INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, OCTOBER 17, 2018

The full Interagency Autism Coordinating Committee (IACC) convened in Rockville, Maryland, at the Neuroscience Center, 6001 Executive Blvd, at 9:00 a.m., Joshua Gordon, M.D., Ph.D., Chair, presiding.

PRESENT:

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

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

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

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

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

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

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

PRESENT: (continued)

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

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

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

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

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

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

DAVID MANDELL, Sc.D., University of Pennsylvania

ANDREW MORRIS, M.P.H.,(representing Jennifer Johnson, Ed.D.) Administration for Community Living (ACL)

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

KEVIN PELPHREY, Ph.D., George Washington University and Children's National Medical Center (attended by phone)

EDLYN PEÑA, Ph.D., California Lutheran University

PRESENT: (continued)

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

ROBERT RING, Ph.D., Vencerx Therapeutics

JOHN ELDER ROBISON, College of William and Mary

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

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

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

MELISSA SPENCER, Social Security Administration (SSA)

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

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

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

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PROCEEDINGS

DR. JOSHUA GORDON: Welcome to the meeting of the Interagency Autism Coordinating Committee. I would like to thank those who came in person in the audience. I would like to particularly thank of course the committee members who are here, and maybe on the phone as well. And I’d like to thank everyone out there following us over the web and the telephone. We have a really compelling and interesting agenda for the day, so I won’t waste too much time in the beginning.

I do want to welcome two members who have been with us in the past, but are joining us officially. Judith Cooper from NIDCD. That is the Deafness Institute. And Jennifer Johnson from the Administration for Community Living. We welcome them now as regular members of the committee, as opposed to what their former role was, which were alternates.

With no further ado, I’ll turn it over to Susan for the roll call.

DR. SUSAN DANIELS: Good morning and welcome. Glad to see many of you here and welcome to those on the phone. We’ll go ahead and do our roll calls. Josh Gordon.

DR. GORDON: Here.

DR. DANIELS: Judith Cooper.

DR. JUDITH COOPER: Here.

DR. DANIELS: Alice Kau for Diana Bianchi.

DR. ALICE KAU: Here.

DR. DANIELS: Linda Birnbaum.

DR. LINDA BIRNBAUM: Here.

DR. DANIELS: Carrie Wolinetz for Francis Collins.

DR. CARRIE WOLINETZ: Here.

DR. DANIELS: Elaine Hubal.

(No response)

DR. DANIELS: Tiffany Farchione.

(No response)

DR. DANIELS: Melissa Harris is not joining us today.

MS. MELISSA HARRIS: I'm here. I am here on the phone.

DR. DANIELS: Oh, you are on the phone. Great. Thank you.

MS. HARRIS: Yes, thanks.

DR. DANIELS: Jennifer Johnson.

Robyn Schulhof for Laura Kavanagh.

MR. ANDREW MORRIS: Andrew Morris is here for Jennifer Johnson.

DR. DANIELS: I couldn't hear.

MS. ROBYN SCHULHOF: I'm here. Robyn.

DR. DANIELS: Oh, okay.

DR. GORDON: Ask if Jennifer Johnson is here because I think someone was on the phone.

DR. DANIELS: Andrew Morris, are you there for Jennifer Johnson?

MR. MORRIS: Yes. Jennifer will be there present at the meeting this afternoon.

DR. DANIELS: Okay, thank you. Cara Long for Walter Koroshetz.

DR. LAURA MAMOUNAS: No, it is Laura Mamounas for Walter.

DR. DANIELS: Laura Mamounas. Okay, thank you. Laura Pincock.

DR. LAURA PINCOCK: I am here.

DR. DANIELS: Marcy Ronyak.

(No response)

DR. DANIELS: Stuart Shapira.

DR. STUART SHAPIRA: I am here.

DR. DANIELS: Melissa Spencer.

MS. MELISSA SPENCER: Here.

DR. DANIELS: Larry Wexler.

(No response)

DR. DANIELS: Nicole Williams.

DR. NICOLE WILLIAMS: Here.

DR. DANIELS: David Amaral.

DR. DAVID AMARAL: Here.

DR. DANIELS: Jim Ball.

(No response)

DR. DANIELS: Samantha Crane.

(No response)

DR. DANIELS: Geri Dawson.

(No response)

DR. DANIELS: David Mandell.

DR. DAVID MANDELL: Here.

DR. DANIELS: Julie Taylor is not going to be here today. Kevin Pelphrey.

DR. KEVIN PELPHREY: I am on the phone.

DR. DANIELS: Oh, okay. Hi, Kevin. Edlyn Peña.

DR. EDLYN PEÑA: Here.

DR. DANIELS: Louis Reichardt.

(No response)

DR. DANIELS: Rob Ring.

(No response)

DR. DANIELS: John Robison.

MR. JOHN ROBISON: Good morning. I am here.

DR. DANIELS: Good morning. Alison Singer.

MS. ALISON SINGER: I am here.

DR. DANIELS: I have completed the roll call. Is there anyone that I missed? Alright.

DR. GORDON: Now we need to approve the minutes.

DR. DANIELS: Were there any comments on the draft minutes that were circulated to the committee? Any questions or concerns? Can we have a motion on the table to accept the minutes? Second?

UNKNOWN SPEAKER: Second.

DR. DANIELS: All in favor of accepting the minutes?

(Chorus of "ayes".)

DR. DANIELS: Any opposed?

(No response)

DR. DANIELS: Any abstaining?

(No response)

DR. DANIELS: It looks like the motion carries to accept the minutes. We will have the minutes posted to the website after this meeting. Thank you.

DR. GORDON: Great. Thank you, Susan. As I mentioned at the outset, we have a really exciting agenda for the day. The first person we are going to hear from is going to be here making her first presentation in the role of National Autism Coordinator. We introduced her at the last meeting in the spring. It is Ann Wagner. Ann, many of you know because she has been working for NIMH, overseeing the science of autism at NIMH, and actually co-leading the NIH-wide committee to oversee research in autism. But Ann graciously volunteered to take on the role of National Autism Coordinator at the request of the Secretary. Ann is going to give us a report as to what she has been up to in her first few months in that position.

DR. ANN WAGNER: Thanks. Good morning everybody. I did introduce myself last time to this committee, so I will not do that again. But I did want to just put up a reminder about this position in the National Autism Coordinator role that was authorized by the Autism CARES Act of 2014. The first autism coordinator was Dr. Thomas Novotny. He took the lead on developing another requirement from that Act, which was the 2017 Report to Congress on Young Adults and Transitioning Youth with Autism Spectrum Disorder.

I started a few months ago, as Josh said. What I have done so far is convened a

Federal Interagency Workgroup on ASD. Several of those folks are here in the room. But this is an internal working group of representatives from across government departments and agencies that have programs related to autism spectrum disorder. And the goal of our committee is to coordinate the implementation of activities in response to recommendations from the IACC, from reports to Congress and other sort of official recommendations to the government.

What I learned after our – there are 32 people on this committee. I have had a great response. A lot of people have been interested in participating and I will show you who is represented in a moment. Before I do that, I did want to say that after our first meeting, I realized that I really needed to understand more about what all of these programs do. I have been setting up individual and/or small group meetings with all of the people who are on the committee. I have managed to do about half of those and traveling to their work places. It has been really, really interesting for me and I have learned a lot. Next slide please.

The Department of Health and Human Services has ten programs represented. I am not going to go through those. But the asterisk on this slide and the next indicate the people who I have met with so far. Again, I have managed to do about half of them so far and the rest are scheduled to occur in the next few weeks. And the next slide please.

Other departments and agencies involved are Education, Environmental Protection Agency, Defense, Justice, Labor, Transportation, and the Social Security Administration. Next slide please.

I thought one of the important things to do right away is to start looking at the recommendation from the 2017 Report to Congress. We have been doing that and we are looking at – we are sort of gathering information on what activities are ongoing now that would address the recommendations and what some of the gaps are. Just some ideas of the things we have found and are doing. We have identified some new activities and related to the epidemiological data collection and monitoring set of recommendations. CDC is piloting a teen SEED study. The SEED study saw children when they were between 2 and 5 years old and now this survey will follow up with those participations when they are 14 to 15 years old.

CDC has also posted their funding announcement for the re-competition of their monitoring sites and they have included a new option to conduct follow up of the children who were diagnosed at age 8 as they turned 16.

We are analyzing. There are a lot of surveys out there and I know there are recommendations related to surveys. We are collecting protocols and analyzing what is out there now to figure out what is covered and where the gaps are.

Research. There are a lot of newly funded research projects that address this developmental age group. I just put up there some of the topics that are covered to give you an idea of the various range of topics being covered. There are several things related to successful employment. There are things related to internships. There are some projects related to health care, transitioning to health-related independence and improving primary care for autistic adults and engaging siblings and family future planning.

One of the recommendations related to research was the need for better and more appropriate measures of functional outcomes for transition age youth and adults. We have identified that there are some projects developing such measures. We are convening a sort of subgroup to take a look at what those are and figure out if there are other gaps and how best to share information so people are not duplicating efforts. I am very happy to say that in this we are not finding any duplication of projects. Next slide please. Oh, left of my last slide.

My last slide was just things that I am going to be doing next. I am continuing with the small group meetings. We are going to take a closer look at the recommendations related to services. And the third thing was, we are - a topic at our agenda for the next meeting is a discussion among the federal programs of the strategies people are using at the federal level to influence policy and programs at the state and local level.

DR. GORDON: Are there any questions from the committee for Dr. Wagner?

DR. PEÑA: There was an acronym TAY in the earlier slide. What does that refer to?

DR. WAGNER: That is transition age youth. Sorry.

DR. PEÑA: Thank you.

DR. GORDON: Any other questions? I have just one comment then to add. I want to say that I think already we have seen in just a few months a lot more activity perhaps than we saw in quite a while out of the position of the National Autism Coordinator. I want to commend Ann for her work. There are also two other people that have been helping Ann out in this effort. First, of course, Susan Daniels, who was instrumental in helping Dr. Novotny with the report and laid the groundwork for a lot of the things that are already now ongoing in response to that report that Ann outlined and has been helping Ann as well. And then also Frank Avenilla, another NIMH employee, who has been working in autism for some time and he has been helping Ann out with many of these meetings and with compiling of the data. I want to thank those two additional people and thank you, Ann, for your hard work.

Moving right along then. We are going to move to our first presentation of issues on the day. I am pleased to welcome the Autism Society to present on unintentional injury in children and youth with ASD. We will have a half-hour presentation followed by plenty of time for discussion before our morning break.

I welcome to the podium Dr. Jack Scott, who is a member of the Autism Society Panel of Professional Advisors as well as the Executive Director of the Florida Atlantic University Center for Autism and Related Disabilities.

Dr. Scott, thank you for coming to speak to us today and take it away when you are ready.

DR. JACK SCOTT: Thank you. Thank you for inviting me and I appreciate the opportunity to be here. I am representing the Autism Society of America. You are all familiar with their activities and status within the world of autism, but the largest grassroots autism organization in America. I should note importantly that they have developed and implemented many safety programs and trained over 20,000 law enforcement professionals in the country at this time, helping to inform them as to the importance of that intersection of autism and law enforcement. Law enforcement and safety is the focus of my topic, safety, especially from unintentional injury.

In other forums, you have heard about the risk that children with autism, persons with autism can face from a multiple of sources often due to medical complications. But the issues of unintended injury are the focus of my talk here this morning.

If we were to ask our children with autism spectrum disorder at higher risk for unintentional injury, wandering, and even death, the answer is obvious to anyone who is here, anyone who knows anything about autism. Deficits in expressive communication, receptive communication, the tendency to perseverate on things, to disregard rules, to perhaps live in their own world and not the world that would contain more safety guidance seems to be a problem. Where does this come from remains a mystery.

I seem to think that early social referencing problems cascade. Instead of a child understanding mom or dad's cues at the very earliest of ages, they miss those cues and forever remain out of sync in terms of understanding and abiding by safety issues.

We see a number of studies that support the assertion that persons with autism are considerably greater risk for mortality, early mortality, a mortality age that may be approximately half that of people who are regarded as typically developing. We see this in a number of studies. Factors that seem to contribute to this are moderate to profound intellectual disability, epilepsy certainly or the complications that can result there, and not fully explained at this point, female gender. We are perhaps fortunate that there are fewer females with autism, but their risk status and virtually every study shows out to be higher.

There are many other studies. This is just a sampling of four of the important ones. We see European researchers perhaps in somewhat of a lead on this. Shavelle, Strauss, and Pickett, going back now to 2001, the early 2000s, but with their studies of deaths, mortality in California with some frightening numbers. The death rates for females there are troubling. There is some possible issue with low numbers there, but remain very problematic. But all of these studies and several others report the successive mortality for people with ASD.

But what we are really talking about are children who typically die. They are people who die at other ages. The focus of my talk will really be on children and especially young children, those who are at age 4, 5, 6, 7, and 8 and beyond, but children who do not understand rules of safe conduct and who seem to lack self-preservation skills in a profound way so that they will do things that we would all regard as reckless and life-threatening and do them with parent impunity.

This little boy who was a frequent eloper when he was younger. Now, he is about 12. His parents had the most difficult time trying to keep him contained. You will notice that he has a project life saver device similar to other safety devices that have allowed the Palm Beach County Sheriff's Department to track him on numerous occasions and fortunately to bring him back safely.

Drowning becomes a critical issue in this. The finality of a drowning. Near drownings are horrible as well and the cost to society and families and individuals who suffer that are catastrophic. But we know, for example, that in the United States for children 1 to 4, drowning is the most common cause of death. Yet, for children with autism, it almost certainly continues. We have motor vehicles in there for unintentional injury. But if we were to have solid numbers, it may well be that it continues on up to age 10. The lack of solid data is one of the topics that I will be addressing here. We do not know. I have to be very tentative with this kind of assertion.

This is a graphic that is not for children with autism, but children overall. But it helps to illustrate what I think is an important point. We see the highest age range for children who drown. It is in this 1 to 3-year-old region. You can see the very tall spike there for that.

What seems to happen in our autism community is that many of the children remain developmentally and from a judgment perspective and self-preservation skills perspective in that 1 to 3, 1 to 4 age range and consequently in this very high status. They remain there for an extended period of time with the adjacent complications.

We know from a number of studies. We see this from the IAN studies back in 2010 and here, Cathy Rice more recently, 2016, in terms of wandering in children with autism. This study I like because it does seem to have some solid academic backing to it, but 37 - 38 percent of these children with autism and intellectual disability are wandering and only a slightly smaller percentage for those with autism without intellectual disability. This is parent reported within the previous year. That is a pretty frightening situation. And for many of these children, it continues on for many years. It is not just a one-year situation at age 4 or 5, for example.

This little fellow here, Jared McGuire, died in 2006 in Palm Beach County in Greenacres. At this point, I had been the executive director of our regional autism center, the Center for Autism and Related Disabilities, one of seven in the State of Florida, designed to provide non-residential supports for families of children with autism, people with autism and the community.

Jared died. I heard about this while I was at an autism conference. I was shocked and stunned. At that point, I was unaware that the mortality rates for children with autism were approximately three times that of typically developing individuals. I began to concentrate on this issue, realizing that at that point if I was an established expert in the field of autism, textbooks on it, articles, center direction. If I was not aware of this risk status, how many others who were autism professionals were not aware and certainly many parents are not aware.

The IAN study from 2010 suggests that as many as 50 percent of the parents report that they had not been alerted to the high risk status of their child, that they had not been told of pediatricians, of psychologists or many of the professionals that they have worked with up to that point that their child was at much higher risk. Further, disarming the parents and their understanding and ability to deal with this. But I was stunned by Jared's passing.

Here is a police officer, Deputy Ray Griffith, who I understand from some of his colleagues is a tough guy. He is not the kind of guy a criminal wants to come across. It is February. I do not know and I am not sure whether he is sweating or whether he is crying, but you can in the background see the covered body of young Jared.

This is a drain on our society. This is horribly painful for parents of course, but it is among the most difficult I am assured issues that law enforcement has to deal with. It is a tough situation.

We are all aware, I am sure, of Avonte Oquendo in New York City. Thanks to the Autism Speaks, there was tremendous publicity and attention focused on his passing as there should be. He was later found washed up and probably drowned fairly soon after having been missing from his school.

A number of the types of problems that I will be talking about come into play. A school where there was a lax policy or perhaps no policy for calling it in. Where there was substantial delay to notify law enforcement. A failure to completely embrace his safety issues in the IEP and the other documents that would govern his program. These things continue in many cases across the country.

We have technology available to help with this. I happen to be very fond of Project Lifesaver International. They are headquartered in Virginia with another office near me in Port St. Lucie, Florida. They use a very robust technology, radio frequency devices. You see it here on the little boy and again up here. They use relatively simple radio tracking technology to help get a direction to guide searches.

There are new technologies that need to be more fully researched. The market place is now dealing with this both in a positive and negative way. We see any number of devices, some that will pan out and others sadly that will not and may jam people up as they do not work out all the way. But these things are available. They tend to be expensive. These devices and the service run about $300 to get started. For many low-income families that can be quite a challenge even if there may be some supports for it in some ways. In our area, we have a nonprofit that helps provide support for these for families of lower income.

Here are some of the responses, the elopement missions for the Project Lifesaver International group over the last several months. They tally these nationwide. It is too small for you to see other than the fact that there is a substantial list there. If you were to analyze it, you would notice that there are several repeat customers, children who may elope multiple times. Even as families work hard to contain their child or schools and transition, it can be a very difficult situation.

This young fellow, Maddox Ritch, from North Carolina. We are all familiar I am sure with his passing recently where he was missing for six days out at a park, hiking with his father. He went missing and then was found and had drowned. Many of us are familiar with this. Once a child is missing and missing for more than a day certainly, it becomes regional and soon national news.

