disorder and has genetic testing done and there will be something that comes up in the micro-array or some SNP test or whole genome sequencing and so on. The counseling for the family is to best understand the relationship between the mutations or the variants that are identified and what might be expected for the child's phenotype and are there then interventions that can be utilized. We do not have enough information about the relationships between the variants or the mutations in many cases and the phenotypic outcomes that one might expect.

When I read this and I understand the point that Diana made and what is being done in the prenatal realm, but I think in the pediatric clinical genetics realm, it is

really the genetic testing and counseling the family about what does it mean to have this variant. And there is not the population of providers who best understand how to do that. I think that this is really looking more at that lane as oppose to the prenatal although the prenatal is a part that we have to acknowledge exists out there. I read this quite differently.

DR. KOROSHETZ: I was involved in the first genetic testing for Huntington's disease. The key part of that was to incorporate really informed genetic counseling. That was not prenatal. That was people getting their own diagnosis. The fear among the community was that this genetic information would be given without counseling. The guidelines for the counseling are incredibly important I think if genetic information is being released. I kind of get

Sam's point, but I do not think that the concern is strong enough to take out that genetic counseling piece. I think you are assuming something that may not be the main picture and the counseling is absolutely key.

DR. AMARAL: I want to just say that both of these comments are really important in the discussion in the work group and actually the example that came up was the CHD8 mutation that is highly penetrant in producing autism. The reason that this verbiage was put in is because a lot of the individuals that have mutations that that gene go on to have colon cancer.

How you express that you have a mutation because you come in as a patient with autism is really important for the families to consider their medical management. Then you want to have much more persistent surveillance.

DR. GORDON: I apologize because I just came in, but I understand we have been talking about this for about 15 minutes. I want to refocus a little bit. What we are trying to do is approve the language that is there. Although I appreciate the nuances of the difficulty of what we are talking about, I think we can all agree that understanding the causal relationship between genes and clinical outcomes and using it to inform guidelines is something that is a valuable thing to do.

DR. WEXLER: Without taking a position on counseling or not counseling, I think the point was made is that it is being done and the exemplars that were given, the critical nature of it being done. I view the IACC as it is supposed to be helping to coordinate research related to autism. Running grants myself, this is a public statement to folks

who are applying for grants as to what is important. If there is a value to counseling within especially NIH then excluded it - I do not know if that is the message that you want to send because you might actually have people applying for grants to explore how to best interact with parents whether prenatally or postnatally based on whatever genetic findings happened to be found.

From an organization standpoint and from a functional standpoint of what this strategic plan is supposed to do, I think we need to think about messaging.

DR. GORDON: It is strategic plan for research and care and services. This is an Interagency Autism Coordinating Committee. I would like to take a vote on this issue. I would propose that we vote on whether the language as currently written is adequate for the committee. Do I have a motion? Do I have

a second? All in favor? All against? Anyone on the phone against? Anyone abstaining? The motion carries. Let's move on please because we have a lot more to do on the strategic plan.

I do not mean to minimize. I am glad people felt like they had the opportunity to object, but I think it is clear that - if not a consensus, at least a majority --

DR. DANIELS: Earlier, I did not hear a lot of other comments on Question 3. Is it okay to move on to Question 4?

There were some feedback I received on Question 4, talking about wanting to see a little bit more in-depth review of progress on drug treatments and new opportunities arising from advances in neuroscience, discussion of novel therapies for the future such as stem cells, a more robust discussion about key issues involved in things like

RTMS, a more robust discussion of combination therapies, which was discussed quite a bit in the working group calls, but it is only a short portion of the text. And ensuring that interventions include the whole spectrum and diverse population, which was discussed by the group, but may have gotten a little bit lost as we edited it down. We could try to put that back in. Those are some of the items that were identified for me so far.

Are there additional items or do we need some discussion on some of the things that I just mentioned?

DR. AMARAL: If I can quickly say, Susan, that all those items I think will need some substantial revision because I think the text as written does a really good job in terms of handling behavior therapies and all aspects of that. But, again, just in terms of what this document is supposed to do. It is

supposed to be leading the way for research over the next five years or so.

You get the sense when you read the document that there are not any pharmacological treatments or that pharmacological treatments are not going to be used in conjunction with behavior therapies. I think what we need to do is actually highlight the fact that this is a real big gap. We need to invest more resources and trying to figure out how to do this.

One example is stratification. A lot of drug trials failed because they are not adequately stratified. Either they are stratified based on endophenotype or they are stratified on genetics or something. I think we should highlight the fact that stratification of the autism population. Everybody knows it is heterogeneous, but it

does not seem to come into play when people are designing treatment trials or drug trials.