But what we are not familiar, what we’re not familiar with is the steady drumbeat of deaths of children with autism from drowning, other elopement-related issues, and other sources, suffocations, poisonings. Joshua Theodore in my region in Miramar in the Fort Lauderdale area drowned in September.

Ezekiel Matthew Surratt in North Carolina in his grandmother's pond with his entire family searching for him almost as soon as he went missing and not able to get to him in time.

Many of these children as we know from our knowledge of early intervention had they been able to reach adulthood could have been very productive individuals, contributing to our society. In either case, they deserve to live. And the sad fact that they died and died at such an early age is of tremendous concern to me. I hope to share that concern with you all here today. He is not wearing his seatbelt correctly, but that is trivial at this time.

Law enforcement training is available to assist in these searches as part of the fix. The Autism Society with their Safe and Sound program, as I mentioned, provided training for over 20,000 law enforcement officers.

In conjunction with the Pensacola Police Department, the Take Me Home program, is an enhancement to the 911 system that can allow parents to pre-register their child, their child status as at higher risk for elopement. In most parts of the country, it can be very difficult or even impossible for a family to register their child with 911 so that that information can be immediately available to first responders. We see that as a complication that should not be there.

We have other programs with other organizations. The Autism Speaks with their Autism Safety Project. Emily Iland has some really nice materials with Be Safe and

Experience Autism. We have a large number of qualified professionals who provide countless trainings for people for law enforcement professionals. Dennis Debbaudt is a regional neighbor of mine and is probably the one who does more of law enforcement training in the country than anyone else.

This training is out there, but it is not part of a national agenda to make sure that all police officers are trained, including federal officers in this.

There are things like these autism emergency contact forms that we encourage parents to use to record information about their child, provide a picture, to give indications of the child's propensities for water or other special interest that may help guide a search. If a parent does not know that their child is at risk, things like this become irrelevant. They are not motivated to complete forms like this and to engage in the kind of careful planning that would be necessary in terms of additional locks, additional safety procedures, policies within the home in terms of locking doors and supervising the child, having a clear chain of custody so that if around a pool or bodies of water, it is crystal clear who is in charge of the child at that time.

We see problems with schools where often schools now increasingly with resource officers will think we will take care of it internally. But a comprehensive search for a missing child whether a child with autism or other vulnerabilities cannot be achieved by school staff and certainly not by one or two school resource officers. Project Lifesaver International – it is not just devices, but training with local law enforcement. When a child with autism is missing, schools must contact local law enforcement immediately, we hope, so as to institute that search.

We see delays in the Avonte Oquendo situation that could have been as much as an hour. And a tragic death in Florida in the Tampa/Hillsborough County area. We saw a delay of almost an hour for a child who could perhaps have easily been rescued.

School principals seem to delay on this and it is somewhat inexplicable as to why they do that other than they do not wish to have a negative notation go to their central office and that fact seems to be the most prominent issue. That fact in light of our context is trivial and perhaps laughable if not for the seriousness of our subject here today.

This is Chief Gene Saunders who is the founder of Project Lifesaver International. I am done with my pitches for them, but we have worked with them on a research project, testing the use of their aerial drones to help expand the capability there. We saw some merit to that.

In terms of some of the needs and some of the things that the Autism Society hopes that people in this room and who are attending electronically will be able to help address and facilitate the solutions too. We really need data on the issue of autism child deaths in the United States, deaths of persons with autism across the board, but with special attention we hope to the child deaths. We do not know, and I hesitate to put up numbers that I know would be so soft as to not be worthy of this forum. But we need to address these weaknesses.

We see that some researchers have even resorted to newspaper accounts to try to get a handle on this. In our modern society, that is a very poor substitute for the kinds of data that we need to have. Death certificates do not contain an autism status. It does make it much more complicated. But there is sophisticated capability within our community to allow us to get solid numbers on the mortality for persons with autism.

We do need to have some greater standardization of the reporting formats so that we can help to get this. This may mean that some of the information that goes to National Vital Statistics and others are altered so that we do have relevant fields. Many of the newspaper reports freely mention that the child has autism. This should not be secretive. Most parents seem like they would be willing to share that information. Sadly, for the younger children, many of them may not have yet been diagnosed or made eligible through a school process so the parents may not even know that the child has autism spectrum disorder.

We would like to see research and support lead to the tracking and searching procedures and the technology that is at work there. Canada, a number of years ago, had a national effort to review the available technologies at that time. Right now, the market is driving these things, but in a halting kind of way as we see devices come in and then go. It is my belief that devices that can be used that are designed to be used in conjunction with law enforcement are the best way to go. We do not often see that with many of the market-driven solutions that in many cases are nothing more than gimmicks, giving parents a false sense of security and often wasting their time running around when a comprehensive search is needed. But we do not see the funding for this and the motivation for that at this time.

Swim instruction is often important. I am thinking of a death for a boy in 2017 in Palm Beach County. A 15-year-old with autism and epilepsy who died in an early morning swim before his family got up. He was swimming on his own, which he should not been and he kind of knew better, but he died and almost certainly as a result of an epileptic seizure during his swim. But many of the children who drown apparently do not know how to swim and swim instruction would seem to be extremely important.

In the US, unlike most other highly developed countries, we do not have universal swim instruction except in the most limited number of cases. Juneau, Alaska has some and Palm Beach/Fort Lauderdale region, Broward County/Fort Lauderdale has what I am aware of as the most comprehensive swim instruction, school-based for children with disabilities and all of the students. They now have close to one half million children who have been trained in these water survival techniques without a reported loss of any of the trained children and many reported rescues of other children with no loss of life to the trained children.

This is funded cooperatively by the school district and our local funding agencies in the county. Teachers like it because they do not have to go in the water. They do not have to get wet. Many of them choose to, but certified instructors take care of this. On this, we really do not have solid data information on the status of this. How much can this help with this issue?

Sadly, in Broward County, in this SWIM Central effort that I am telling you about, is it picks up at about first grade. The deaths to children who are 4 and 5 and may not have gotten to first grade continue in making it one of the most dangerous places in the country for young children in terms of the drowning efforts.

We hope to see funding for elopement research. The elopement or wandering – both terms are used many ways interchangeably in the behavioral community. We see the preference for the term elopement, but with the DC description of wandering. We may see that term predominate. But descriptive research and intervention research to help us understand more fully what is going on there with this wandering phenomenon. Sadly, for so many of the children who die, we really have no idea as to what is going on there with them. It is not like they can later tell us what has happened.

We know that behavioral assessment and using functional assessment procedures seem to be the most efficacious set of treatments that are available right now for the elopement issues. Here are two representative studies on that.

It would be wonderful to have a nationwide conference on this broader topic of unintentional injury with a focus on these high-risk areas especially. The elopement leading to drowning and poisoning.

While I am mentioning poisoning, we know from a nice study in South Carolina by McDermott and colleagues that there is approximately seven to eight times greater risk for poisoning for children with autism, which was surprising to me, but in another way, not surprising. The visual nature of so many of these children makes items very tantalizing. The pica problem, ingesting inedible objects can contribute to this. Fortunately, poisonings are usually not fatal. We do not see the high numbers of deaths from that, but nevertheless, a quite significant problem.

Fortunately, we have Kevin and Avonte's law that is now in place. Nine-year-old Kevin Curtis Wills and 14-year-old Avonte, who I have already talked about. These are Avonte's pictures. But it is imperative that this law be sufficiently funded to do the job. This is much more of a legislative issue, but our legislators will look to many of you here in this room and participating in this conference for guidance on this. Hopefully, this will be seen as the bipartisan issue that it should be and will receive sufficient funding to get the job done to provide training for law enforcement, money for devices for children and families so that they can help assure the safety of their child or children.

First responder training goes hand in hand with this. It has increased in many states. It is really on the upswing. But there is still a shortage of research on this topic overall. We suggest that every state have mandatory and comprehensive training on this. Florida now has initiated training, but many in the advocacy community are concerned that it is too shallow and does not really do what it needs to do.

Again, mentioning the tracking devices. Hopefully, these could be funded on a fairly easy basis for all who might benefit and whether it is a Project Lifesaver or some other kind of device, something that passes some reasonable degree of scrutiny on this should be made available to families.

As mentioned previously, 911 could be enhanced so as to do this. It is our hope that people here will be able to influence the 911 system so as to – there are many technical issues that confront 911 right now, but making it possible for families wherever they are to load up data, to have their child status preloaded with 911.

In my county, we have tried to make that easy, but there are 37 or so municipal police agencies. It is hard to advice parents and each has their own process for how they would then forward that information to 911.

The information that is needed to families is important. Through everyone here, through their advocacy and information-sharing efforts, we need to help make sure that families understand the risk especially to young children who have autism so that they can engage in prevention strategies for elopement, for poisoning and for other safety hazards that the child may face.

In general awareness category, this pervasive lack of self-preservation skills on the part of so many of the younger children, but continuing for many needs to be added, we think, to the characteristics of persons with autism.

An awareness also that there is approximately three times greater risk. In terms of why professionals perhaps still are not fully informing the parents remains perplexing. I think this is going down. Newer studies hopefully will show that that is not so prominent, but all professionals providing diagnostic information and information about a child and their autism need to be sharing this kind of information with families.

We would like to encourage a few things in terms of federal programs specifically. We hope that the Centers for Disease Control and Prevention could perhaps develop some increased cooperation between developmental disabilities and child injury. I am well aware of the excellent work they do in terms of the injury prevention area. It is quite noteworthy.

I look longingly at the Indian Health Services and their injury prevention project from a number of years ago where the Native American Indian population was identified as the highest risk for injury and unintentional injury in the country. There was quite a vigorous response to that. Now, there is a special federal responsibility for American Indians. But if we were to look at this, we may find that children with autism are at the greatest risk, greater risk than any population, perhaps even greater than

American Indian children and warranting a comparable significant federal response.

We have, as I was mentioning, very child injury prevention efforts, and we have excellent efforts within the other sections of CDC. But apparently, there is not sufficient cooperation. The child injury agenda that continues, the 2012 agenda, quite a noteworthy document and achievement and effort, makes no mention of either disability or autism in over 100-page document about these issues.

The Center for Birth Defects and Developmental Disabilities. We had hoped there would be greater cooperation between those areas for a new autism focused safety initiative. I think that is quite conceivable.

Here, you see the major areas from the big risk areas from the agenda listing drowning number three, but not listing wandering and elopement for ASD. We would hope that things like this could be in future agendas either recognized within the broader agenda or separately recognized as a separate initiative.

I’m running out of time here. I’ll skip that one for now. No I won’t.

The CDC efforts for surveillance are quite extensive and perhaps the epidemiological strength of that center could be extended to the mortality for children with autism and linked with the injury prevention so that we have that combination going forward.

We think that there is also a role for the National Institute of Health, National Institutes for Mental Health, to help recognize this issue and carry it forward and to help us understand both from what is going on within the child where they engage in these unsafe behaviors and the technologies that are available, but in other ways to help us deal with this problem.

We would like to see federal training in autism for all federal officers where there is a reasonable possibility that they would be involved in a search or in the safety issues for persons with autism. There is some of this, but it is not universal, and we think it could be accomplished.

In terms of education policy, we would like to see that state education agencies do have policies and procedures addressing elopement for students with autism. Most do not. There is only one that we are aware of that has targeted elopement policies in the State of Florida. It happens to be Broward County/Fort Lauderdale area. Mostly it is left to their school and the principal to work it out. We have policies for everything. We have policies for a shooter. And now through the Department of Justice, we have active abduction policies that schools around the country are obligated to follow. Abductions are a very important problem. But there was an articulated federal strategy to make sure that every school in the country was in sync with those abduction policies. We would hope that there could be a comparable effort so that every school had legitimate elopement and other safety procedures with mandatory training and other ways to make it happen. Many schools do not, as I mentioned.

The new issues in terms of crisis training, which is now so prominent in my State of Florida because of Parkland especially. Big impacts there. But there will be huge impacts in terms of those training for children and practices for children with autism. It is hard enough for an adult to understand what is going on and we are doing a lock down for a shooter. But for children with autism, we need special training, special care, special materials developed so as to see that their special needs are met and they are not unduly harmed in the process of all the practices that go forward with that.

For children with ASD with an IEP, which will be the vast majority of them, we would hope that there are special factors built into their document, their IEP, governing those training and drills.

We know that parents know that for school purposes, safety is very important. Eighty-one percent of the parents tell us there has not ever been a safety goal on their child's IEP, but 93 percent know that it is very important. Similar studies by Ivey show the same pattern for teachers. Teachers know it is extremely important. And skills can be added readily to the child's program. But in some places, they are excluded, saying that does not really fit with our agenda for any number of reasons, but questions such as a child being able to respond to what is your name, what did you eat, what happened, being able to show an identification card, become very important. We feel it should be included in the child's program.

The extension of the behavioral requirements. We have requirements that children receive a function-based assessment for problem behaviors. But this can also be and should also be applied to child's elopement behavior. We are not aware of many instances in which that actually happens. Children who elope from school. They should be able to get the benefits of these functional assessments to allow them to be safer.

Our specific asks. A nationwide tracking system. Sound public policy, as we all know, is based on accurate data. We do not have the accurate data on the total number of child deaths and autism mortality in this country. But if we have that, I think that would provide the impetus and the Autism Society believes it would provide the impetus for that national agenda. I think it would be a scary wake-up call if we knew the true extent of the autism deaths and near deaths that we see.

Strategies to sufficiently fund Kevin and Avonte's Law. I am going to keep our fingers crossed that our legislators pony up the money on this. We can all do quite a bit to influence them, we hope.

Enhance IDEA, the federal governance of special ed services, to include these ASD safety issues, elopement especially and other safety issues.

And for CDC, we hope there may be the need for additional funding to target safety and ASD issues with greater collaboration between the injury prevention and developmental disabilities area.

NIH and NIMH perhaps formulate plans to address ASD safety as a national health issue. In terms of how this breaks down with agencies, you all know that much better than I or people in the Autism Society, but certainly within this room. There is the capability to help make this a national agenda with significant federal funding.

We expect to see, what we would like to see, are incidents of elopement and wandering and death will decrease. Incidents of unintentional injury and accidents will decrease. Families will be more informed of ASD, the safety issues relating to their child and consequently a reduction in family stress, knowing what you are dealing with. Forewarned is forearmed. And that persons with autism will be safer overall in their home and in their community. Each of these we think is reasonable and quite doable.

But we hope that on behalf of the many families and individuals with ASD across the country that safety outcomes will improve for children and adults with ASD and that fewer will be injured and die.

We further hope that with continued efforts by the Autism Society and other autism organizations, like Autism Speakers, parents, professionals and advocates, and the federal government, with the facilitation of this committee, that greater safety awareness will be achieved and that safety for all persons with autism becomes a shared value. As a shared value, we will not forget this. We will help make good things happen, but that it becomes a shared value for all members of the autism community. Thank you very much for your attention on this.

(Applause)

DR. GORDON: Thank you, Dr. Scott. Before we resume a general discussion, are there any questions that you would like to have Dr. Scott address? Go ahead, start with David.

DR. MANDELL: Thanks for that very compelling presentation.

DR. SCOTT: Thank you.

DR. MANDELL: You brought up the issue of research in this area. I was reminded of a joke article that was written about parachute use to prevent death and major trauma by gravitational challenge. Aren't there some of these things that we should just do and what do you see the research agenda part of this being?

DR. SCOTT: Take that a little further.

DR. MANDELL: Why do we need research to show that using trackers with kids enables us to potentially - it seems like a lot of money, potentially, going to study whether tracking kids reduces their - or not knowing where they are. I am wondering. When you talked about their needing to be a research agenda tied to reducing unintentional injury and death in people with autism, what is the research part that you were thinking about?

DR. SCOTT: We do not have much research on this at this point obviously. Is it saving lives? How many lives are they saving? And then certainly the various technologies. Radio frequency technology is some old time stuff. This is some late '60s, '70s type technology. Newer technologies are out there. We do not know the differential benefits of those for tracking children with autism and other vulnerabilities.

It takes time for any of these systems for them to come into play. Children can drown and be injured in other ways within seconds, minutes certainly, and it takes time for law enforcement agencies to respond. We do not know in terms of what parent information is needed in order to keep a child secured. What are the protocols that should be in place for a child who is an eloper? These things - we see them from practice coming in different ways, but those are mostly anecdotal and mostly seat of the pants. In an increasingly evidence-based world, we are at a bit of a loss there. What is the evidence that supports doing these kinds of things that I am talking about? It is often too many gaps in it right now. I hope that helps.

DR. GORDON: Judith.

DR. COOPER: Thank you very much for this presentation. I had a question about identifying preschoolers who are at risk for elopement or wandering. I am wondering if you have any data, any surveys, any questionnaires that have been collected to say these particular – this profile of children, these are the ones we really have to watch out for so that we could almost target education to particular – of those that are most at risk. Anything about that?

My other question is the tracking devices. Very concerned about of course the cost and those low-income families will not be able to purchase. Do you know about funding with regard to insurance companies or other agencies that might provide those devices?

DR. SCOTT: In many areas of the country, we see many nonprofit foundations and other groups. In my county, we have a nonprofit organization that provides subsidized devices, free devices for low-income families. There are parents who report that they can get it for Medicaid in certain situations. But the families that I know that are doing that are extremely empowered. I do not know of any of the poorer families that are able to access those devices through federal funds at this time. The access there becomes problematic.

Your second question was the profile of the children. Children at ages of 4, 5, and 6 seem to be very much at risk. Intellectual disability as we see from Rice and the other studies seems to be a factor that contributes quite a bit. Beyond that, children who show a propensity to wander. If a child wanders, they are very likely to wander again so if they do it or show an interest. If they are busy playing with locks, latches, trying to explore ways to get out, children who bolt away at school. Those are most likely at higher risk. I do not know that we have good research on any kind of definitive profile.