I will stop there because I know we are short of time. I would like to see some substantial oomph to the biology side.

DR. DANIELS: And we do have resources within the committee. Geri Dawson could help us with the stem cells. We have Rob Ring on the committee who could help us. There may be some others here who would like to contribute to that.

DR. MANDELL: Paralleling what David said, on the behavioral intervention side is an excellent, well-written summary of what we know now. But I do not get from the summary what the gaps are in behavioral research. Perhaps because of this, this is leading to objectives that are pretty - it is not that they are vague. It is that they are very

broad. The only place where they are not broad is in technologies. I found it weird that we have so many gaps in behavioral treatment, in pharmacological or biological treatments in their intersection. That is, do medications potentiate learning so that you would see greater response and longer-term response to behavioral treatment? I liked a lot the piece on markers of treatment response, more sophisticated markers of treatment response. That part I thought was in some ways the best part of this section. But it did not make it - that stuff does not line up in my mind with exactly the way that the objectives are written. I know that that is a heavy lift and probably not for discussion now. I understand if people feel like we need to move forward. But in keeping with the spirit of this, this is going to set the proposed research agenda for the next

handful of years. I do not think we have directed people enough.

DR. DANIELS: Perhaps in the revision process, we should rethink the objectives to be a little bit more specific about the next steps and where we need to go.

DR. REICHARDT: I just would like very briefly is my own thinking about this is I think we need ways similar to what is being done in cancer to basically direct drugs to the specific areas where they are needed given the complexity of the brain. I see that as a big gap.

DR. GORDON: I would echo that from NIMH perspective.

DR. AMARAL: One final comment is that the issue of biomarkers of treatment outcome I think is an incredibly one. It was a lot of enthusiasm. I understand the enthusiasm for the studies that have been done, but there

are only less than a handful of studies that have really looked at biological biomarkers of treatment outcomes. This is an important area and I think it has to be seen as a remaining gap so that we can put some more effort into it.

DR. DANIELS: I think this feedback is very helpful. It seems like this chapter probably could use some more substantial revision. I think that based on these comments unless there is anything else that we have not covered could guide us on those steps. If it is okay, let's move to Question 5, services.

The question now is what kinds of services and supports are needed to maximize the quality of life for people on the autism spectrum. We have three objectives. Does anyone have substantive comments on the content of this chapter?

Not hearing any, I think that is a good sign. It sounds like maybe people felt this resonated pretty well with thoughts of the overall committee.

The reducing disparities in access and outcomes cover a number of different areas. That has been a high priority for the committee over the years and is highlighted in Objective 2.

If there are no comments on this section, can we move to Question 6? Lifespan issues. How can we meet the needs of people with ASD as they progress into and through adulthood? We have three objectives here. Any comments on Question 6?

In the second objective here, it focuses some attention on co-occurring physical and mental health conditions.

DR. GORDON: Also, I would emphasize given some of the comments today from the

public and from our speakers to create programs - train more general physical and mental health. Providers are important.

DR. DANIELS: And suicidality is mentioned here.

DR. MANDELL: This was a great chapter. This was so thorough and covered so many issues. I really like how the objectives are tied very much to the background.

The only question I have in the objective is about the need for a prevalence study in adults with autism. Unless we think that the prevalence has changed over time, it seems like the bigger issue is identifying adults with autism and making sure that they have the services they need rather than conducting a prevalent study, which is really two very different studies.

MS. CRANE: I lobbied for the inclusion of a prevalence study. I do not think that

the incidence of autism has changed over time. However, it is a live debate. It is something that people have been arguing over quite a lot. It is, therefore, something that I think we need a study on in order to settle that question.

It is also something that policy advocates end up needing in order to identify the scale of the need for services directed at autistic adults. We need to know exactly how many people there are out there.

I agree we really also need studies on identifying autistic adults and developing better measures that will enable clinicians to identify autistic adults. I think we need both.

DR. DANIELS: I think the identification of autistic adults is in there, but we could go back and check. Just make sure that we have captured everything that you mentioned.

Anything else in Question 6? Not hearing any, I am going to move to Question 7 on infrastructure, surveillance, workforce needs, and outreach. Because there are four different topics there, we have four different objectives, each to cover one of those topics. And the question is how do we continue to build, expand, and enhance the infrastructure system to meet the needs of the autism community. Were there any comments on this section?

In this objective, this is where surveillance to understand the needs across the lifespan is mentioned specifically in an objective. There is a discussion of the need for surveillance studies that cover the adult population.

I am not hearing any here either. If it is okay, we will move to the next thing, which is - just very quickly, you have

already approved the duplication of effort statement. Just checking back to make sure nothing has changed about that. We already went over it in January and you have made edits. I think that that is fine unless there is anything else.

Then I am going to move to the ASD research and budget recommendation. This is an area where we will need a little bit of discussion. We talked about this at the last two meetings that the strategic plan is required to have a budget recommendation attached to it. We discussed that there would be a separate research budget recommendation and services budget recommendation, but at this point in time, we are not ready to make the services budget recommendation because we have discussed with David Mandell of doing a study. Our office has been in communication with him about getting him the data and

resources that would be needed to conduct a study that would give us the information to do this. That would be for a future strategic plan update.

But in this one, we do have the information to be able to make a research budget recommendation. The OARC staff has put together a set of slides to try to help us go through this and hopefully make a decision on how we want to do the budget recommendation.

I am not going to take the time to go through this, but part of the rationale behind some of this is talking about some of the costs of autism, including loss of productivity due to things like underemployment and family caregivers needing to stay out of employment to help with family members. I will not go into that in great detail, but this is just some rationale and background that we put in the narrative.

We wanted to go back through historical data since OARC has been collecting data on research funded by government and nongovernment funders since 2008. The first figure here shows combined federal and private autism research funding and we also track this in constant 2008 dollars to see how much purchasing power we have lost over time. When adjusted for inflation by using constant 2008 dollars, the growth in the combined federal and private autism research budget from 2008 to 2015 is 31 percent, an annual growth rate of 4.5 percent compared to an annual growth rate of 7.7 percent if you are just tracking it in regular dollars. This information helps us understand where we have been losing some of our purchasing power.

You have objectives now. I am not going to go through this. But we do have an idea from the committee of what are the important

areas where we need to invest for the future of autism research.

The office taking this data came up with four options for how we could project an estimated budget. We could do Option 1, which would be to maintain a steady rate of growth in the research budget based on historical data. Option 2. We could recoup dollars that have been lost to inflation since 2008. Option 3 is to return to the historical high of 2010, which was due to the American Recovery and Reinvestment Act. Option 4 is to significantly grow the autism research budget. We have four slides here to give you an idea of what this might look like. I am going to have Karen Mowrer from our office talk through these.

DR. MOWRER: I will try to be brief, but these are just examples of each of those options. This is what it would look like if

you extrapolated the annual rate of growth that we saw from 2008 to 2015 into the future, which is a 7.7 percent annual growth rate. There, you have seen we have extrapolated that out to 2020, but could talk about what year we might want to do that too.

This is what it would look like to adjust for the loss of purchasing power due to inflation. To negate the loss of purchasing power at the 2015 funding level, you would need approximately \$402 million to be equivalent to that \$343 million in 2008 constant dollars. Again, what year would you want to target to reach that could be a point of discussion. You can see that it is also somewhat near the amount of the 2010 high of \$408 million.

And then this is the scenario of returning to the 2010 peak funding level. Again, that was reached because of the

supplementary funds provided by ARRA. You can see this is an example. We have shown what a steady rate of increase would look like through 2020 to reach that level. That is a 3.6 percent increase per year if you go to 2020 to reach that.

The idea is if we used this model, you could refer back to ARRA and how a lot of those projects were really poised to be funded when that money was available and point to some of the outcomes that came from that funding as an example of a new infusion of funding was provided how the field is similarly positioned to capitalize on that investment.

And then this is the fourth option where we look at the idea of doubling the budget and picking a timeframe for doing that. This, again, is an example going out to 2020 and to double the budget by then. That would be a

14.85 percent increase per year to reach that.

DR. DANIELS: Thanks Karen. These are the four options that we have come up as a way to do this, working back from historical data. Louis, do you have a comment?

DR. REICHARDT: I just had a question of whether it is possible to do a fifth option, which is calculate what the inflation rate is for the real cost of doing science. We know that the equipment that is needed to do state-of-the-art science is constantly evolving, constantly become more expensive. My impression is for that and some other reasons that the rate of inflation in some is actually somewhat greater than the cost of living.

DR. MOWRER: We actually used for the adjustment for constant versus actual dollars of BRDPI, the Biomedical Research and

Development Index, which is inflation for research specifically that NIH uses.

MR. ROBISON: Can you explain to me how the budget choices that you just showed align with the stated desires of the president to cut the budget of NIH and my absolute absence of knowledge about how our Congress and Senate use what we should be budgeting for? I hear so many different things. I do not know what to make of that.

DR. DANIELS: In terms of the process of the IACC, your job is to look at the opportunities for research and decide if you were going to be projecting a budget recommendation, what that would be. It is kind of independent of what government bodies might be doing or what the Congress may end up doing in terms of appropriations.