Sadly, in schools, getting this information out, even in preschools, if the child is not already identified and made eligible, schools are often hesitant in sharing autism-specific information as that kind of presupposes the child is autistic and then there could be a jam up in terms of why weren't you doing more, why weren't you providing autism services? I think those factors of intellectual disability, lower IQ, more perservative behavior, certainly focused on locks, latches, trying to get out of a place.

What we do see in terms from the IAN study 2012 in terms of why children do it, many it just appeared they were adventurous and seemed happy when they were out there wandering. Some escaping from a sensory situation they did not like, but that was actually the lowest of the rated factors. Others to get something they wanted or to see something, a park, ducks, the swings. And rather than asking and saying can we go and bugging their parents for this, it is often easier for the child with autism just do it on their own, a direct access to the preferred re-enforcer.

We can tell on an individual basis with a child by some of the behavioral functional assessment techniques and just run through several conditions and see in which condition is the child is mostly likely to escape or to bolt.

(inaudible comments)

DR. GORDON: No, somebody probably opened the door. Can we close the door in the meantime?

(inaudible comments)

DR. GORDON: Sorry about that. There is an alarmed door someone must have left through the wrong exit. If you need to leave the building, hopefully it was not us, but if you need to leave the building, leave through the atrium please. Sorry.

Actually, next I think was John and then I have Alison and Edlyn and Sam. If you would like to ask Dr. Scott a question by all means, but we can also proceed into general discussion if you have points to make other than that, but you can stay up at the podium if you will.

MR. ROBISON: I would also like to thank you for a thought-provoking discussion. My response is based on my experience as an autistic person, my experience as a parent of an autistic child who was a very determined and successful wanderer and my experience these past five years being involved with autism schools in Massachusetts where we have high support kids, one of whose primary challenges for the teachers is wandering off.

In listening to the proposal, first, I would like to suggest that outside of what everyone else thinks about the intrusive technologies to monitor kids with electronics for wandering, I realize from all of my life experience that when you put a monitoring device on a kid, you create a powerful incentive to beat the system. You tell the kid beat it and you are free. And to overlook that, to me, that is an obvious fundamental failing.

What no one is talking about in this presentation or anyone else is what is obvious to me with these programs and that is kids are not wandering to escape horrible abuse most of the time. They are not wandering because they are stupid, mindless creatures that cannot figure out what they want to do. They are going places because they are inquisitive children just like every other child. If we want to solve the problem of injury and death, we should be teaching children how to explore the world safely. If we conclude that they are killed by cars walking into highways, we should be teaching highway safety at age 1, not fitting them with a monitoring device that tells us they are 50 feet from the road about to get hit.

We should be teaching them how to be safe around water.

I think that we often look for either explanations that are grounded in fantasy like the kids just wander for no reason or we look for a hidden horrible meaning like the kids wander because they are being horribly abused and they are fleeing out of desperation. I think it is a simple answer most of the time. It troubles me that we cannot implement even a simple answer like that in this society. I think that is what it comes down to.

DR. GORDON: Alison.

MS. SINGER: I think it is pretty well understood that prevention is the primary goal of these policies and that the tracking devices are a secondary intervention or when prevention policies fail. I think we definitely want to focus on prevention.

We also want to focus on what we are able to do in this committee. Wandering is actually an issue that the IACC has taken up several times. It is an area where I believe we have contributed in a meaningful way. The studies that were just cited were commissioned by the IACC and in some cases conducted by past members of the IACC including Dr. Rice. And the CDC was instrumental in using that data to get an ICD-9 code so that pediatricians are able to provide anticipatory guidance to families, which is part of prevention. I do think that we have spent a good amount of time focused on prevention.

But what I wanted to really ask is about a year ago, we sent a letter to the Department of Justice, specifically about Avonte's law, which Dr. Scott referenced, and asking about their intentions to fund first responder training that would be specific to autism, which is part of Avonte's law and similar to what they support in terms of all timer specific training for first responders. Whatever happened to the letter that we sent to the Department of Justice? Can we get someone from the Department of Justice to come to this meeting and respond to the points that Dr. Scott has made or even to have a member from the Department of Justice join this committee because so many of the issues that we take up from a policy perspective fall under the realm of the Department of Justice?

DR. GORDON: Go ahead, Susan, if you would like to respond.

DR. DANIELS: We did have the Department of Justice come here before. We have had the National Center for Missing and Exploited Children here before. We did not send a letter, but I know that there was discussion of being able to send a letter. We are happy to invite DOJ to come to a future meeting to talk with us about their work in this area, what is new, what is the progress and what they are doing on Kevin and Avonte's law. If the committee would like to have them come, we can invite them for either the January or April meeting to join us and talk to us about their programs.

MR. ROBISON: I would second a motion that we invite Justice and I would not limit this to child wandering. I would certainly ask about first responder training for autistic people of all ages and all abilities.

DR. GORDON: If it is okay, John, we will table the motion for the moment until we have had time for fuller discussion. We will come back to that motion later. Is that all right?

Next I have Edlyn. Anyone else, by the way, want to get on the list?

MS. CRANE: I will.

DR. GORDON: Okay, sure.

DR. PEÑA: Thank you for your presentation. I appreciate it. I just had two thoughts, one of which John already touched on quite eloquently, which is I am a mother of a 10-year-old son with autism who has left our home several times. I am also a director of an autism center in California. We had a conference last week. Almost 400 people attended and increasingly every year we have more autistic participation, which is wonderful. But this is the first time that we had two children under the age of 18 leave our conference and go explore on our college campus. One of the students was found at the pool. That was very frightening. I would never forgive myself if something had happened to those children. It was the first time we had ever experienced anything like that on campus.

Now, I am working more proactively with our campus safety officers who were called within about five to seven minutes of the children being reported missing. I wondered if you had any other recommendations for service providers or parents when a child does go missing. How fast should it be reported? Is there anything else we can do other than to train our police officers or campus officers?

And then just to reiterate John's point about proactive, there is research out there by – an example is Dr. Olga Solomon who talks about wandering in terms of children exploring, being proactive, taking an initiative to go out and see things and not underestimating their intelligence or not trying to escape, but rather to go out and seek adventure or whatever they are really interested in.

I like the idea of being proactive in terms of teaching safety around cars, swimming. All of those things are really important as proactive measures rather than thinking about this reactively.

DR. SCOTT: Swim instruction is certainly very important in this regard and parents understanding the nature of their child's elopement. It may be during a time of boredom. It may be during a time when there is too much stress in the family, too much commotion. Their brother or sister's birthday party. And being able to identify and then heighten security during those times.

I am all too well aware of the issues surrounding the freedom of people to wander in a free country. This is quite prominent in the United Kingdom that wandering is seen somewhat differently there. It is at much greater exploration. But here for the person who is able to represent their case either through an assistive device or in some other way and they are able to say I really want to get out there and roam around and tour and do things. I think we have to be prepared to respect that.

The pictures of all of the children I showed – it would be very difficult to facilitate that conversation with them at that time in their life nor would we allow them to wander, to go in those places unsupervised. If you have any children of that age and you get out at a Target store or a mall, you would not let the child walk on their own independently to the store through the parking lot. It would be dangerous. You have to either hold their hand or insist that they are standing right next to you. This is in a way comparable.

There is an issue that I know also gets raised about the voluntariness of this, the intrusiveness. What we have in Florida – we have some legislation that allows for devices to be provided in some cases, but it is all with parent cooperation. Parents have to be completely in favor of this. If not, it is simply something that is not done. Important there.

At what point can the child represent their case to say this is too intrusive? There is a point at which the child – we need to able to respect that. But even on a more simple basis, those devices can be taken off as easily and the child can rip it off. If they cannot rip it off – if they know how to use scissors, they can take it off easily there. If they do not know how to use scissors then we need to be doubly concerned that they are out there roaming unsupervised and what is a very dangerous world for a 4, 5, 6 year old. It can be a real big problem.

I had almost ten years as a wilderness camp counselor with emotionally disturbed children. Being out in the open on the Appalachian Trail and other places had a tremendous therapeutic benefit for almost all of the kids. Frankly, we did not worry if a kid ran off. If they ran off, their self-preservation skills were intact. They were going to be able to find their way. But if they would have been children with autism, there should be tremendous concern because often they don't. (Inaudible comment) provided us with evidence that they have sound self-preservation skills and that then becomes the critical issue. If parents were to leave the child to wander, they would be guilty of neglect. They would be in trouble as I think they should be.

But I recognize John's point. In the advocacy community especially, we see as a very prominent issue. There, we have eloquent spokespersons for autism, but it is the children who will not get to be eloquent spokespersons who die that we need to I think also keep our attention focused on. I suggest that all of these children with good early intervention had a chance to grow up could have been somebody making a solid contribution here in this room, but they do not have the chance to do that.

DR. GORDON: Thank you. Sam.

MS. CRANE: I want to address that because as John pointed out not every case of wandering is in response to abuse, but I do not think that we should discount the possibility that sometimes it is in response to abuse and in addition, there could be conflict within the family. There could be situations in which the child is trying to escape a specific person, who then has access to the wandering device.

In addition, I do not think that we should discount the fact that some of us who are contributing in the room do have histories of wandering. I certainly wandered as a kid. I would consider myself to have a wandering problem now. This is my tracking device. This is the device that I use to let people know where I am if I am completely lost and I do not know where I am.

A lot of the kids who are labeled as not having self-preservation instincts – I would say that everyone wants to live unless the kid is deliberately suicidal, which is sometimes something that happens. The child might not recognize danger, but once they are taught to recognize danger, is going to respond to danger. Sometimes what is happening is that the child once they are out of their element, once they have gone somewhere, they follow something that is interesting and now they are completely lost. That is a point where people panic and they do not necessarily know how to get back.

Sometimes the best training is what I would call orientation training to help people. Here is what you do if you are lost. Just acknowledge that sometimes this kid is going to be lost and here is what you do. We see this in situations where the kid is lost in the woods or lost in an area that they cannot be found by first responders. Sometimes it is because their instinct was to hide when they were lost because they were afraid and no one was around. I wanted to point that out.

I also want to be careful about technological solutions that do not take into account the voices of people who have histories of wandering and can now talk about it because some of these devices as others have pointed out, they are not going to prevent a problem once you have found out that the kid – if the problem is the child has gone across a highway, by the time you know that that child is missing, they have already gotten across the highway. That is an issue. And also you want to try and design these devices so that you can facilitate their usability as the child grows and becomes more self-determined. It is why I really like my cell phone because I use it and it is not something that gets turned on by someone else unless there is a serious missing person situation.

DR. SCOTT: A key piece of police training for searching for children with autism and the safety of children with autism is the notion that a child will typically not help in their own recovery. This is a similar pattern to those with dementia and Alzheimer's. And usually the child is found in an area that has already been searched. They are not looking to be found. Often fearful. There are strangers looking for me. They do not respond. If we were lost, we would say I am over here. I am stuck. I have this problem. Law enforcement training is helpful in that way.

The picture I showed where this boy drowned could otherwise be considered not a harmful environment for a child. Most children by the ages of 3 and 4 would have the self-preservation skills to not go in. We might be able to wade through that. We do not know what is happening in these elopements that go to drowning.

Here, in terms of the pattern of residential development in the US, so many of the nice developments have water features all over the place, certainly in Florida, but increasingly around the rest of the country. This one has been almost certainly dredged where there is a gradual decline. And then because of the way they use the back hoes and the tools, it is much sharper. That apparently is what catches some of these kids. They wander in and they are playing in the water and then suddenly they are in deep water. And there a panic seems to set in that maybe there is an interaction with their autism. I think there is in terms of what happens. We do not have very good evidence about their motivations for doing this other than knowing that they will tend to leave for several reasons.

The concern about abuse I think is in a way offset. If a parent calls this in – some parents are very hesitant to call it in, possibly those who are being abusive because they do not want to have any police involvement, any community involvement. But when a parent calls it in, police are trained if they are trained in this area to be suspicious. This is a concern we hear from many parents. They say the police did not seem very sympathetic. They were asking me questions almost like I did something. And the police bring that suspicious instinct to the situation. But if there is abuse, hopefully that interaction with the police – if the police suspect that there is some abuse, they are going to be able to call it in to the appropriate social service agency and the child is now getting help, especially if the police are trained. If not, they may be more easily blown off and say the kid had autism. They wander so I am leaving it alone.

MS. CRANE: But that is only when the tracking device has to be mediated through the police, which is not true of all tracking devices.

DR. SCOTT: It can be true in an elopement where there is no tracking device and the police do bring the child home. If they suspect that there is abuse then they would be able to follow up on that and we would have community involvement.

DR. GORDON: Thanks, Dr. Scott. Stuart.

DR. SHAPIRA: Not a question but some additional comments. First, just to expand a little on the answer to the Judith's question. There have been recent studies that tried to tease out some of the issues related to increased risk for wandering or for unintentional injuries and in addition to intellectual disability and others that have been mentioned more recently attention deficit disorders as a co-occurring condition have been shown to increase the risk and providers need to pay attention to children who have that as a co-occurring condition in conjunction with autism.

But I did want to make some comments about CDC and CDC's work and some have already been brought up today that CDC has recognized that safety is a significant issue among children and adults with autism and has worked in this area for quite some time. As Alison mentioned, CDC partnered with the IACC and with others to develop the ICD-9 and subsequently the ICD-10 health care administrative codes for wandering, which have helped to document wandering and to prompt important discussions about safety with caregivers, with individuals who wander and with providers.

CDC has partnered with others to understand how common wandering is among children with autism and as well as other developmental disabilities. This includes Cathy Rice's paper that Dr. Scott and others have mentioned as well as some other additional studies that have looked at the issue.

CDC was also a representative on the IACC Safety Subcommittee and CDC staff have assisted in data collection on wandering and have worked with partners to raise awareness of wandering as an opportunity to improve safety and decrease unintentional injuries.

I did want to mention a little bit about CDC's autism's surveillance and research work that focuses actually on a broad spectrum of factors related to well-being of children with autism and their families including injury and safety. Those are included in the surveillance in the research work. Using CDC's existing platforms of the Study to Explore Early Development or SEED and the Autism Developmental Disabilities Monitoring Network, or ADDM Network, CDC works to quantify the risk and protective factors for particular outcomes among children with autism.

CDC has actually heard the concerns from the community. As Dr. Wagner has mentioned that CDC is working to expand our knowledge from childhood into adolescence and adulthood. Both the ADDM Network and SEED have developed longitudinal component to expand information on well-being of adolescence with autism and factors that increase the risk for mortality and morbidity such as unintentional injuries. We are moving into that space with our current platform.

DR. GORDON: Thank you, Stuart. We have about ten minutes left of discussion. I think it is time to return to John's motion. John, would you restate what you have requested?

MR. ROBISON: I think that we should make a formal request to the Department of Justice to come join us at IACC and listen to our concerns and arguments for why we need federal funding to train first responders. And I believe that our first responder training concerns need to focus on the issues of wandering raised with young children, potentially response to young children in times of stress and also dealing with autistic adults in times of stress. Those all seem to be major potential flash points that end up with autistic people injured.

I would like to make the motion that we discuss that and that we make a motion to ask them to join us.

MS. CRANE: I would like to second that motion.

DR. GORDON: We have a request that we ask Justice to send a representative or representatives to this committee to hear the committee's concerns about not just safety issues, but with regard to individuals with autism who have gone missing or et cetera, but also in dealing with individuals with autism who come across the law enforcement for other reasons. Is that right?

MR. ROBISON: I think, Josh, that it goes very quickly from being a misunderstanding issue to being a safety issue. That is the problem that we see in the news.

DR. GORDON: We can do that as a committee, request the Justice to appear?

DR. DANIELS: It would be easier just for me to invite them to come just like we do for every other kind of speaker we have.

DR. GORDON: But I think John and maybe Samantha, you were going to say. If not, I will let you speak after – was really suggesting that we would also present a list of issues to them that we either would like addressed or that someone from the committee would make a presentation about our concerns. Am I correct?

MR. ROBISON: Yes.

MS. CRANE: I would even support adding DOJ as a member to IACC, which is what Alison had also suggested. IACC can include any agency as a member, any agency that has a significant nexus with autism. I know that ASAN has requested repeatedly that DOJ be added as a mandatory member, but we can still add them as a member even without a mandate.

DR. DANIELS: We cannot compel an agency to join us. If they are invited to come and speak, certainly members of the committee can say that we would love to have you join us. If they are interested, they can request membership on the committee.

MS. CRANE: Couldn’t we at least invite them to request membership on the committee?

DR. DANIELS: We do not issue invitations to agencies to then request things from us, but we can – if they are here and you would like to tell them that you would like to see them join the committee, they can consider that within their agency and then decide if they want to make a nomination.

DR. GORDON: There has been a motion to invite Justice to participate in a meeting so that we can have this discussion. There was a second. All in favor? Any opposed or abstentions? No. Susan will issue the invitation. We will let you know if there is any difficulty, but I would imagine that they would come and we will try to schedule the next, most convenient IACC meeting, either the one in January or the one later in the spring, which I think is April.

I would request that we have a volunteer or two to present the issues that were raised by the various speakers that we have heard not just today, but in the past. I see Alison already raising her hand. It would be great if you could crystalize them and maybe work with Susan to form a 15 or 20-minute presentation. If we could provide that in advance to Justice that might be very helpful in terms of having them being able to collate what they are doing and what they plan to do and what they might have difficulty accomplishing.

MS. CRANE: (inaudible comments)

DR. GORDON: It would be great if the two of you could work together on that. That would be wonderful. Yeah, David.

DR. AMARAL: I wonder whether we should include in this mandate getting some input from them on just people with autism in the judicial system and maybe even in the penal system as well. If you are going to talk about wandering and how --

DR. GORDON: I am wary of the idea of loading down too many things on one session. I think if we focus on safety for the first one and then hope that they have a productive enough experience that we can get them to be a voluntary member. And or as you all know, the legislation authoring this committee is expiring. They are working on the renewal. There is some discussion, I believe, as Sam mentioned, of including Justice in the membership in the legislation. But either way, it would be nice to try to have them come on a regular basis so they can contribute to these discussions. David.

DR. MANDELL: I did want to interfere with that motion, but in the spirit of Alison's point about prevention, much of the prevention of wandering and then negative consequences of it come through environmental modifications and Justice does not do environmental modifications, but CMS does. I wonder if the broad topic is safety and we want to have a focus on prevention as well whether it is worth making - and they are members of our committee. And that also may lead to specific policy asks around using federal dollars for environmental modifications.

DR. GORDON: Melissa, I believe you are on the phone. Do you have any thoughts or comments in response to David? You might be muted. Melissa had to drop off. We will communicate that to Melissa and see if there is an opportunity to have her as well speak on that day of CMS' efforts or at least make sure that she can make it so that she can respond to the safety discussion.

Thank you all. It is time for our break. It is actually right on time. 10:30. We are going to take a 15-minute break and we will be back here at 10:45.

(Whereupon, the Committee took a brief break at 10:30 a.m. and reconvened at 10:45 a.m.)

DR. GORDON: Thank you very much for coming back on time and we are going to stay on track. The next section of our agenda is devoted to committee business. I will turn it over to Susan.

DR. DANIELS: Hello. I wanted to go through some committee business items to keep you informed of what the Office of Autism Research Coordination is doing and activities of the committee. Next slide please.

I wanted to first say thank you to the OARC staff for the work that they have done again in coordinating the many activities of the IACC including this meeting. I would like to ask members of the team to stand so that you can just see who they are and say hello to them, but thank you so much for everything that you have been doing to make everything run smoothly and to provide all the information that is needed to have successful meetings and activities.

(applause)

DR. DANIELS: Next slide please. One of the activities we have going on in the office right now is our office is on behalf of the Office of the Secretary of Health and Human Services, preparing the Autism CARES Act report to Congress on federal activities on autism spectrum disorder. This is a project that is in progress. The report details progress on activities related to autism and other developmental disorders across the federal government. We have coordinated responses from various federal departments and agencies in preparing this report. It is in final preparation now and we expect that it will be released a little bit later this calendar year. In the January meeting, I hope to be able to share some highlights of this report with you. Stay tuned for that. Next slide please.

I also wanted to give you an update on the 2016 data set IACC Portfolio Analysis Report. This final report is expected by the end of the 2018 as well and is in the final stages of preparation. This is the first portfolio analysis that is coding projects to the newest strategic plan that we released last year. We expect the final report soon.

The 2017 IACC Portfolio Analysis so the 2017 year data set is being collected right now from various federal agencies and private organizations. We expect that report in the next calendar year. Again, stay tuned and of course we will let you know when all of those reports are available and present them to the committee at future meetings. Next slide please.

I wanted to discuss with you the 2018 IACC Strategic Plan update. As you know, in the Autism CARES Act legislation, it is required that we provide an annual update to the strategic plan. As you also know, the previous year or two years you spent working on the strategic plan version that was released in 2017, which was quite extensive and a lot of work for members of the committee and all the external panelists who helped us with preparing that new strategic plan.

In order to meet these congressional requirements, I am proposing to you that we do this annual update in a shorter format this year and summarize some of the activities of the IACC and progress to date related to the strategic plan. What we would propose is including three things. A summary of the Health Outcomes working group and workshop that we will be discussing in a few minutes, but many of the activities that have been going on with relation to this particular working group and some of the issues that the committee is interested in pursuing in that. We would be able to provide a summary of that activity.

Number 2 would be a summary of 2016 IACC Portfolio Analysis Report. We will have the report out and we could do a short brief update on what was found in relation to the strategic plan and especially the new strategic plan.

And then the third piece would be a summary of the Autism CARES Act Report to Congress, which describes all of the federal activities related to autism.

With these three portions in this summary that would conclude our Strategic Plan update.

This is what I am proposing to you as a way for us to get the requirement completed by the end of the year. And the way we would do this is that we would prepare the summaries within OARC with our staff and then send it to you for approval. And if you approve it -you could make comments, et cetera for consideration for this report. We would issue the report in a timely manner and complete this requirement. We would propose to complete it by the end of 2018 as required.

Are there any questions or comments about this proposal?

MR. ROBISON: How much change do you envision us having from the overall goals and concerns that we articulated? It seems like just yesterday in the introduction and report that we wrote, for example, we said that we believe now an emphasis on adults should rise to the fore. That has not really changed. What is different in your mind?

DR. DANIELS: Exactly. It is just that we are required by Congress to provide an annual update. The annual update would not be changing the Strategic Plan at all because you did a very comprehensive job of presenting a Strategic Plan with brand new objectives, all of the updated areas that the committee was interested in addressing in 2017. We do not at least within the office and within the leadership here for the committee did not see a need for us to alter the strategic plan that you just provided, but rather to provide a summary of activities that we have had going on that respond to the Strategic Plan or describe progress made to date, for example, by federal agencies what we have collected in terms of the research portfolio and the work that the committee is doing on issues related to health outcomes. It would really be more of a summarizing document rather than a change in the strategic plan itself.

MR. ROBISON: I would like to actually bring something up that I was going to propose at the next IACC that relates to adult autism knowledge that is needed to advance the strategic plan. Can I take a few minutes and outline that concern or do you want to do this later? I think this directly relates to what we could say in this update.

DR. DANIELS: What I would recommend for this update is that we do something like this that is a summary that does not require new thinking and development of new activities because we do not have any other meetings planned in order for us to come together and think of new ideas that we are going to present and new recommendations that would be forming another working group or something like that. We really do not have a lot of time before the end of the calendar year. But if you want to take up other new discussions that you would do that after that.

MR. ROBISON: I will offer to do what I did before and I will offer to write to draft our introduction, conclusions, and say the same things with new words.

DR. DANIELS: We do not really need that for this – since this is just a summary, it is really a summary of these three things. It would be easier for us to just draft it and have you guys review it. But if you feel that you want more involvement, I think it will become a lengthier process.

MR. ROBISON: Do we just need a motion then to do that by email, Susan? Is that all we need?

DR. DANIELS: Yes. That is what we need.

MR. ROBISON: I will make a motion that you draft it and we review it.

DR. DANIELS: Thank you. Is there a second? Thank you. All in favor?

(chorus of ayes)

DR. DANIELS: Anybody opposed? Anyone abstaining? It sounds like there is unanimity in the committee to go forward with this type of a summary update to the Strategic Plan for this year. John, if you do want to share more specific points about adults in autism, we can schedule some time on a future meeting if you want to take a few minutes to talk about that.

MR. ROBISON: I think I could do that as a presentation maybe in January.

DR. DANIELS: That would be great. We can talk about that offline.

DR. GORDON: Thanks, John. Susan, if I might interrupt for just a moment. I recognize that there are a lot of people out there in the audience and watching that may not have understood what just went on. This committee spent quite an extensive amount of time in the previous year or year and a half to extensively revise the Strategic Plan and it was really just finished a few months ago. The content of the Strategic Plan, which outlines a whole number of recommendations, which I encourage everyone to go to IACC.HHS.gov to look at if you would like. It is really quite comprehensive and timely and there is not the necessity to comprehensively update it. We are going to basically provide these additional specific areas of updates and do a more extensive revision when next required.

DR. DANIELS: Thank you. Moving on to the next slide, please. We would like to give you an update on Improving Health Outcomes for Individuals on the Autism Working Group that the committee formed. This committee got up and running in September. We would like to give you some updates on that. I am going to have David Amaral also share with us in a few minutes about a recent activity.

But the IACC voted to convene a working group on health and wellness issues for individuals with ASD. This working group is exploring ways to support research to better understand the health conditions that affect individuals on the autism spectrum, to increase community and provider awareness of these conditions and how to treat them effectively and also to foster development of practice guidelines, policies, service approaches and other efforts to improve health and quality of life for people on the autism spectrum. Next slide please.

The scope of the working group again as a reminder is health and general wellness for people with ASD, co-occurring physical and mental health conditions, premature mortality, which we did touch on this morning in our presentation, patient-provider interactions including medical practitioner training, and parental and family mental health. Next slide please.

This is a listing. I do not expect you to read it here in the meeting, but when we post the slides later if anyone wants to look at this. This is the list of working group members and we also have an official roster on the website under the working group of the people who are participating in this. There are several IACC and federal members to the working group. We also have several invited external members and experts that have joined us for this working group.

We have held one phone call that took place in September prior to the workshop and then we held a workshop just a couple of weeks ago on September 27, which was called Addressing the Health Needs of People on the Autism Spectrum. Next slide please.

What we expect in terms of working group activities and products over the coming year before this iteration of the committee would come to end is that the workshop has taken place now. The working group is interested in producing a written document that provides an update and possibly recommendations on this issue. Any written document that comes out of the working group will come to the IACC for review and approval to become the official document of the IACC.

Continued discussion will take place on working group conference calls and any additional meetings or workshops and in IACC full committee meetings. We will give you an update each time on what this working group has been doing. It has been a very active working group and a lot of enthusiasm around the table for the issues we are working on. We will be functioning up until September 2019.

Here, I would like to turn it over to Dr. David Amaral, who is the co-chair of the working group, along with Julie Lounds Taylor who could not be with us today to tell us a little bit about what happened at our workshop a couple of weeks ago, which was from the feedback received very successful and brought a lot of really critical issues to the table and gives us a chance to think about these. David.

DR. AMARAL: Thanks, Susan. First of all, I wanted to thank Susan ad the OARC team for getting another meeting organized. It was a very efficient meeting, very well organized, and gave us a chance to discuss some interesting issues. It was a meeting that was both productive and really animated. Right from the very first presentation, people were already discussing. It extended on all the way until the end of the meeting at 5 o'clock. It was very interactive, lots of communication.

There were really two tracks. One was trying to identify the extent of the problem, how common are co-occurring conditions and to what extent do they cause problems for families and individuals on the autism spectrum.

And then the other track that we discussed during the day was how do we get the word out to practitioners, not necessarily in academic institutions, but out in the community who may not be as aware of these problems as academic physicians.

As you can see in this first slide, we started off the day with a scope of the problem and we went over data from Lisa Croen and others indicating that people on the autism spectrum have a shorter than expected lifespan and that they are suffering from a whole host of medical problems, many of which you would not associate with autism, things like cancer and diabetes and others that at this point it is not entirely clear why there is a higher prevalence of those diseases in autism. That actually conditioned a lot of the discussion during the day. Is that because individuals on the autism spectrum are not able to access medical care as well as others or is it that something about the biology that causes autism also leads to some of these medical co-occurring conditions. I think while we discussed it, we did not come to a firm conclusion.

Under Susan's guidance, we tried to be very focused during the day. We only talked about three co-occurring conditions. We talked about epilepsy, gastrointestinal disturbances and sleep disturbances. We had presentations by experts in all these areas. What basically we found was that all of these conditions are affecting sizable proportions of individuals on the autism spectrum and causing tremendous disability. Even though it has been appreciated that these are associated with autism that that awareness probably has not gotten out as widely as one would hope.

And certainly we still heard about families that were having difficulties convincing their primary care physicians that the gastrointestinal problems should be treated as anybody else would have GI problems treated. And oftentimes the GI problems get pawned off to well that is just because they have autism and it is full stop. There is not adequate treatment.

We also talked about approaches during the day to bring awareness to physicians. We had a presentation, for example, on ECHO Autism by Michah Mazurek. That is a situation where you have academic physicians that provide a nucleus and then you have more rural physicians of a community that through video conferencing can present cases and get expert advice from this nucleus. This is something that Michah had started at the University of Missouri, but now is piloting it throughout, NIH-funded piloting throughout 11 sites around the country. This seemed like a reasonable way to try to get the word out quickly to physicians.

Part of what came out during the day is that there actually are a fair amount of resources to provide families and physicians with information. But how you put it all together and make sure you proselytize so that gets out to the community and that we need some better ways of doing that, I think. The next slide.

During the day, a number of policy issues that we at least touched on came up, things like developing better tools and guidelines for primary care physicians to survey for medical conditions. If you have a nonverbal individual with autism with intellectual disability, how do you ascertain that they have a problem? How do you detect pain? How do you detect issues that they are not feeling well?

Part of the issue was that often times during the transition to adulthood, you have a pediatrician who has been taking care of a child and then all of a sudden now you have to have an adult physician. They do not really know how to deal with a person with autism.

There were notions during the day that there is actually fear in –real lack of interest in some parts in adult physicians dealing with individuals on the autism spectrum. There has to be more education about that, the need for adult physicians to receive training and how to work with patients with disabilities such as ASD.

The last two points and you can read this, but developing a team approach for providers, patients, and caregivers, including consultation of specialists during primary care visits. Again, primary care docs often times do not have firsthand knowledge about autism or these comorbid conditions. Actually, having pediatric gastroenterologists who can also work on a team to provide the support was something that came up during the day.

One of the things that was sort of daunting was that people realized to do a complete comprehensive medical analysis of a person with autism takes longer than the typical 15 minutes that primary care docs usually do when you go in for your annual visit or whatever. And sometimes it takes specially trained individuals to help out. In research, we do things that are complex by employing BCBAs who can help us have a child or an adult be comfortable in a research situation; yet, we do not do that in primary care practice so if we can have actually behavioral support in primary care. But there has to be a mechanism for that and the insurance companies have to buy into that. All of these issues are things that we hope we would be able to present in the white paper document as recommendations for improvements in medical care for people with autism. Next slide.

I think it was Dr. Nina Schor who was at the meeting who had this statement, which I thought really crystallized the whole thing. She said families, clinicians and researchers are all on the same page concerning the importance of treating co-occurring health conditions to improve the quality of life for autistic individuals.

It may be a while and it may not even be the best use of our time and our effort to try and go after the core symptoms of autism because often those are the ones that do not cause the disability. But things like anxiety and gastrointestinal problems and sleep disorders are treatable conditions that we can go after now. It actually goes back to the very beginning of this IACC when we were encouraged to try and go after low hanging fruit to improve the health and quality of life of people in the autism community.

It is one of the rare occasions in the autism community where there is no controversy about this. Everybody agrees this is a good thing to do. We just have to come up with better systems for doing it and better supports to do it.

The last slide. Again, Susan kept us focused on those co-occurring conditions. But during the day, we heard about others and particularly mental health co-occurring conditions. The one that was probably most common was anxiety. There is evidence that anxiety disorder is occurring in something on the order of 50 percent or more of people diagnosed with autism. There are ways to treat anxiety, but not necessarily being implemented at the moment. Suicide, another major issue that again touches sort of tangentially on the discussion we had this morning. ADHD, which is increasing becoming more apparent in autism and self-injurious behavior.

There was the notion that we should have another comprehensive discussion of these mental health conditions to put it together with more biologically oriented ones that we had in the first working group.

Finally, there were a couple of unanswered questions. There were many unanswered questions, but some of the ones that can be research based are, does the underlying biology that causes autism also cause the co-occurring health conditions. We do not really know the link between anxiety and GI problems, for example -- parts of the brain that are involved in anxiety also do control gastric secretions. Maybe there is a link there, but there is very little research.

I think one of the things that people were asking during the entire day is and I do not think we actually know this yet is to what extent the reduction of co-occurring conditions would help to ameliorate the core features of autism. As Beth Malow said, if you could deal with the sleep problems in autism and if they were regulated, would the social impairments or some of the other issues related to the core features of autism be ameliorated as well? We simply do not know at this point. Certainly, if sleep was improved, probably cognitive abilities would be improved. There is a lot of research showing that sleep does impact cognitive abilities. We have not looked at the relationships between trying to treat, which we can do now, the co-occurring conditions and whether that would have an impact on the core features of autism as well.

Again, just end there by saying that this was a very animated, positive day. Lots of good discussion. I think people are enthusiastic about developing this white paper and getting the word out as broadly as possible.

We heard about lots of tools that we can use already and I think we will be able to make suggestions about how to bring some of those tools together and make them more widely known through this committee. Thanks Susan.

DR. DANIELS: Thank you, David. We have some time for discussion if anyone would like to comment on the workshop, if you attended, or you have questions.

MR. ROBISON: One thing that I think would be important for us to take on as a group is a public misconception. You said in there that the committee discussed whether the underlying biology that produces autism is also involved in the mental health and the physical medical issues that are so common with us. I think that it is likely that that is so. That seems sort of intuitive.

But there are a significant number of people who emphatically deny those kinds of connections. I think when we deny those connections, we deny the reality that, for example, epilepsy and autistic people is far more treatment resistant than epilepsy in non-autistic people. Many of these conditions are much harder to treat and require different strategies.

I think that it is almost like we need a name or a recognition of this bigger thing that is autism. While it may confer in our minds a mix of disability and exceptionality, it also can bring really resistant complications. I think for us to deny that that is autism, which is a common thread in the public thinking, I think that that is counterproductive for us. I wonder what you think about trying to address that in our communication.

DR. AMARAL: I think that is a really good point. On the one hand, some of the treatments that are actually being used for typical individuals have not actually been adequately tried or tested in individuals with autism on the one hand. But it is highly likely, I think, that there will be atypical responses in autism and we need to know that as well because the physicians who are going to be treating individuals with autism once we encourage them to treat them need to know where they can expect extreme responses or atypical responses. I think it is a really, really good point.

We did touch on that a little bit during the work group. We need to gather more data on how to shore up by experimental data what you just said, which I think many people think. We just need to find the data to support it.

DR. DANIELS: Alison.