MR. ROBISON: In our report to Congress, we would give them these four choices or would we choose --

DR. DANIELS: You would choose something or we would have to have a scenario to suggest this would be a budget recommendation coming from the committee. In the past strategic plan, we had an individual budget recommendation for every objective, but these objectives now are so broad that it makes it a little bit difficult to do that. That is why we decided to go with something looking at the entire research budget as a whole.

MR. ROBISON: Do you folks, as NIH insiders -- do you know what the right answer to this is with government now or is it entirely up to us? I do not know what --

DR. DANIELS: You are an independent advisory body. You have a chance to think

about this, debate the merits, and come up with your scenario.

MS. CRANE: They are not going to necessarily listen to us. But what we have to do is just make a recommendation.

DR. DANIELS: This will be something that funders read that Congress will read and take into consideration with all the other consideration they need to account for.

DR. REICHARDT: I would just say in that context, I think it is crazy not to be aspirational. The opportunities in research are very high. We certainly will not get the funding that one expects, but one should at least make the case considering the huge number of opportunities in neuroscience.

DR. GORDON: I think it is fair to say that if we did everything in this plan, the cost would not be \$685 million a year. It would be 2, 3, 4, \$5 billion a year. That is

a big range because we obviously have not done the calculation. It would be very challenging to do the calculation. But it would be fair to say it would be a lot higher than \$685 million.

That statement needs to be made for two reasons. One, we do not want to give the impression that whatever number we pick, that that is enough to do everything in the plan because it is not. Number two, if we tell them this is how much you need and we do not put that in there then they are going to expect us to do it if they give it to us or they expect us to do half of it if they give half of us to it. I think that is an important thing I would put in there.

DR. BIRNBAUM: For those of us who are federal members, we cannot tell Congress what to do, but the committee can. But I think it is very important to understand that in the

last few federal budgets, which have come from Congress, in fact, NIH has received significant increases, but they have been largely set for specific areas, which in the past was something that NIH did not want to happen, but in fact that is what is happening so that BRAIN gets specific funding.

Alzheimer's gets specific funding. Precision medicine gets specific funding. If this group should decide to recommend a large number, it is possible that someone in Congress will agree that that should be some specific funding.

DR. WEXLER: I do want to remind folks of when Tom Insel and our Assistant Secretary and the GAO inspector went before congressional committee and Tom was being badgered about duplicative research and this committee is certainly familiar with it.

One of the things he did was he turned around to them and he said how much are you spending on AIDS and how much are you spending on Alzheimer's. You are talking about 1 in 60 births a year now. They did not know, but he did. I am not from NIH, but it was in the billions. I would agree with Dr. Gordon.

DR. GORDON: I can give you some of those numbers. The expenditures on AIDS are about \$3 billion per year. The expenditures on Alzheimer's are now 1.2 and are projected to go up to 1.6 if the House Budget is passed.

DR. BIRNBAUM: It is likely it might even go higher with the Senate.

DR. GORDON: That is just for reference. That is per year.

DR. WEXLER: I would agree with Louis that aspirational is not a bad idea.

I also will say on the other side from what I have heard is that they are talking about putting limits on indirect costs as part of research grants.

DR. BIRNBAUM: At last in the House Bill that is explicitly blocked. The House says you will not cut indirect costs.

DR. WEXLER: At this point. All I am saying is that dollar amounts are very relative. If it is a 25 percent indirect versus 50 percent indirect, the money stretches a lot farther. I just raise that just as something to - you say it will never happen.

DR. BIRNBAUM: I am not saying it will not happen, but cutting indirects will not cut the cost of research. It will just mean it has to come and be described from directs.

DR. WEXLER: I understand that, but I am just saying that when you represent dollars, it is actual dollars that you can --

DR. GORDON: I do want to focus the discussion back because we do have to pick a model. John, go ahead and say something. Keep it brief.

MR. ROBISON: If I am understanding you all correctly, it sounds to me like our committee should make a statement in our plan that we have changed our aspirational goal with this revision of the strategic plan in recognition of the fact that we need a two-forked thing. One, the basic science and two, the delivery of benefits to the community now and that we do not have the funding to accomplish that expanded goal. That is a reason that we need specific targeted funding well over and above what we previously have had because that is a change in this version

of the plan. If I am hearing you all right, we need to make our specific wish clear so the Congress or the Senate has a shot at giving us what we need. That is how I am hearing you all.

DR. GORDON: Thanks John. Let's just say that there are four options on the table. I do not mean to distinguish another one. But there are four options on the table right now that Susan has put forth, this being I think the most ambitious, the doubling in five years, and the least ambitious being to continue the current rate of growth. Is that correct?

I would like now the discussion to be confined to either a concrete suggestion of some other method or argument about one of the four methods that we discussed.

MR. ROBISON: I am suggesting her most aspirational plan, doubling five years, justified --

DR. GORDON: I see people nodding. Do we have a motion to approve that?

DR. DANIELS: Do we have a timeframe you want to put on that? We just arbitrarily picked five years, but it could be four years. We also started with 2015 just because we have the 2015 data. We could start in 2016, but get to a doubling faster depending on --

MR. ROBISON: Why don't we ask for three years in this President's term? That makes sense to me.

DR. REICHARDT: I would recommend the doubling and I would recommend five years from last year.

DR. GORDON: That is the current plan, five years from last year. I had a motion. Is there a second? All in favor? Any opposed?

DR. WEXLER: We are making up numbers. Double seems like a great idea. Maybe it has more face validity than triple, but triple has more face validity than quadruple. I think the concept of sometimes you get what you ask for. You could always not get it or maybe someone says there is a middle ground. They asked for triple. We will give them one and a half.

DR. GORDON: Since we had another argument, let's just re-do the vote. All in favor raise your hand? We are voting on the current plan, the doubling. If it fails then we will have to figure out another one. I am personally going to abstain because quite a lot of that funding is going to come to me. We are committee members. You can make

up your own decision. I am going to abstain. A substantial chunk will go to you and - you have to make up your own minds. We are a member of the committee. We are voting for this proposal currently. Larry has made a more ambitious proposal. Who would like to see all in favor of the doubling in five years in 2015? Raise your hand please. All against? Everyone else should be then abstaining.

DR. FARCHIONE: Once you pointed out about federal employees.

DR. GORDON: I do not think we can pass it.

MS. CRANE: Maybe we should vote on the ambitious proposal first. The triple.

DR. WEXLER: Could I just say in terms of federal employees, me being one of them, we are not allowed to recommend to Congress. This is an independent body's just general

here is what we think would do the job. I will abstain too.

DR. GORDON: Let's be very clear. We, as a committee, including the members of the committee who are agency representatives, have been asked to tell them how much this will cost.

DR. DANIELS: When you are voting on this, this is a part of the overall strategic plan. It is not going to be like there is - when the strategic plan comes out, there is going to be a list of names of who voted for this particular section. It will be a part of the whole. It is fine for people to abstain. Federal members are permitted to vote, but you are also permitted to abstain if you feel like you need to. Keep in mind that we also have several public members who are missing today.

DR. KOROSHETZ: The previous questions like this we went to the legal people at NIH to ask this question. And the official answer is that appointed to a FACA committee, you can exercise your right as an individual to vote your conscience. It does not officially go for advocacy.

DR. BIRNBAUM: And we are officially representing our institutes.

MR. ROBISON: Isn't it true that all of us who are not federal employees would wish for the maximum allocation of federal dollars to address our concerns in autism. Can't we get agreement with that around the table? If that is true, don't we want to vote as the independent part of this for the largest thing that Susan has put on the table? Can't we move ahead with that?

I guess I sense that we are stuck with a procedural thing where the folks we depend on

at the end of the table cannot speak up because of their federal status, but we want the biggest thing we can get. Do any of you not want that who is independent? You all do. Tell us how to do that, Susan.

DR. GORDON: I think she is giving you four different plans.

DR. DANIELS: These are based on historical data. They are not just pie in the sky. There are some facts to back some of this up, but we just need to make a choice or offer an alternative.

MR. ROBISON: May I make a motion? Susan has given us for thought through plans. She cannot say more, but those are thought through plans based on our collective work. May I suggest we put our votes for the largest of those plans?

DR. GORDON: All in favor, raise your hands. Any opposed?

MR. ROBISON: We have done it.

DR. KOROSHETZ: Just for the record and there are people who may be on the phone, I think all the federal folks believe that with the highest model here that we could make very good use of the money.

MR. ROBISON: I do not doubt it for a second. I have absolutely no problem of conscience asking for money --

DR. GORDON: We are going to put forth a budget recommendation that will be this model. It will have the following two statements appended to it. One, that this is not enough money to do everything in the program, but it is a reasonable and aggressive start. I think Walter said it better than one. Hopefully, someone took notes when he said it. That we can spend wisely and efficiently over those five years.

MR. ROBISON: I am happy to go on record as being the person who made the motion and I am not a recipient of the money. I have no dog in the hunt other than being autistic.

DR. DANIELS: That was the big one for the strategic plan. These are some other questions that I had for you regarding additional funding, but you do not really have to answer it. You can just stick with the budget recommendation and let it be. Let me just pose it. Given the current distribution of funding across the strategic plan, I did not know if you want to think about the balance of what is in the strategic plan. And should additional money come to the autism budget, should it be spent in a way so as to shift the balance? You are free to say we do not want to talk about that or if you think that you need to make any statements, we can include it in the narrative.