MS. SINGER: That was a great summary. Thank you. I wanted to just add a little bit to the comments about aging out of your pediatrician. One thing that I thought was very interesting that came up for discussion at the meeting there was not resolution was the idea of needing the equivalent of a developmental pediatrician for adults and whether we should as an organization in the white paper advocate for the creation of a new type of medical specialty for adults that would have specific training and do rotations and fellowships specifically in autism and developmental disorders. I thought that was a really interesting point of discussion.

DR. DANIELS: Samantha.

MS. CRANE: I think just following up on John’s point, I think another thing that did come up in the discussion and it is important to add is that a lot of the time when we have studies on treatments for epilepsy, autistic people are excluded from those studies and vice versa. People with epilepsy are often excluded from some studies about autism. We have really limited research on these intersectional populations that could answer questions of whether and why we respond differently to the standard treatments for some of these medical concerns.

I also thought it would be really worth bringing up that with some things like sleep, for example, we have a lot of good research on general sleep strategies. Again, often that research is based on what works for sleep disorders for people who are not autistic. We do not have very good research on people with really intractable sleep problems or problems that are resistant to behavioral or life style interventions. We have very poor understanding of the underlying biological or social causes of why we are seeing this more in autistic people than in non-autistic people. It is an epidemic in our society, I will use the term epidemic, of people using their phone screens or their computer screens late at night and everyone knows that that can sometimes interfere with sleep. That is true of everyone, but it does not explain why autistic people are having a much harder time with sleep than non-autistic people.

We really need these studies that actually look at the population of autistic people with these co-occurring mental or physical concerns.

DR. AMARAL: Could I just comment about the epilepsy issue? I thought it was really interesting that this is a place where there is still need for some basic epidemiological and biomedical clarification because we heard from Sarah Spence that in autism, about half the people with autism have a seizure prior to 10 years of age and then half have a seizure in late adolescence and adult years. At this point, it is hard to predict who is going to have which type of seizure.

It would make sense if there were some additional information about what is going to predict somebody that is going to be at high risk of having seizures so that maybe prophylactic approaches could be taken.

This is actually again one of the in a sense real difficulties for families with autism. They will have a child that we will go through all of the issues of childhood and they get into the adolescent years and they think they are home safe and all of a sudden at 19 they will have their first grand mal seizure. It just comes out of the blue in a sense.

This is a place where I think if researchers could figure out whether it is a genotype or whether it is some other predictive aspect of the disorder that would say this person is at high risk for epilepsy.

I agree with you, Sam. The idea of eliminating people who have autism from epilepsy research and epilepsy from autism research does not make any sense whatsoever to me. I think we should really encourage a broader inclusion of people in both areas of research. But it would be helpful if we could come up with some predictive biomarkers as well.

DR. PELPHREY: This is Kevin. I just wanted to second what David was saying about how important this is and it really needs to be a focus of work in the future.

DR. DANIELS: Yes, and it was also interesting the chicken and egg issue with epilepsy that was brought up, which was a really useful discussion as well in terms of whether epilepsy drives autism or autism drives epilepsy.

Do you want to say something about that?

DR. AMARAL: I do not have all the details. I was supposed to look it up and it has been too briefly since we have this meeting.

One question came up is that if there are subclinical epileptic form activities without a seizure, could that be contributing to some of the autistic symptomatology? That has been in the wind for 15 years or so that that might be a possibility.

But I gather that there is a study and I wish I had more details about this. I will try to get them and circulate them – of individuals with tuberous sclerosis where epilepsy is also very common. The study is to prophylactically treat those tuberous sclerosis patients to see whether they reduce the number of those individuals who go on to have autistic symptoms as well. That is the basic outline.

Again, it raises the other question. Should we be surveying for epileptic form activity in people with autism earlier to try and perhaps do something prophylactic. Again, there was not a lot of evidence presented, but it was one of the intriguing notions that more comprehensive surveillance of people with autism might actually be able to bring up.

DR. DANIELS: Thank you. I think Stuart was next.

DR. SHAPIRO: I did attend the workshop and I had a thought afterwards so after it already ended about your comments relating to having behavioral support available in a clinical setting and from discussions that we had afterwards that came to mind that the Joint Commission requires having translation services, competent translation services in clinical settings in the hospital and maybe some approach to engage the Joint Commission would help to institutionalize having behavioral support available in those situations. It would not answer the question entirely, but might be a direction to go along that route to see about institutionalizing it.

DR. DANIELS: David.

DR. MANDELL: Related to Stuart's comments. Medicare last year implemented three new codes for behavioral health integration and primary care, two for sort of general integration, which probably does not meet our needs here, but another for implementing a collaborative care model.

It might be interesting to think about whether that collaborative care model could be applied here because one of the big challenges in creating this new position is you have created a new position without necessarily a way to bill for it. Is there a way to incentivize primary care doctors to take advantage of this and therefore perhaps be more attentive clinicians and more willing to take on people on their case load who have autism and other developmental disabilities?

The other thing I was thinking about is that I think that this is a set of issues that clinicians who work with individuals with Down's syndrome and some other forms of intellectual disability have been dealing with for decades. I wonder if there is an opportunity for this committee to learn from them about the strategies that they have used to think about transitional care and providing care to adults for chronic conditions that emerge in childhood.

DR. DANIELS: Thank you. Are there any other questions? John and then next Josh.

DR. ROBISON: I would like to add that this discussion brings to the fore a number of very real medical problems that autistic people suffer from and suffer is truly the right word, for example, of discomfort of sleep disorder, GI pain, and so on.

I think that we need to help physicians understand that there is a difference between somebody saying I am autistic and I do not want to be cured. That is a way of being and I do not want to be cured of it. That is not a denial of our desire for help with what makes us suffer. We can say I am happy as an autistic person, but at the same time, we can say I think it sucks living with constant diarrhea, with constant intestinal pain, with not being able to sleep. I would like to be absolutely clear that that is a very important point for us to deliver to the medical community. A tolerance, acceptance, and understanding does not preclude the desire for treatment of real problems.

DR. DANIELS: Josh.

DR. GORDON: Did the workshop discuss at all collaborative care models because they have been explored through research both by

NIH and also by the National Institute for Children's Health Quality?

DR. AMARAL: We discussed it sort of in the abstract, but we did not actually get down to specific models if my recollection is correct. The way the work group functioned was to highlight certain issues that we then wanted to focus in on either through conference calls or perhaps even through a second work group. The issue of collaborative medical care providing is something that will be a component of one of these subcommittees. They will then generate both information and recommendations.

DR. DANIELS: You did raise a question about some other issues that the working group is interested in addressing. Did you have particular suggestions or comments on that?

DR. AMARAL: I think for a lot of this we can continue to work through conference calls and Zooms and things like that. But I was impressed that the in-person working group was so generative that we sort of fed off each other. I wonder whether it would be worthwhile to propose a second working group dealing with these specific issues particularly the more mental health related co-occurring conditions that are again identifiable and treatable.

I think that if we have those two then that would generate a core of all of what we would need to put together the document.

DR. DANIELS: You are not talking about starting another working group, but rather an activity.

DR. AMARAL: I’m sorry, another activity, but an in-person one. I was trying to figure out how we could deal with all those things just by conference calls. I think it would be helpful and be generative to have a separate in-person session on this and then deal with everything else related through conference calls.

I, frankly, was very pleased and surprised by how enthusiastic people were about the first meeting. But these things kept sneaking in and you kept saying no, we are not going to deal with that. I think if we can focus on that that would be my suggestion.

DR. DANIELS: Jim

DR. BALL: Just a quick question. Are you going to generate separate white papers or one total off of everything?

DR. AMARAL: I do not know yet. Again, I think it will depend on the working group and what people think would be the most effective way. It could be one working group with chapters or – I am sorry – one document with chapters or separate documents. I think we haven't gotten to that point yet. We have started highlighting things that are of interest to address. The actual product we have to discuss further.

DR. DANIELS: Alison.

MS. SINGER: This is one of three working groups that we had voted and was first in the cue. I am wondering when the Housing Working Group is going to get underway.

DR. DANIELS: Our plan is to have the Housing Working Group start at the beginning of 2019. This is one working group and the Housing Working Group. Those were the two that at the last meeting in April we talked about getting those off the ground and trying to complete some work by the end of the period for this committee, which is September 2019. With the Housing Working Group, you also may end up wanting to have some kind of an in-person activity. If we are doing in-person activities, we need to have some sort of prioritization on which ones because we only have a few more months to work. We have about a year. We have some scheduled meetings like our full committee meetings in addition to whatever these working groups will be doing.

DR. GORDON: Do we have membership yet for the Housing Working Group already proposed?

DR. DANIELS: Not formally. We have a draft list, but need to add more to that list and then start making those invitations.

DR. GORDON: And maybe we should get that going so that they can get up and running as soon as possible after the new year given the hard close of the sun setting of this version of the committee with the legislation.

DR. DANIELS: Right. That is the plan. Is there any particular request regarding activities or in terms of prioritizing different things that these groups – the only reason I am asking is for planning purposes.

We have a full committee meeting scheduled for January, a full committee meeting scheduled for April and ordinarily would have a full committee meeting scheduled for July. The INSAR meeting is in May. We have certain things that are already kind of on the schedule and plus annual autism awareness month activities in April.

DR. AMARAL: I guess I would just say given Alison's suggestion that if we are going to have this second meeting that we do it pretty early in the year, maybe February or March, and then that would free up OARC for doing the housing maybe in the spring.

MS. SINGER: I think the Housing Working Group will want to have at least one in-person meeting we should save time and resources for.

DR. DANIELS: Do you feel comfortable with us taking in that information and then going ahead and trying to figure out what might work in terms of planning and then getting back to the working groups about that? How do you feel, Josh?

DR. GORDON: I think that should be fine. The question is whether we can get enough participation from the Housing Group members, given that there is probably going to be overlap with the members of the current working group. We will have to see whether we can schedule something. I think probably you would want something in January or February realistically in order to be able to produce something by the end of September.

DR. DANIELS: Right. We would have the first meeting of the Housing Working Group will be a phone call and then if we want to plan some kind of in-person activity, it can be after that. The external membership will probably be fairly different for the Housing Working Group because it is a pretty different topic.

With IACC members, there were only a small number of IACC members that are members of the Working Group, official members of the Working Group that are going to be on all the calls. I think there are opportunities for other members of the committee who are maybe more interested in the housing issue to get on that. I will send out an email and request that you let me know if you want to be on the Housing Working Group or if any federal agency wants to send a representative to be on that Housing Working Group.

DR. GORDON: Thanks for bringing that up, Alison.

DR. DANIELS: Alright. It sounds like we are at a good point to close this part.

The next order of business is the summary of advances discussion. Next slide. We received a number of nominations for the summary of advances and each of the nominations is listed on the slides in front of us. If there are members of the committee here who have submitted some of these and you would like to talk about any of these nominations, please feel free to share with us what you thought was particularly compelling about these findings.

DR. GORDON: Not in reference to the two that are on the screen, but I would just point out that there are a number of the proposed studies that impact on the genetic causes as well as the environmental causes of autism. I think it is really tremendous that we are beginning to make considerable progress, which is wonderful.

The challenge posed by the many papers that you will see as you look through the packet from both the genetic perspective and the environmental perspective is the complexity. We have so many different - it is more accurate to say etiologic factors or causal factors than it is to say causes because no one factor is going to be causal in many cases, but the complexity is quite daunting.

However, there are some signals in that complexity that are promising that we can make progress. I will just point to you that there is at least one or two of these studies, actually more than one, for example, that focus on rare genetic factors that raise your risk dramatically for autism such as the

SHANK3 mutation, which we have heard about before in this committee. There are several studies using SHANK3 mice to try to understand the implications of SHANK3 mutations on brain function and behavior.

I will add in the editorial comment that these are mouse studies. They are at best I would say preliminary stabs at mechanism and to the extent that they are limited in our ability to understand how much they translate to the human condition. Nonetheless that is one pathway forward from this myriad causes to an understanding of what goes wrong and at least a subset of those suffering from autism. There is a lot of promise on a lot of these papers. I think it is going to be challenging for us to pick just a few that we might want to mark for the summary of advances in the end.

DR. DANIELS: Thank you. We have on this first slide I know that the first one, the EEG study, was one that David, you had nominated. Do you have any comments about that?

(inaudible comments)

DR. DANIELS: And actually, on the packet that is inside your folders, we have the actual justifications that each of you wrote. If you need that, it is in your folder and that is online for anyone who is watching this webcast.

DR. AMARAL: I can just say that this adds to a number of papers that have come out in the last two years showing that you can see early signs as early as six months of alterations either in brain structure and function. This is an EEG study that I do not understanding how it actually gets done. It is looking for patterns of EEG coherence and the difference is in individuals who are at high risk for autism in the EEG signal. The advantage is that EEG is relatively easy compared to some of the other things that have been done like MRI to acquire from young children. This is the second or third report coming from this group, showing that there are EEG predictors of autism risk.

Again, it highlights that these signals even though you do not see behavioral alterations, you do see brain alterations very early on. That is why I nominated it.

DR. DANIELS: Thank you. Next slide, please. The last two were ones that were nominated by Geri Dawson and she is not here today.

Next slide. This one was nominated by Alison Singer. Do you have any comments on the top one or the following one from Molecular Psychiatry? It was nominated by

Linda Birmbaum. She had to leave, but Cindy Lawler is here.

DR. CINDY LAWLER: I can talk about that. Briefly, the advance here is the development of a model that can be used as a resource to understand what is being observed clinically and that a proportion of mothers of children with autism have a specific pattern of autoantibodies.

A few years ago, the group at UC Davis that has really been driving this area of research was able to identify the specific proteins that are the targets for these autoantibodies. With that information, we are able to synthesize all pieces of those proteins that are known to be immunogenic called epitopes. In a mouse model prior to breeding, inject a mix of those small bits of proteins and confirmed that the mice on their own then developed autoantibodies to those proteins and then of course looked at least in this particular study characterized the behavioral features of the offspring and found some interesting differences relative to control with respect to reciprocal social interaction and stereotypy and also some head size. The advance is really this will help us understand mechanistically what that clinical association is.

DR. DANIELS: Thank you. And Alison, do you have anything?

MS. SINGER: Yes. This paper came from Matt Siegel’s group. It is an advance really I think for two reasons. One is that it demonstrates that it is possible to do studies of this very understudied population of individuals with severe self-injurious behaviors and intellectual disabilities. We talk a lot about how difficult it is to bring them into the clinic and how difficult it is for consent. This shows that it is able to do it.

And then secondly, it speaks specifically to factors that confer risk for self-injurious behavior. This is very actionable information for families in terms of prevention and in terms of participatory guidance.

DR. DANIELS: Thank you. Next slide. We had nominations from Geri Dawson and also from Walter Koroshetz. I know Laura is here. Do you have any comments, Laura, on that second one?

DR. MAMOUNAS: Yes. This is the paper that I think Josh was referring to looking at Shank3 mouse models. We were intrigued by this because it very nicely shows that histone deacetylase type 2 may be involved in some of the behavioral deficits seen in

SHANK3 mouse models of Phelan-McDermid syndrome.

Other studies, for example, in Rett syndrome have implicated HDACs. But this one sort of rises up a step in that it really delineates quite nicely both the upstream and downstream molecular mechanisms involved in the HDAC2. They treated these mice with a fairly specific HDAC2, class 1 HDAC inhibitor romidepsin. With three days of treatment, they showed that they got a very, very long-lasting improvement in the social behaviors in these mice.

Also, I think what is important is that they showed that they could get this effect in more than one model – more than one SHANK3 model. I thought it was interesting that treatment in the juvenile mice at younger ages had a much more profound effect on the rescue – rescued much more profoundly than later on in adulthood.

There are some caveats. I personally am not a big fan of the social behavioral assay because we do not really understand the circuitry. We do not really know whether this assay – whether prefrontal cortex is necessary and/or sufficient, using this assay. We do not really know whether it is a really good phenolog for social behavior in humans.

The other limitation is that I wish they had done PKPD measurements to show that what are the drug concentrations in prefrontal cortex. Even so, they really nicely did a lot of rigorous studies, blinded, randomized, replication, different approaches, electrophysiology, mapped out the upstream/downstream events. I think that is what we were enthusiastic about.

DR. GORDON: I would add to it that because of those mechanistic details, you are not relying just on the social output, the social behavior output, which I agree is tremendously problematic.

Also, it is a pathway forward toward imagining and being able to study these things in models that are more relevant to the human whether it be human cells to look at the molecular and electrophysiologic phenotypes that can be affected here and/or a non-human primate models, which are being constructed for SHANK3 where you could actually look at social behavior that might be more relevant. I think it is exciting from the perspective of being able to set the stage for those studies that really will help translation later.

DR. MAMOUNAS: From a treatment perspective, therapeutic perspective, it is really interesting the long-lasting effect that this has. I think a lot more research could be done in terms of – it is obviously involving a epigenetic mechanism, but what that actually is really opens the way for these kinds of treatments for a lot of these neurodevelopmental or autism disorders.

DR. GORDON: I am less optimistic about that because quite often things that are long-lasting in mice are not at all in humans, but point well taken. At least this has a theoretical mechanism by which it might be long-lasting. Nonetheless, it is an exciting step forward.

DR. DANIELS: Thank you. Next slide. Moving to Question 3: Risk Factors. The first one was nominated by Geri and the second by Josh. Any comments here?

Next slide please. These were nominated by Linda. I do not know, Cindy, if you have any comments on that top one and then Geri, who is not here for the second one.

DR. LAWLER: I can talk a little bit about the top one. This received quite a bit of attention. It is from investigators at Columbia. It is a very well powered studied based on population cohort in Finland, looking at the association between DDT, which is an insecticide that has been banned for decades in most places; however, because it is very persistent, fat soluble, all of us have quantifiable or most of us have quantifiable levels of this insecticide.