MR. ROBISON: I think it should shift to lifespan and services because we have made that change in our strategic plan this year that we need to ramp up our deliverables to the community and those are the areas that cover the deliverables.

MS. CRANE: I absolutely agree on that. I think it is important to note that even things that would otherwise belong in other questions, things like research on health outcomes, health issues for adults, research on screening for adults, research on risk factors, treatments and interventions for adults, all of the things that pertain to adults get put into Question 7 or many of them get put into Question - Question 6. I am sorry. I cannot count anymore. As a result, it is really a problem that even though most of us spend the majority of our lives over

age 18, only 2 percent of funding is going towards our needs.

DR. TAYLOR: I think if we want to increase our funding for things that give us deliverables, we may also then want to enter into that Question 4 too so treatments and interventions just more general. Even though that is a bigger slice of the pie right now, those things sort of hang together in terms of the three questions that are really focused on turning things around fairly quickly in terms of what can we do for children and families and adults sooner rather than later.

DR. GORDON: I am good to go on record as being against any specific recommendations about balance. And the reason I am going to do that is because I think it is hard to know, number one, what good science will come in and which categories and what

opportunities there will be. It is easy to say we want to fund more things on lifespan. We are doing a good job of increasing the number of applications at least at NIMH that come in with regard to lifespan through targeted announcements. But it is hard to know whether that will continue and how much that can grow.

My own preference would be to keep any recommendations rather general. I do not have a problem with saying that picking out lifespan and services and interventions research as areas that could grow. But I would be wary about making two specific recommendations about this.

DR. MANDELL: I think there is a lot of value in the plan that you just proposed. One area that is particularly concerning to me is that I think one of the reasons we do not have more funding in those areas is we do not

have more good scientists in those areas and incentives for scientists to go into those areas. I would at least like to think about how we could include language that would relate to what is in Question 7 around developing the science workforce, not just in autism broadly, which is certainly needed, but in these specific areas, which I think will do as much to enhance the science as specific RFAs or PAs in those areas.

MS. CRANE: I can understand that we do not want a very specific dollar amount for any one area. But I hope that we can all agree that 2 percent for all research pertaining to adults including services research, including treatment research, including risk factors, screening and diagnosis research, almost everything that has to do with adults, which is all in this question. Two percent is just completely

unconscionable, given the number of people who are adults or who hope to one day be adults in our community.

DR. KOROSHETZ: I kind of agree that the 2 percent is not defensible. We need to say something about that this really requires resource growth.

DR. DANIELS: We could maybe make a statement in this budget section, which we have worked on a draft narrative. We could add something about it with an emphasis toward translational research, especially in intervention services and lifespan issues.

DR. TAYLOR: I do not know how specific we want to get, but we could potentially give examples like the ASD mechanisms - I think of a couple of researchers that I know of who were childhood intervention researchers who developed programs for transitional youth or adults because there was a mechanism there

for that and kind of drew them into this area.

DR. GORDON: This data is 2015 data, which is before the adult announcements in funding. I am sure that number has already gone up. I do not know by how much, but I am sure it has already gone up. It is a good point. Two percent is indefensible. I am not trying to defend it, but it is important to recognize that Questions 2 and 3 though they are not about adults specifically, obviously impact adults. But still even with that, I will grant you. Two percent is too low.

MS. CRANE: When we have been talking about which studies go in which question, if there is a biology study that is specifically on adults that often ends up being put in Question 6 rather than in Question 2. I think that is fair because we need to track which studies are on adults and if we do not track

that in this way, we are not going to be able to get an accurate number. I do not think we can assume that the other categories are somehow secretly about adults.

DR. DANIELS: We are tracking that. In fact, with the data system we are developing, we are going to be able to track it even into a finer level than we can now. I think that I have heard good information here and we have what we would need to do revisions.

If there are further comments on the strategic plan, I requested that you give us written comments by Friday, August 4. In terms of a process, what I would propose is OARC taking all the written comments that we receive by August 4, incorporating them into a draft and possibly sharing that with the chairs of each of the working groups to run that draft through them. And then we could bring it back to the committee and either

take - we could have a phone call to talk about it if we think we hope that by then we are in pretty good shape. I am hoping to avoid having to bring it back for further discussion in October. I would really like to finish it up, not just for us, but really to get the plan done so that we can move forward on other projects and ensure that the plan is in place should funding be available. Then you will have a plan that is ready to go. How do you feel about that possibility?

DR. GORDON: I see nodding, but I am not sure what you are nodding to. Let's be explicit. Susan has proposed that we come back with a phone call for final approval as opposed to approving it now.