The study was around 800 autism cases, 800 controls. One of the major advances is they were able to take advantage of serum samples that were collected prospectively mid-pregnancy so much prior to of course the autism diagnosis and look at the levels of DDT and the study found an increased risk for those moms who had the maternal levels that were in the top quartile of exposure. When they did some subgroup analysis, the risk was particularly pronounced in cases with comorbid intellectual disability. This is nice especially because it used a biomarker of exposure, not subject to recall bias, not an indirect imputation of an exposure, but really direct measurement in etiologically relevant period of time.

DR. DANIELS: Thank you. Next slide. On this one --

DR. LAWLER: One more time. This is particularly exciting. It builds on work that we have heard here earlier about the novel use of shed teeth or baby teeth as a record of chemical uptake especially metal uptake beginning in pregnancy around the second trimester when teeth begin developing. It is a very time-resolved pattern.

One of the features that are particularly novel here is that to be able to capture that time resolved pattern, you need new analytic techniques that can extract features of the cycling of metals. Here, we are talking about essential metals, copper and zinc, and being able to distinguish autism cases from controls in four different study populations, not based on the average levels of these essential metals, but on characteristics of their natural cycling of those metals. It is really an exciting approach that is being used very widely in many of the studies that we support for neurodevelopmental disorders, not just autism.

DR. DANIELS: Thank you and the next one was nominated by Walter and Geri.

DR. MAMOUNAS: Geri is not here so I will just comment. This was really interesting because it really gets into the dark matter of the genome in terms of damaging de novo mutations. Most of the work has really focused on protein-coating regions and identifying variants and de novo variants. This one really digs down and shows that they were able to show that in a very large cohort of subjects with neurodevelopmental disorders, about 8000 individuals, that a small fraction of them showed de novo mutations in intronic non-coding regulatory regions, speculating that these are affecting - these are either enhancers or effecting splicing.

They showed that they could enrich in really highly conserved regions of the non-coding regions and those variants that are really enriched in fetal brain. That was interesting.

I think the caveat is that it is a fairly small fraction. They really only found that about 1 to 3 percent of patients that did not have a diagnostic coding variant that they estimated would carry these de novo mutations in the intronic region. And that maybe only about .15 percent of all variants in these non-coding regions would lead to a highly penetrant mutation, leading to a neurodevelopmental disorder. But I still think it is interesting or we think it is interesting and it really starts to study what we call the dark matter of the genome.

DR. DANIELS: Thank you. Next slide. We had a couple of papers here. The first one was nominated by Geri. The second by Josh. Any comments?

DR. GORDON: I do not have anything to add onto mine beyond what I have already said about the genetic ones in general.

DR. DANIELS: Thank you. Next slide, please. This one was nominated by Larry. I think he might have stepped out.

DR. GORDON: Larry had to step out for a conference.

DR. DANIELS: And then the next one was also nominated by Larry. We will skip over those. If he happens to come back before the end, we will give him an opportunity to say something.

The next slide. The top one was nominated by Julie Taylor, who is not here, and the second by Geri Dawson, who is not here today.

Next is one that was also nominated by Julie Taylor. That is the end.

Thank you so much for your submissions. At the next meeting in January, we will be doing the final round and making selections for the 2018 IACC Summary of Advances. We will give you an update on that at the next meeting. Thanks.

At this point in the program, we are ready to break for lunch.

DR. GORDON: Great. We are little bit ahead of schedule. We will meet back here at 1 o'clock for the public comment session where we will hear summaries of written comments and then have the opportunity to discuss them. I know that there are a lot of written comments for us to go over. There were no oral comments requested in advance this time. We will just have the written ones to discuss. We will see you back here at 1 o'clock. Thank you.

(Whereupon, the Committee recessed for lunch at 11:52 p.m. and reconvened at 1:02 p.m.)

DR. GORDON: As I mentioned, we did not have any prior registrations for oral comments. We will turn it over to Susan and her team for the written public comments and then we will have a discussion as a committee as a whole.

DR. DANIELS: Correct. We will have Dr. Oni Celestin from my team provide a summary of the written comments. We did not receive any requests for oral comments for this meeting. And then we will have plenty of time for discussion of the written comments. Thanks Oni. Please go ahead when you are ready.

DR. ONI CELESTIN: Good afternoon. Can you hear me? Since the April Full Committee Meeting, the IACC has received written public comments from 22 commenters. For the purposes of this presentation, we have organized these comments into six broad topics. The committee has been provided the comments in full, but they will be summarized briefly here.

The first topic is concern about medical practices and potential causes of autism. There were six comments on this topic. Ms. Christie Riehl expressed concern about the recognition of ABA as an evidence-based approach, given the apprehension in the self-advocate community about its effectiveness. She would like the IACC to address these concerns.

Mr. Yuval Levental believes that vitamin D deficiency may be a cause of autism. He wrote about his personal experience with taking vitamin D supplements and would like to increase awareness in hope that it may be a beneficial treatment to other autistic individuals.

Mr. Ryan Carboni is concerned that there is no accurate diagnostic test for autism and that he and others have faced severe consequences from being misdiagnosed.

Mr. Oren Evans believes that fluorescent lighting and other lights with strobe effects may be contributing to the increased prevalence of autism. He submitted a document to the IACC explaining his hypothesis.

Ms. Resa Warner is concerned that anti-psychotic medications are being used to treat autism. She also believes that more research needs to be done on metal exposures in auto-immunity in autistic individuals.

Dr. Eileen Nicole Simon encouraged the IACC to investigate several factors that could be contributing to autism symptoms. In particular, she would like the IACC to discuss the importance of the inferior colliculus and its susceptibility to damage from alcohol, drugs, or environmental toxins. She believes that brain injuries caused by Wernicke's encephalopathy, bilirubin exposure, or umbilical cord clamping may contribute to autism. She would like IACC members to discuss her comments.

The second topic is vaccines and autism. There were six comments received on this topic. Mr. John Best believes that autism is caused by mercury in vaccines and that chelation should be used as a treatment. He also expressed frustration with the IACC.

Ms. Kristin Sullivan believes that vaccines cause autism and expressed concern about the US vaccination program. She also recommended a new book by JB Handley.

Ms. Maureen Block asked the IACC to investigate the science presented in a book by JB Handley and to change the childhood vaccination schedule.

Ms. Tammy Kraft recommends that all IACC members read JB Handley's new book and believes that the evidence presented in the book accurately describes the experiences of her son with autism.

Mr. Tim Kasemodel wrote about the significant medical issues that his son with autism has faced. He expressed concern that vaccine injury leading to autism has not been fully considered. He also recommended that IACC members read JB Handley's new book.

Dr. Kerry Scott Lane believes that autism is caused by metal intoxication and oxidative stress from vaccines and Tylenol. He submitted several documents to the IACC, including a summary of a review article discussing the links between oxidative stress, inflammation, acetaminophen and autism.

The third topic is service needs, resources, and policy implications. There were three comments received on this topic. Ms. Peggy Helm-Quest commented in response to the panel on employment for people on the autism spectrum, which was held at the April 2018 IACC meeting. She felt that there were several challenges and barriers facing autistic students in higher education that were not addressed by the panel. She is particularly concerned about the potential for civil rights discrimination in these settings and that many of these institutions do not have sufficient experience serving these students.

Dr. Linda Papadimitriou-Varsou believes that the IACC should address the environmental and epigenetic factors that contribute to autism. She also believes that increased mental health services are needed to reduce the rate of suicide in autistic individuals. She encourages a more holistic approach to treatment and recommends increased resources and counseling for parents of children with ASD. She is also concerned about the effect of poverty on individuals with ASD and their families. She encourages federal agencies to implement policies that will reduce poverty.

Ms. Patricia Duncan submitted a comment on behalf of the organization Autistic Adults and other Stakeholders Engage Together or AASET. They are holding a one-day meeting in November and wish to invite colleagues interested in implementing research that addresses topics important to autistic adults.

The fourth topic is Title X funding. There were three comments received on this topic. Ms. Robin Bresette, Ms. Carin Burns, and Ms. Kara Churo all wrote individually in support of Title X funding for the health and safety of all citizens.

The fifth topic is safety of individuals with autism. There were two comments received on this topic. Ms. Emily Iland encouraged the IACC to consider the importance of training police officers about autism as well as training autistic individuals how to safely interact with police officers. She recommends a community-based, personalized approach to these trainings and emphasized the importance of building relationships between police and members of the disability community. She highlights training programs that are being used to accomplish these purposes.

Ms. Josefine Krapp expressed concern about the treatment of autistic individuals in the criminal justice system and in psychiatric hospitals. She expressed concern that autistic offenders assigned to psychiatric hospitals would not get adequate or appropriate treatment there. She requests that the IACC advocate for more laws to prevent the classification of Asperger's syndrome as a dangerous mental disorder as well as more appropriate treatments in psychiatric hospitals.

The last topic is the role of the IACC. There were two comments received on this topic. Ms. Idil Abdull expressed concern about the decision to limit oral commenters at the IACC meetings to one presentation per year. She believes that many parents are concerned that they are not being heard when such a limit is imposed.

Ms. Lisa Wiederlight submitted a comment on behalf of SafeMinds expressing concern about a lack of urgency from the federal government related to autism. She is particularly concerned that the federal response to autism excludes certain portions of the autism community. She shared the results of a stakeholder satisfaction survey implemented this summer by SafeMinds, The Thinking Mom's Revolution and Talk About Curing Autism.

About half of the respondents who had heard of the IACC felt that the work of the IACC had impacted their lives negatively or not at all. Ms. Wiederlight urged the federal government to engage a more diverse group of stakeholders in order to understand how the IACC can better meet the needs of the community.

She also feels that the survey reveals that many in the autism community feel disenfranchised by the IACC and do not feel that the current structure of the public comment section allows them to adequately discuss their concerns with the committee.

Furthermore, the survey revealed that many stakeholders do not present oral public comments because they are unable to travel to Washington, DC or unable to make child care arrangements. Ms. Wiederlight recommends that the IACC hold meetings across the country or consider the use of technology that would allow community members to present oral comments without having to travel to DC.

Finally, Ms. Wiederlight conveyed that the full survey results will be released later this year and that SafeMinds welcomes the opportunity to discuss it with the IACC.

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

DR. DANIELS: Thank you, Dr. Celestin. And just to remind everyone who is listening in on the phone or on the webcast that the full text of the written public comments is in the packet and it is on our website for anyone who wants to see them.

Is there any discussion?

MS. CRANE: I have two comments. One, I see that there is actually a question that Christie Riehl has asked to both John and me about our advocacy around applied behavioral analysis. I just want to note that I take self-advocate concerns about applied behavioral analysis very seriously. I think when we do talk about ABA, I consistently want to advocate for better engagement with the self-advocacy community in designing studies, making sure that long-term effects of ABA including mental health concerns are studied and making sure that other interventions also get research funding because I think there is some really promising interventions out there that are under researched. The second is -

DR. GORDON: Sam, can you hold that second thought for a moment? I have a follow-up question to that first if you do not mind. Are there particular concerns in the self-advocacy community about long-term effects that you are thinking about when you say that or is it just the uncertainty that you are concerned about?

MS. CRANE: Yes, there definitely are. It has been a while since we had this conversation on IACC.

Dr. GORDON: And it probably preceded my tenure.

MS. CRANE: I will recap a little bit. There are many self-advocates who are concerned about a variety of aspects of how ABA is implemented. One is that often behavioral interventions are targeted at behaviors that are not bothersome to autistic people ourselves. They are targeted toward masking rather than building skills. That is a significant concern.

There is a concern about the effects of any intensive 40-hour or 30-hour per week intervention on children's mental health and ability to have unstructured play time and follow interests. There are concerns about the potential for ABA to reduce people to behaviors and result in a more control focused relationship between the parent, the educator, and the child than what self-advocates often consider would be appropriate. That is just a brief rundown. I am not sure we want to have this whole conversation right now.

DR. GORDON: No, but I wanted to make sure that I at least understood the summary. Thank you very much for that. I recognize it is probably part of a longer conversation that I need to have at least, but thanks.

MS. CRANE: And second, I wanted to talk about the case of Darius McCollum, which is what Josefine Krapp talked about because I think it is extremely important. This is a man who has a long history of involvement with the criminal justice system as a result of his special interest in transit. Darius started out hanging around the New York City Subway. He made friends with subway operators. The subway operators taught him how to use the subway controls and would allow him to drive the subway for them. This resulted in him being arrested, which I think is very unfair because Darius was autistic. He did not understand that this thing that people were encouraging and allowing him to do was illegal. But he was arrested for impersonating a subway operator. He was sent to prison. He spent quite a lot of time in solitary confinement. Prison conditions were not really good for him as an autistic person. He did not have an accurate diagnosis. He was misdiagnosed with obsessive-compulsive disorder. He did not get very good treatment or counseling.

And then after released, he kept getting into trouble with the criminal justice system for similar offenses including most recently, he tried to pretend to be a Greyhound bus driver. He got in the driver's seat of the bus and started driving the bus with passengers in it from Point A to Point B. He was not going off on a joy ride. He was just trying to be the bus driver.

Darius was recently found by the trial court judge in New York to be not guilty by reason of mental disability. But then the judge found that he was a danger to society and in fact found that he was the highest level of danger. This is going to result in his commitment to a state psychiatric hospital. Those commitments can be pretty much permanent because once someone with a developmental disability is committed to a psychiatric hospital in this context, they often cannot get out unless they show that they have been cured, which is not going to happen.

ASAN had written a letter to the judge urging the judge to consider the home and community-based services that could be available to Darius to try and help him manage his behavior. We know that people with very challenging behaviors can be successfully served in the community. That was apparently not accepted as a comment. We really need to address these stereotypes about autistic people in the criminal justice system and make sure that people in the criminal justice system including judges understand the resources that are available to people like Darius to help us live safely in the community.

DR. GORDON: Thanks for that summary. I note that Ms. Krapp notes New York Post article about the case for those who might be interested in further reading on it. John.

MR. ROBISON: First of all, I think as Sam pointed out, Christie addressed her comment about ABA specifically to Sam and I. -- And build on what she said with respect to specific causes of concern for ABA. My concerns about ABA stem from the responses I see in my students at college and in high school programs. I want to be clear that I am not opposed to ABA, all forms, all places.

We have BCBA therapists in (inaudible comments) and I see them engage -

DR. GORDON: Can you say what BCBA is --

MR. ROBISON: Board Certified Behavioral Analysts. That is the thing you become with a

Master's in ABA. These behavioral analysts engage in respectful, interactive, and productive therapy (inaudible comments) do things like organize to bring their books to school or how to behave in settings or how to act in a class. These are therapists who respond to young people's concerns about helping them in life and it works.

What I also see though are students who come to groups and they burst into tears recalling how a therapist forced them to act normal or act like they were supposed to, which might have meant not flapping their wings, not rocking and so on. That normalization and forced behavior change in very young children is not a therapy that the autistic person ever consented to and it is something that I believe might the evidence of my student shows left lasting harm even as the behaviorist said we succeeded in our job.

I want us to learn how we can change the profession to be productive and to work with autistic people in a consenting environment. That is my answer to Christie with respect to what I would like to see happen and how I feel. I think I have made my concerns clear right now.

What I would like next to address is the next fellow's comment. Yuval Levental. Now, Yuval has --

DR. GORDON: John, can we pause for a moment? Let me just ask if there is any more comments or thoughts on the ABA issue because I saw some hands go up.

MR. ROBISON: ABA is going to open the door, yes. I will come back.

DR. GORDON: Do you want to do that first?

MR. ROBISON: Let us carry on with the ABA discussion.

DR. GORDON: Okay, we’re coming back. Great. I see Alison and I see David. Alison.

MS. SINGER: John, I hear your concerns, but I want to point out that the population for which you are reporting outcomes is a population that is able to go to college. I think when we think about --

DR. ROBISON: This is high school, too, Alison, not just college.

MS. SINGER: General education high school?

MR. ROBISON: No, special ed high school.

MS. SINGER: I am going to talk about individuals, children, school-aged kids, teenagers who are very severely affected by their autism and for whom ABA is really the only for many families the only intervention for which they have reported any meaningful progress. Not all ABA programs are focused on eliminating behaviors. Many of them are focused on basic skills of daily living, taking turns, waiting in line, doing a less preferred activity before you engage in a more preferred activity.

I can tell you from my own personal experience with my daughter that when she was able to finally understand first and then, first we eat chicken and then we eat ice cream or first we wait in line and then we can go on the carousel. That was life changing for her. It enabled to participate much more meaningfully in community activities because most community activities do not stop and enable the person with autism to run to the front of the line.

I don't - I understand that there are adults who have very clear and very heartbreaking stories about their experience with ABA. It is troubling to me in many ways because I think in some cases this is what has led many of those individuals to really resent their parents for putting them in ABA programs that they think were harmful and that has really eroded the relationship that many of them have had with their parents. I think that is really sad.

But I also do not want to lose sight of the fact that for many children who are severe with their autism and have no other recourse, this is a way for them to learn language. This is a way for them to learn to participate meaningfully in community events.

MR. ROBISON: Alison, you touch on the terrible ethical dilemma that we have with ABA because there has been real life changing benefit to many people, but there has also been real life changing harm. What we need as a goal is to eliminate the harm while keeping the benefit.

DR. GORDON: Let me get to David and then Sam. Is that okay? David.

DR. MANDELL: I think that what I hear a lot of people describe as ABA is very consistent with the way that ABA was practiced in the '70s and '80s and not as consistent with the way that evidence suggests that ABA should be practiced now given our evolving understanding of what successful behavioral interventions are and what kinds of skills and behaviors they can be used or should be used to target.

My first thought is maybe it is worth it if we are going to take this up in any way as a committee that it might be helpful for us to have a shared understanding of what we mean by practices based on the principles of applied behavior analysis as they should be practiced now and whether we should invite someone to help us come to consensus about that.

The second thing is I want to make a distinction between applied behavioral analysis and bad application (inaudible comments) there is a lot of crappy therapy out there for people with autism just like there is a lot of crappy therapy for people with depression and anxiety and any other condition that you can think of. I think there is a separate issue of changing community practice so that it is more consistent with what we think of as best standards for people with autism. I think both things should be within the purview of this group, but I do not think they should be confused.

DR. GORDON: Sam and then I think what we will do is wrap up and move on to the next topic.

MS. CRANE: I just wanted to address a couple of things. One is I think the concerns that I have expressed about ABA and maybe again they are not universal, but the concerns I have expressed are concerns that we have heard equally from people who are nonspeaking, who were labeled as very low functioning as kids. If 40 hours a week of intensive interventions are tiring for a kid with minimal disability, it is also going to be tiring for a kid with pretty significant disability. If suppressing hand flapping is bad for someone like me, it is probably also bad for other people. I think we are all in agreement that there are certain skills that are really important to teach to kids. I do not think that is a point of disagreement for us.

The concerns that the self-advocacy community is expressing are concerns that I really think are shared by many people including people who have significant communication challenges, significant behavioral challenges.

Second, when John was talking about kids in high school who were bursting into tears because they were being forced not to flap, those are high school kids, right?

MR. ROBISON: Recalling their childhood.

MS. CRANE: Yeah, and when was that?

MR. ROBISON: Just this winter.

MS. CRANE: Just this winter. These kids at the very earliest were being given those therapies in the 2000s. This is not something that was limited to the '70s and '80s. This is an ongoing concern. It is something that we are hearing from young people to this day. That is a real concern. I really would like to think it is just bad apples, but the bad apples are really common because we are hearing it from quite a lot of people.

DR. GORDON: Sam, can I ask another follow up if you do not mind? I apologize if I am getting too personal. Feel free not to answer. At some point, you were trained, if you will, or attempted to be trained to control your hand flapping. Is that what you are saying?

MS. CRANE: I was not diagnosed early enough to get ABA. I am basing this on the experiences of others.

DR. GORDON: Then we will ask about those others and maybe you will know the answers, maybe you will not. My question is is it the case that it might be advantageous in certain situations to have the skill, but then in other situations to also have the ability or the decision capacity to ignore that skill if you know that it is more important to exercise a behavior and not be anxious about not being able to do it. Do you get my drift?

MS. CRANE: Certainly, being able to not flap my hands when I really do not want to flap my hands is a nice skill. But I do not believe that a behavioral focused training module would teach a person to decide when they do not want to flap their hands. If it is behavior focused then it tends to be about when someone else does not want you to flap your hands.

DR. GORDON: That is why I asked the question, right? Because I wanted to make sure that - David, I think, made an eloquent point, which is that there is ABA that is done well and ABA that is not done well. You are making another eloquent point and John, you are making the same point and that is that ABA that does not take into account the needs and desires of the individual in the moment is probably my guess is ABA that is not done well. But if it is considered ABA that is done well then that is where you would say we need to do something about it.

MS. CRANE: And that gets into the question of what actually defines ABA and what does not define ABA, which I think is way beyond the scope of this conversation.

DR. GORDON: I said that was the last, but we are going to go ahead and move on.

DR. PEÑA: I’ll keep it short, I promise. I have a son. He is 10. He has had ABA since he was 2. In the last eight years, I can vouch for having gone through five companies, I live in the LA area, two of which do take into account the interests and needs of the patient or the client. The other three did not. These things are happening now where these model programs in the LA area, I will not name names, but nationally recognized teach your child or teach the parent to yell at the child for flapping their hands or any self-stimulatory behavior, anything that happens you yell no and you put their hands down or you could use aversives. A child who could not stand having ChapStick on their lips, that is what they got when they misbehaved or were noncompliant. These things are happening today. There are a lot of bad apples.

I think ABA can be done really well. We have a great company now. They are very relationship based. They take into account that my son is nonspeaking and he can communicate with them. This is an issue that is happening on a national basis while there is all wonderful evidence and ABA has the monopoly on therapy. We still have a lot of work to do.

DR. GORDON: As promised, I am going to close the discussion on ABA, but a couple of comments first. Clearly, I want to thank Christie Riehl and others. I do not know who may have raised that in the comments because there is a lot to be discussed here.

Secondly, there is a lot to be discussed here and I do not think we are going to be able to solve this in this current discussion, but it is something that we are going to want to come and revisit. Whether we are going to be able to fit that back in before reauthorization and the new version of the committee or not, I can tell you that we, at NIMH, will have the institutional memory to make sure that we come back and address this.

Third, I just want to specifically address the issue of other therapies. As you have seen from some of the summary of advances stuff that we have been putting out over the last couple of years, there is research on other therapies. I agree. My understanding is that out there in the community, ABA does have somewhat of a monopoly that hopefully we can come up with additional options and the best of all possible worlds. But we will come back and revisit the ABA issue.

And now I promised I would go back to John for a second point. Anyone else who would like to raise other issues other than ABA please let me know and I will put you on the list.

MR. ROBISON: These next points. Another comment that I was asked - there are actually two comments that we can take together. Yuval Levental. Yuval wrote a comment talking about his experience with vitamin D. Prior to writing about vitamin D, Yuval wrote a very thoughtful essay to me and posted on our blog about his experience with Botox and the idea that by changing his facial expressions, he changed his internal feelings. He obviously is a smart, thoughtful young man on the spectrum. He wants to do these things to make himself a better person. I do not think any of us should challenge one's desire to do what we wish to ourselves in pursuit of that goal.

He asks questions about that and he offers information about that. It bothers me that with our committee and all the resources of government that we do not have a mechanism on our website to provide thoughtful answers to folks like him from a qualified scientist, not from a member of the public like me.

I know that I have raised this issue before and Susan, you said we do not really have a means to do it. But when I look at how many people write us and ask us for an answer, it is not a lot. It is 10, 12 people every meeting.

That takes me to the next comment where I was asked the same thing and that is Eileen Nicole Simon. Ms. Simon – you all heard her raise the issue about oxygen deprivation during child birth and cord clamping. I clearly am not qualified to render her an expert opinion on that. When she says to me why hasn't IACC ever answered me about that question, I think Ms. Simon is raising a valid concern. I do not know if that is an important thing in autism, but I feel like Ms. Simon is one of our constituents and she deserves an answer.

The final point I would like to make about these public comments in general is we also had a number of comments, as we always do, about vaccine and autism causation and the generally poor function of our committee. I agree. When we look at the summary of advances, we have precious little to show for studies that offer the promise of translation of research and to benefit. There is not much of anything up there. In that, I do feel like we are not living up to our charge to the public.

I feel that when people write with things like vaccine allegations, they are seizing upon theories because we did not provide answers. Rather than us to say you are crazy. That is discredited. We need an answer and we are not offering that answer. I feel like we owe a duty of respect to all of our constituents to be responsive.

I would be happy to help write responses, but I feel like I am not qualified to answer someone like Yuval or Eileen. I just would like to bring that up because I do not think the number of people who ask us for response is overwhelming.

DR. GORDON: I think that is a provocative point, John. I would like to hear if there is any reaction to that particular point from other committee members before we move on to the next. David.

DR. MANDELL: I think it would go a long way towards making people feel heard. I think we see the same points come up again and again. It may be that we have at the very least positions on some of these issues or some synthesis of evidence on some of these issues that we can share back with people. I think some of the other comments we may be less likely to respond to.

DR. GORDON: I, myself, jotted down with a question mark answer on those two that you made because I think there we probably do have something to say. And then the question is what the best mechanism is to do that. That is something that we can try to work on from the NIMH perspective when it is a research question in any case. We do often field questions from the public and do our best with our limited resources to answer them on general topics when they come and say to my office or to our communications office. We may be able to find some way to at least answer some of them where there are clear scientific questions or queries for evidence.

Another possibility would be doing something like a fact page where when we get something like this, we not only answer it, but we put it up on the IACC site so that when someone else comes in with a similar comment because often these things are repeated. This is not the first time we have seen many of these questions come in. We can refer them to that page.

Any other suggestions or thoughts? Yeah, Susan would like to, go ahead, share.

DR. DANIELS: With the function of the FACA committee and receiving public comment, the purpose of the public comment is to make you all aware of issues that are important to the community. And these discussion times are a time for you to discuss them.

In order for the committee to respond to an individual, you would need to come to some kind of consensus about an answer. It is really not something that is very easily feasible to do for every single question that comes in. And most federal advisory committees around the government do not individually answer every single inquiry that comes in. Specifically, however, we do have these discussion times.

With regard to Dr. Simon, she writes in frequently. I do remember a particular time that Dr. Koroshetz actually went into quite a bit of detail about some of her comments. Committee members do try to share their opinions, but you all may have different opinions related to each of these comments. We encourage you to share them here.

In the office when we receive scientific questions that are not directed to the committee or maybe questions about services, et cetera that are things that we can answer, we do send back a response. For example, someone says can I find some information on women and girls in autism. We will send back a response and give them a number of suggestions of places to go. But when the committee receives a comment that is there to influence your thinking in terms of recommendations you may be proposing, ideas you may have for research agendas, et cetera, it is meant to be received and collected.

However, you are free to in these sessions respond individually to some of these comments.

DR. GORDON: Walter, go ahead.

DR. WALTER KOROSHETZ: Susan, what do you think about the idea for the group to say we would like a paragraph on X, Y, and Z and go on the website. I think it would answer – what people have said is that we do not want to ignore things, but it is not a personal engagement. This is a topic and we want to just get the information out of what we know about that topic. Is that something that would be easier?

DR. DANIELS: A fact kind of thing though – it would need to be done in a way that where the committee has the authority to be responding to such an inquiry. Example, if you were going to make an authoritative statement about the role of auditory colliculi and you wanted to on behalf of the committee somehow make some official statement, I think it just becomes difficult as to how much authority the committee has to speak on those issues.

DR. GORDON: I think Susan and I and other parts of the NIMH staff that – like I said, we normally handle requests such as these, can come up with a mechanism, I think, where we can select some, maybe on recommendation of committee members, and then put the responses out to the committee via email to make sure that we are not speaking on behalf of the committee and either respond as NIMH alone if necessary or as the committee. We will work on something.

I am hearing from a few members of the committee that there is a desire to find a mechanism for some, not all, but some of the comments to be answered directly in some form. We will try to work on a way that is both adherent to the regulations around FACA committees and also to our responsibilities to our constituents.

Is it another comment on the same topic?

MS. SPENCER: I just think that – I think, John, you made the comment that people need to feel heard. And whether we can answer it or not, I think we should at least put something on the website that says here is how we deal with comments to maybe explain something that Susan said because otherwise I think people do just feel blown off.

DR. DANIELS: There is information about public comments on our website. We have a section on public comment. I believe it does say that we do not give individual responses to comments, which is standard procedure for any federal advisory committee.

DR. BALL: Is there a way to take the information during this time when we are having the discussion and synthesize it so then that way people can see that we are discussing those topics?

DR. DANIELS: It is in the minutes; however, if it were going to be made into an official statement again, we have to be very careful about the committee making an official statement that once the committee says this is the answer --

DR. BALL: But even just access to the minutes.

DR. DANIELS: It is on the website. They are always on the website.

DR. BALL: If we can direct them there.

DR. GORDON: For those who are newer than me to the committee, it is my understanding that before we would typically have a public comment period and then really limited or no discussion on the comments. It is really in the last few meetings where we have been having these more extensive discussions on the public comments. I am hoping that having these open discussions will at least convince that although we cannot respond to and discuss every single comment that we do take them seriously. I think so far we have already had the ABA discussion very seriously. I think at least some people will feel heard.

I am hearing that if there is a way for us to begin to communicate at least where we do have some answers, we will look into ways of doing that.

Let's move on to other comments that you wanted to discuss. David has his hand up and then I have you next, Judith.

DR. AMARAL: Thanks. First, I just want to add one last comment to this previous discussion just to say that I think we definitely hear that some of these comments are very reasonable comments and particularly the comments by Dr. Simon that have come in over the last couple of years. I have gone back to try and look at the literature to see if there is any reasonable response that we can give based on the literature. There just aren't the data out there to answer the question. It would rely on postmortem studies of the brains of individuals with autism, developmental disorders of the colliculi. They just do not exist. Nobody has done them.

What is important is perhaps to educate institutes about areas of research or gaps need to be filled. That would be one thing. But sometimes we do not answer. Dr. Simon, if you are listening, sometimes we do not answer because there is no answer, but we need to articulate that better. I think the kinds of things that were discussed and trying to provide feedback to people who are writing in to us is really important. Thank you for the comments. We will try and do better in the future.

And then I had a real comment that I wanted to make. That actually relates to all of the comments about the vaccines. I just want to as a personal comment say that we are heading into flu season again and the CDC published in June of this year that there were 172 deaths of children from influenza, 80 percent of whom were not vaccinated. This is a record number. I just find it as a parent and hopefully someday a grandparent heartbreaking that more and more I am hearing about children that are dying from preventable illnesses because of the notion, which is unfounded that autism is caused by vaccines. I survey this evidence. I really do not see any evidence whatsoever that there is a link of any kind between vaccines and autism.

There was just another study published on DPT and autism. If anything, it showed that the people who were vaccinated actually were at slightly less risk of having autism than those who are unvaccinated.

Again, I just hate to hear these reports on national television that more and more children are dying of measles, which is a preventable illness and other illnesses. I do not know what to do about it. Here is a case where the evidence is overwhelming; yet, there is sort of a myth being perpetrated that is leading to children dying. I just wanted to say that I find it very heartbreaking that that is the case.

DR. GORDON: Thank you, David.

DR. COOPER: I wanted to raise the issue that – I do not remember who wrote it in the written comments, but it had to do with access or availability of coming here to make oral comments. I think our process is wonderful that we offer this opportunity, but it is very much biased against families who have financial constraints or family restrictions that just do not allow them to travel.

I am wondering if it would just be out the realm of possibility to allow oral comments via Skype.

DR. DANIELS: Written comments are available to everyone across the country and even around the world. They can always make those kinds of comments. That is the mode by which people who cannot travel are able to.

In terms of video, we have explored those opportunities before, but jus the feasibility of doing those kinds of things and being successful at them every single time is very difficult. It is not something that we are doing at this time.

DR. GORDON: If there was a substantial chunk of the committee felt like we should look into it again, we can do so. I am curious if there are other thoughts about that particularly from the advocacy members of the community.

MS. CRANE: I think it would definitely make it more accessible to a lot of autistic people, not only because we are less likely to travel, but also because we might not be able to tolerate even with accommodations that are being given. We do not always have the ability to tolerate an entire day here.

DR. GORDON: With the advent of Smartphones and videotaping capabilities, would you consider a videotaped oral testimony or oral comment as something that was accessible or more accessible than travel? Would that be limiting as well?

MS. CRANE: Potentially. Skype can be easier than videotaping just because it is an app to navigate.

DR. GORDON: There may be issues around Skype with regard to government use, but that is a potential roadblock. There are other apps available.

DR. BALL: Why does it have to be video? Can't they have an access number and give it orally? Or is that something…

DR. DANIELS: Similarly, it is just that technical problems can crop up even when we have our members trying to reach us by phone. Sometimes the phone does not work. There are issues that can crop up and we do not want to have frustrations because of technological problems that are beyond our control. If we were going to do that, we would have to accept that sometimes it is not going to work. There will be user problems on the other end or there might be problems on our end. We would have to deal with the additional complications of that. It is doable, but it definitely has its risks.

DR. GORDON: There are a number of federal members who sit on other FACA committees. Are there other FACA committees who regularly take oral comments remotely?

MS. SPENCER: I am not sure which committee I am on that does it. But I know that they do some oral comments by phone. You are right. It does not always work well. I think is the ISMICC, the Serious Mental Illness Coordinating Committee.

DR. GORDON: We will look into that. It sounds like there is enough interest on the table. People obviously have to preregister and it will mean perhaps more oral comments, but that is probably a good thing.

MR. ROBISON: While we are talking about technical accommodations and facilitating these comments, this has been brought up before, but I would repeat that many of us would absolutely appreciate an improvement in the live closed captioning system so we could watch the IACC stream and read what is being said. I cannot participate, for example, in phone IACCs like when I could not come to the meeting a few weeks ago. I cannot make sense of listening to the stuff over the phone just because - is it because I am autistic, I am old, I am deaf? The fact is if it was streaming in words on the screen, I could have taken part. I hear that a lot. I wish we could do better.

DR. DANIELS: We do have captioning, I believe.

MS. ROBISON: It does not always work, Susan.

DR. DANIELS: That is my issue about technology. We have that technology. It is on, but some people – their browsers or whatever does not work with the technology. We do provide captioning on every webcast that we have.

DR. GORDON: I thank you for that comment. I actually put myself on the list unless you think I am line jumping although I do not think there is anyone else waiting. In the spirit of responding to where we can, I think it is worthwhile responding. I think this is a generic response to both Yuval Levental's comment on vitamin D and also Dr. Simon's comment on the various brain pathways that she hypothesizes may be involved in autism.

I think it is a general comment because really what I want to say is something about the scientific process, if you will, and how we go about pursuing questions at NIMH. I think it is relevant to folks who bring up these hypotheses, which as John points out and as David pointed out, are reasonable, thoughtful hypotheses, not bringing up something that we beat with a dead horse, but things which we do not really know.

We welcome open, novel hypotheses for research through our grant-making process. But it takes more than just this would make sense kind of assertion in order to be able to give us at NIMH and our independent peer reviewers who evaluate every single grant that comes in, literally every grant that comes in.