DR. DANIELS: Or you could tentatively approve it now with the changes we have discussed, but you will not have seen the changes. But I could run it by the working

group chairs to make sure that they agree that we have captured what has been said in the room. If you feel comfortable with that, we could try to get it approved now and just make those changes.

MR. ROBISON: I am willing to approve it now. I would make a motion that we put our trust in Susan to do this and we vote to approve it now.

DR. GORDON: Do I hear a second?

DR. REICHARDT: Second.

DR. GORDON: All in favor, raise your hands. Any opposed?

DR. DANIELS: Is there any on the phone because we do not have a quorum with that number? We need 16. Then we do have a quorum. Who is opposed? Anyone on the phone opposed? Anyone abstaining? The motion carries to approve it with the changes we have discussed and with the review of the chairs of each of

the working groups. Then we will go ahead and be working on all of those. Please send us any comments you have. We will incorporate them, get them back to the working chairs. You will be hearing from me before we meet in October. Hopefully, we will have a completed plan to show you in October. The pretty version might not be ready yet depending on how long this takes. But we will at least have the text all done. Thank you.

DR. GORDON: We have about 17 minutes left. We are going to skip over the summary of advances for this time. We will leave extra time for you to discuss those advances at the next meeting.

We now have a few minutes any way for round robin. There were three people who submitted - there is one other business item we need to discuss.

DR. DANIELS: Our plan was to move to doing the working groups. I know I have had committee members ask about when we are going to get to working groups. I would like to complete the plan. Would you be comfortable with us starting the working groups after October or do you want us to start them in the fall like before the October meeting?

We have already taken some initial people to be on the three working groups: housing, safety, and improving health outcomes. Would you like to wait until after we have had the October meeting to convene the first calls for those or do you want to start them in September and October before the meeting? I just need to know so that we know what to do.

DR. GORDON: If we have the people already, let's convene them and we will see

if they have the opportunity to meet before October.

DR. DANIELS: Okay. We will be in touch about that.

DR. GORDON: As I said, there were three people who submitted beforehand items for the round robin. We will go with them first. And then if there is time, we will continue around the table. Let's not start with NIMH. We can sacrifice ourselves if we need to for time.

Jennifer Johnson. She left. Tiffany.

DR. FARCHIONE: I was just going to give a quick update on the patient focused strength development meeting that we had at FDA back in the beginning of May. It was really interesting and enlightening. Basically, for those folks who are not familiar with these meetings, it was a half-day meeting where we had individuals with

autism, their families, caregivers, et cetera and participated in a couple of different panel discussions to try to get an idea of what would be clinically meaningful targets for drug development in autism spectrum disorder.

One of the things that was really interesting was just how different the things were that those folks said were important to them versus some of the things that drug companies are actively pursuing at the moment.

One example that kept coming up over and over again was repetitive behavior so stimming. And the folks who were there basically explained that they did not want anybody to mess with their repetitive behaviors. The repetitive behaviors actually helped them to feel better and that it was whatever was distressing or bothering them

that was causing the stimming that they wanted help with, not the stimming itself. That is just one example.

Also, the idea that just because something is observable and countable does not mean that it is something that is going to change someone's life or make them function better. One woman basically said the number of times that I make eye contact with you during this conversation is not going to affect how functional I am in my day-to-day life. That makes perfect sense.

In any case, it really gave us a lot of useful information in terms of how we, at FDA, will approach companies who are seeking new indications in the autism space. If somebody comes in and says, our primary endpoint is based on restricted repetitive behaviors. They are going to say actually

that might not be the best thing and maybe you ought to rethink that.

The end product of this meeting is something called a voice of the patient report. That should theoretically if everything goes well, be ready some time by the end of the year. But if folks are interested in that meeting, the full transcript of the meeting is available online as well as any slides that were presented. I believe audio recordings as well. If anyone is interested, just Google PFDD, FDA and it should be the first page that comes up.

DR. GORDON: Thank you. Then we have Denise Pintello from NIMH. She is going to talk to us about the ASD --

DR. PINTELLO: Thank you. I feel like we are dessert here. The best for last. I think it has been a fascinating conversation today. I would like to cap that off by telling you

about a fantastic meeting we had at the National Institute of Mental Health last month with scientists from five studies that are conducting research on early autism detection, engagement, and linkages to services.

But before I do that, I want to tell you a little bit about what the ASD PEDS Network is and how it came about. And how it came about is this body, the IACC strategic plan of last year. I know you are talking about this year's plan - last time in 2013, it was framed around seven questions, very similar. In result of those seven questions, NIMH created a series of funding opportunity announcements written by my colleague Denise Juliano-Bult that responded to the last strategic plan.

One of those questions, when should I be concerned, resulted in this funding

opportunity announcement titled research on early identification and linkage to services. We received a number of applications from around the country to test the development of interventions that coordinate screening, evaluation and engagement and treatment for very young kids with a special focus on underserved families. We funded the top five scoring applications and these studies were in these different areas across nine different states and 16 different sites.

Let me just tell you a little bit about who the researchers are and what they are doing. Karen Pierce is testing a triple screen at that well baby checkup. She is screening at 12, 18, and 24 months and providing services.

Wendy Stone is focused on rural settings in the State of Washington. She is testing a screen, refer and treat model. Emily Feinberg

in Boston is doing a comparative effectiveness study, looking at engagement and using navigator models. Alice Carter and her team in the University of Massachusetts is focusing on early interventions and looking at a system-level approach and testing access especially for health disparities.

And lastly, Amy Wetherby and her colleagues are testing a large multi-science study that is looking at online automated tools, screening tools and testing various engagement models to enhance the linkage of treatment and services.

Of course, we had differences. When we looked at these studies together, we compared the differences and the similarities. Everybody had a little bit of both. But when you took these studies together, we found that approximately 70,000 children of these

five studies would be screened. And if you look at the CDC data, we anticipate that about a thousand kids may be diagnosed. We thought there might be a way to harness all of these studies together.

In 2014, we invited the researchers to work together and they eagerly agreed. We called it the ASD Pediatric Early Detection, Engagement and Services Network. They also all agreed to collect data on these four common measures. They are using them now.

Since the grants were awarded back in 2014, they have met together. They have formed a website. They are sharing data. They are translating instruments and sharing that. They are training each other staff for free.

But the other piece that all of you are very familiar with that in 2014 since that time, the US Preventive Service Taskforce came out. In response to that, a JAMA

editorial acknowledged and recognized that the ASD PEDS network. It is highlighted its potential in addressing some of the research gaps.

Since then, we are now in the third year of their five-year studies. They are in the middle actively recruiting and collecting data.

Let me file it to the meeting we just convened. They have a lot of energy. Folks here are really committed to quickly conducting research and getting it out so kids and families can really benefit from this.

Four general themes were discussed. The first one was the impact of parental concern. The presence and absence of parental concern really drives treatment seeking and they are finding various levels of parental concern. Provider-level concern. The concern of

stigmatizing and fear of stigmatizing families and also weighing that with the consequences to toddlers when you take a wait and see approach. They are collecting data on that.

Treatment tracking. Looking at pathways from screening to services. Just because these kids are receiving screening, it does not mean they are going to get services. The services may even be available in those communities, but access is an issue. They are looking at all those factors.

And the third item is the onset of ASD symptoms. Two studies are collecting these data at 12 months. All the others are doing it at about 18 and 24 and 36 months. Maybe there could be a developmental typography of symptoms that they might be able to start looking and comparing trajectories.

Lastly, we have a career development fellow that is conducting an implementation project and talking and interviewing, using a mixed methods approach, interviewing the researchers to look at facilitators and barriers to implementation.

I am pleased to report there will be more to come. Their study should be completed in the fall of 2019. They will be co-publishing findings and jointly presenting some of the major conferences. And of course, they want to somehow explore the future studies that could be harnessed within the cohorts from these networks. These are things and the discussions we will be having.

Lastly, if this body is interested, we would be happy to have the researchers come and present their findings to you some time in 2019 or 2020. Thank you.

DR. GORDON: Thank you. We can go around the table now if there are any burning issues. We have just a few minutes left, but if anyone would like to report on activities.

DR. SHAPIRA: I just wanted to say in two minutes that - a couple of weeks ago, Dr. Brenda Fitzgerald was appointed as the 17th director for the CDC and as well as administrator of the Agency for Toxic Substances and Disease Registry that many of you know as ATSDR.

Now Dr. Fitzgerald has previously served as commissioner of the Georgia Department of Health and the state health officer. She is a board certified obstetrician/gynecologist and she practiced medicine for three decades. She has a particular interest in early brain development, which was one of her priorities while at the Georgia Department of Public Health. I think we will continue to see work

in that area, a focus of that work at CDC, which would include autism spectrum disorder.

And then one other announcement. This is a preview of coming attractions. At the October IACC meeting, the CDC will be sharing more about latest research coming out of our Study to Explore Early Development or SEED and that is CDC's case control study to evaluate genetic and environment risk factors for autism spectrum disorder. More to come on that this fall.

DR. GORDON: Thank you.

MR. ROBISON: I already made enough noise.

DR. GORDON: Thank you very much everyone. We will see you all in October.

DR. DANIELS: October 24. I believe we will be at the Neuroscience Center in Rockville. Thank you.

(Whereupon, at 5:02 p.m., the
subcommittee adjourned.)