It takes more than just a reasonable sound hypothesis. There has to be some reason to think that, yes, that hypothesis has some significant chance of being true. Why? Because to investigate whether the inferior colliculus is involved preferentially in autism as opposed to other illnesses. It is not a matter of let's go look some stuff up. We are talking about a million dollar grant over five years. We are talking about a major investment of money. That means that if we pursue that hypothesis, there are other hypotheses that we cannot pursue. For vitamin D, the same thing.

In fact, my guess is that it would be more than a million bucks for vitamin D because you are talking about a very common thing. Low vitamin D levels is rampant throughout the United States right now and therefore you are going to need a large sample to see if it happens to be overrepresented in individuals with autism and other disabilities. Testing each hypothesis is a very expensive endeavor. That is why we have the IACC though.

The IACC helps figure out where are the important questions that we need answered, where are the hypotheses that we at NIMH that the investigators out there in the scientific community have not been following up on, but which are significant. It is useful to have these suggestions. If IACC members feel there is merit in them beyond just that is an interesting hypothesis and plausible hypothesis, but actually wait, NIMH, you have missed this body of evidence or this reason why it could be important. We want to hear about it. We want to talk about it. We want to say it. But it is important to recognize that for every one of these hypotheses that are communicated to us, our scientists are out there in the community are coming up with hundreds of others. We have to figure out which ones we are going to invest in.

Are there other comments or questions about other issues raised? I just made a list of things that I want to make sure we address. We addressed the vaccines.

Diagnostic tests. There was a comment about a diagnostic test. I wanted to let that person, I forget who it was, know as well as everyone else that diagnostics in mental health in general, something that we are conducting quite a lot of research about. And we actually have awarded a small business grant to a company I happened to have visited yesterday in upstate New York in Syracuse that has a salivary test that they are testing to see whether it helps. Preliminary evidence looks good, but you always have to do the big study -- helps diagnose autism in children. We are actually trying to find diagnostic tests for autism as well as other disorders.

And then of course, there is also the summary of advance paper that David communicated. Another way of doing it might be EEG signals looking at the electrical signals on the scalp that are consequent from brain activity that might also help. We are hard at work trying to find diagnostic tests for autism.

MR. ROBISON: That was Ryan Carboni who made us that question. We could also point him to the NIH clinical trials for autism program.

DR. GORDON: Yes, thanks. Oral comments, we discussed. And the lack of urgency. I am surprised that someone would say that we do not have urgency on this committee to address autism when we have argued for – I believe it was a doubling or was it a tripling. I cannot remember. The research budget where we have pressed hard to try to bring in additional groups like Justice to address issues.

But I recognize that no matter how hard we work, it is really up to our various agencies and partners that we represent to continue to carry on that work. I can see how especially, John, you make rightfully so that a lot of the progress we have to show so far for the work that we have done, for the research that goes on has not yet gotten to the point where we have novel therapies that are really affecting people's lives or application of existing therapies in better ways. I can understand where the urgency is not there might be coming from. I think most of us around the table feel that autism is an incredibly urgent area. I am a little surprised with that comment.

Any other comments? We have it. It is 2 o'clock. We will move on to the next agenda item, which is a panel discussion. To my knowledge anyway we have not discussed it. We certainly have not discussed this issue since I have been here now for just over two years. The panel is on the ABLE Act and financial planning for people with disabilities, which of course obviously impacts individuals and families with autism tremendously.

We have four panel members. We have Stuart Spielman, the senior vice president for Advocacy at Autism Speaks, Bette Ann Mobley, the director of Maryland ABLE, Colin Meeks, who is a certified financial planner for Maryland Financial Advocates and the host of Special Needs Connection Podcast, and Phoebe Ball, who is the legislative affairs specialist for the National Council on

Disability. Thank you, the four of you, for joining us today.

My understanding is we are going to have a brief presentation by each of you and then a discussion that follows. Go right ahead.

MR. STUART SPIELMAN: I am going to kick-off the presentation. While most of the presentation is going to concern ABLE, I would actually like to broaden the context a little bit. ABLE is a way of addressing an issue that faces many Americans and that is the issue of financial insecurity. There are certainly other ways of addressing financial insecurity, but I think it is important to think about the broad context of ABLE in order to understand ABLE and also to think about the problem and how we define the problem, what our understandings are of the problem because our understandings are going to influence our approaches to the problem.

One of the side conversations that Bette and I had before this panel begun was ways to get other sectors involved in addressing financial insecurity: employers, for instance, government, other funders. While we are going to be focusing on one topic, I would really invite thinking and interest in the larger topic.

I am going to begin with the discussion of the history of ABLE. We can go onto the next slide. ABLE actually has its origins in the 529 plans, the college savings plans. These plans originated in the – the genesis of these plans goes back to the mid-1980s. Here again was another kind of financial insecurity, the worry of parents about putting their kids into college that was the fertile ground in which the 529 programs actually started to breed and develop.

Legislation was passed in 1996, establishing the code. And that legislation has developed over time. One of the interesting things and we can talk about this a little bit in terms of scale is how large the 529 industry is right now. Bette Ann, you can correct me if I am wrong, but I think it is somewhere in the neighborhood of $330 billion or more. That is an extraordinary investment. It is larger than the GDP of some countries. We have a very, very active type of savings program, popular savings program for our college and post-secondary while our ABLE effort is certainly at an early stage, but it is coming. Next slide please.

One of the interesting things about the origin of ABLE is that there was an awareness among parents of individuals with disabilities that the 529 plans worked great for some people and for some purposes, but really were not addressing the needs of other people and were not very broadly focused.

There is a special challenge, a special complexity in addressing financial insecurity for individuals with disability and that is their reliance and means tested programs like SSI and Medicaid. No savings program would be productive if it had the destructive effect of eliminating the availability of the means tested programs that sustained people through their lives, people with severe disabilities. This is one of the challenges that we all faced ten or more years ago when we were talking about how we could come up with an analog to the 529 that would actually help people and not hurt people. Next slide.

I am going to do a little side discussion here. In autism, we do not actually have a tremendous amount of I would say economic facts about autism. We do know some things, shout out to David, for some of his work here on the lifetime costs that may be associated with autism, but we do not have a tremendous amount of information. We know that autism, the expenses of autism can be great for individuals and for families to bear. Those expenses have huge ramifications. They take people out of the job market. They put them into jobs where the earnings potential is less, but again I would just sort of a shout out in the wilderness. We really need more information about these economic effects in order to gauge how we approach autism and the investments that we need to make. Next slide.

It took a while as in more than a decade, but finally the discussions about ABLE led somewhere. We, those of us who are working on ABLE, became an overnight success after about a decade. What we saw was that there was a real coalescence among people on Capitol Hill with very, very different political attitudes that this was a useful approach, that this approach would help individuals with disabilities. We saw overwhelming margins of enactment for the ABLE Act. Next slide please.

A little bit of a personal reflection and reminiscence. One of the people most influential in the passage of ABLE was my late friend, Steve Beck. Steve Beck was someone who worked for Dominion Electric. I have two law degrees and there were many times when I thought why does this guy know about the law than I do. Shame on me. Steve was one of those just brilliant, intuitive guys who got his point across and got something really done. Next slide.

One of the important things about ABLE is that not only was it a program originated and passed in Congress, but it is a program that continues to enjoy broad support in Congress. This is not a one shot, did it, gone, forget about it kind of program. Congress in the most recent budget bill charged a number of components in the federal government. I am looking at Phoebe and Phoebe can tell you about what she is doing in this space with making information now and clearing up any misunderstandings and hurdles about ABLE, making sure that agencies remove uncertainties that may be inhibiting people from making investments that they would want to make.

And my final slide has to do with where we are now. We are not exactly at the place where the college savings plans are, but you see that we have in a short period in which the ABLE programs have been in existence, which has really been about two plus years, a little bit more. They have grown substantially quarter over quarter to the point now where assets under management are well above $100 million and the accounts are growing by significant percentages each quarter.

With that, I will pass off to my colleague, Bette Ann.

MS. BETTE ANN MOBLEY: Thank you. I am going to stand here and not behind the podium so you can see more than my eyes. I appreciate the opportunity to be here and talk to you about ABLE. I am here as the director of Maryland ABLE, but to represent the National Association of State Treasurers and that is because ABLE programs, as Stuart said, are part of the IRS tax code and come under the S529A. We are very connected to 529 as the college savings program and there are things that we have that are related to 529, but we have our own federal regulations. I am going to tell you a little bit about those.

It is really important to know that we are part of the tax code. We are not part of Social Security law. We are not part of Medicaid law. There are things that will change within the tax code that long-term may change as it affects ABLE. It is important to know that too as you think about the ABLE program.

This program is so important to people who have disabilities in their families because finally and at last, there is an opportunity to have savings, to have assets, to provide for the things that are so important for today and for the future for people with disabilities.

While the law gave the opportunity for states to have programs, it did not have mandate that states would have programs.

These programs do not receive federal funding. It is up to the state to determine if they will provide funding for the program. As I stand here today, there are 39 states and the District of Columbia that have active programs. If you take a look at this map, the darkened states are states that currently have programs.

If a program is open in a state, it also has the opportunity to determine whether that it is going to be open for national enrollment or for individual state residents only. Most programs throughout the country are open for national enrollments. If you look up there and you think about the state that you represent, your state may be open for any one across the country to enroll in. There are states, however, that have limited enrollment to their state residents only. As an example, the legislature in the State of

Florida chose to fund their program and therefore they only allow enrolment from state residents in the State of Florida. That is one example. There are a couple of others that have the same sort of enrollment restrictions.

As Stuart said, it is a relatively new program, two and a half years. It is the oldest program. Ohio was the first to open. In that time, we now have, as of June 30, 25,619 ABLE accounts nationwide with $120 million invested in these accounts.

This is somewhat, not somewhat, it’s quite a bit smaller than 529 as you can imagine. 529 has been in existence for quite a bit longer than we have. It is a slower acquisition or adoption rate than 529. But part of that is for us to approach a community of people that have for a very long time been distrustful of government programs.

Our outreach is about teaching people about a program and getting them to understand the benefits of this program.

What we have learned as all of us as ABLE administrators have gone out is that it is taking about five touches before someone is really considering investing or putting their money into the ABLE program. It is important for people to understand that this is a program that will help and support them as they move forward.

One of the benefits and the biggest benefit of an ABLE account is that it does not affect eligibility for benefits with SSI and Medicaid. These are critical benefits of the ABLE program.

The federal law says that the assets contained within an ABLE account cannot be used to disqualify people for state means tested programs. Now, there is a caveat to that in terms of SSI when it comes to SSI benefits, which I will talk about in just a minute. But the assets are protected assets for a person with a disability.

It is critical to also understand that it is an asset shield, but not an income shield. This is sometimes confusing for people because when we think about things like SSI benefits, we know that as SSI benefits are for a person with a disability, income can reduce those benefits.

ABLE does not protect the reduction of SSI benefits from income. With SSI, there is also an asset threshold of $2000. For a very long time, people with disabilities could never have more than $2000 worth of assets before there was also reduction in those benefits. What ABLE provides is the opportunity to begin to accumulate assets up to $100,000. Just think about that for a second. A person with a disability who is receiving SSI benefits now has the opportunity to save their money from $2000 to $100,000 before their SSI benefits would be impacted as a result of assets.

If assets are the reason for losing SSI benefits outside of an ABLE account, when SSI benefits are discontinued, Medicaid goes away. Catastrophic for a person with a disability.

Another benefit of the ABLE account is within ABLE when that person's balance reaches $100,000, SSI is suspended. It is not terminated. It is suspended. The termination - the suspension of that benefit is indefinite. When the balance goes below $100,000, the benefit resumes.

We have, as program managers, the obligation monthly to report directly to SSA balances in the ABLE account. That is a direct report that occurs that is not incumbent upon the ABLE account holder. It is incumbent upon us as program managers. The benefit resumes.

When the benefit is suspended and here is such a critical point, Medicaid remains. Outside of ABLE, Medicaid goes away. When SSI is suspended within ABLE, Medicaid remains. That insurance component is a very critical benefit also of the ABLE program.

This next slide covers just what I said. I got a little ahead of myself here so I apologize. It is a new slide program for us. It really lets us know that benefits are able to be maintained within the ABLE account. ABLE has given us the opportunity to exceed that $2000 threshold up to $100,000 and to maintain those Medicaid benefits.

Other benefits of the ABLE account are that whereas other programs and even in the

529 account, it is not always the person who is the owner whereas with an ABLE account, the law mandates that the beneficiary of the ABLE account is the person with a disability. They are the owner of the ABLE account. Now, there is a sense of ownership of the money that is being saved for them and for their future. It creates an opportunity not only for savings, but investment options. ABLE programs offer both a savings type option and different types of investment options Those are going to vary from state to state depending on what kind of program you are a part of.

Here is another part. Remember I told you that the ABLE program is part of the tax code. There are tax benefits to the ABLE program. Monies that go into an ABLE account - the earnings on those monies do not have taxes assessed on them. It is not pretax dollars that go into an ABLE account, but once the money is put into that account, earnings on that money is not taxed. It is free of state and federal taxes.

How does one become eligible to have an ABLE account? One of the things that is part of the law is that currently in order to open an ABLE account, the person must have a disability that occurred prior to age 26. If we think about folks with autism, that diagnosis would have occurred prior to age 26. However, at my age, I just turned 59 three weeks ago, I have met people who years ago were not diagnosed as having autism, but today would have gotten that diagnosis if it had been a diagnosis years ago. They would still qualify for an ABLE account based on the services and supports that they received years ago, which would have given indication that that disorder was evident as a part of their services and supports.

You do not have to be under the age of 26 to open an ABLE account, but there just needs to be evidence that the disability occurred prior to age 26. And you have to show that you were either eligible to receive SSI or SSDI due to the disability, meeting that definition of disability as indicated by Social Security, have a condition listed on SSA's Compassionate Allowances and Conditions, or self-certification, which can be obtained through doctor certification. Programs across the country have on their websites the opportunity for a letter for a doctor to certify that in fact you have a diagnosis that meets the qualifications of a disability as listed by SSA.

It is very easy to enroll. This is one of the other things that was a focus in the development of the ABLE program. Many benefits that people with disabilities have to apply for are extremely cumbersome and difficult and there was a focus on making sure that these programs were easy to apply for.

Every one of the programs that I spoke to, the 39 programs and the District of Columbia, have the opportunity to have online enrollment. There are many programs also have the opportunity for paper enrollment in case someone is not wanting to use technology, but everyone has online enrollment. It is really easy and at most will take about 20 minutes to enroll in the program.

People with disabilities, families of people with disabilities are not used to such a quick and easy program where 20 minutes later, you are in, it is gone. You will know right then whether you have been accepted into the program or not.

In order to open an account, there is not a fee to open the account, but it takes between $25 and $50 depending on which state you are joining to open the account. That is your initial money in your account.

Who can open the account? It is either going to be the person with a disability if they are 18 or older and able to manage their own account or it is going to be someone that we refer to as an authorized legal representative. In the case of somebody who is under the age of 18 that would be the parent. It could be a guardian and it could be a full guardian, but at the very least a guardian of property. It has to be the guardian who oversees the financial matters for the person or it could be a power of attorney over financial matters, at the very least, power of attorney over the financial ABLE account. In Maryland, for instance, we do have the opportunity to have just power of attorney over the ABLE account and other states have done the same sort of thing. There is the opportunity to have limited control over just the financial aspects for the person, believing that we still want people to be as empowered as possible to take care of as many things in their life, choice and decision making and only have the assistance for what they need. This is the case for the ABLE account. How could that happen?

I need to mention here because this is a question that oftentimes comes up and that is that RETT payee is not an authorized legal representative in the case of an ABLE account. That is a Social Security designation and does not count as a legal authorized representative for an ABLE account because ABLE accounts have the capacity to have more than Social Security funds in them. Imagine, grandma, grandpa, Uncle Joe and Aunt Betty could make donations to this ABLE account. The person is working. They could also have employment funds that they could put into this account. And RETT payee designation is authority to oversee Social Security funds. We recognize that for many people this is a great challenge, but we want people to know that being RETT payee does not give them the authority to be the authorized legal representative of an ABLE account. It would in addition have to have at least a limited power of attorney or guardianship if they are not the parent of a minor.

There are contribution limits and these are part of the federal laws that affect all programs across the United States. There are limits to how much can be contributed over the lifetime of the account. Here is another place where the connection between the 529 college savings programs and ABLE accounts come into play. Whatever that college savings limit is for contributions in the state is also the limit for the ABLE account. That ranges across the country from $300,000 to $500,000. Whatever state you are looking at, the limit to the contributions to college savings is going to be the same to the limit for the ABLE program. Whenever that would change within the state, it would change within the ABLE program.

If the person for whom that account is established is not employed, then there is a $15,000 annual contribution limit currently. Again, this is part of the IRS tax code and that $15,000 is directly linked to the current federal gift tax limit. Important to note that because we were the benefit of a recent increase in that tax limit. In 2014, that was $14,000. It rose to $15,000 and so we now have a $15,000 limit. Should that rise in the future, that annual contribution limit would be raised yet again.

As a result of the tax law changes last December, ABLE was able to add an additional benefit for people who are employed. If a person who has an ABLE account is employed, they can contribute beyond that $15,000 contribution limit. They can contribute the lesser amount of their earnings or $12,060. Where does that $12,060 come from you might ask? That is the federal poverty level wage for a single person household for last year. Every year that amount is going to change.

If the person is earning $3,000 this year, they would be able to contribute $15,000 plus the $3,000. If they are earning

$35,000 this year, they can contribute $15,000 plus $12,060. They are limited to that federal poverty level wage. That is a number that would constantly change because it would be based on the previous years, federal poverty level wage for a single person household.

It is a little bit different in Hawaii and Alaska. If you are from one of those states, we would have to get that poverty level wage for those two states.

The other thing that happened for ABLE in the changes to the tax law in December is that now parents or family members who opened 529 accounts and now realize that those accounts are not going to be used strictly for education the way that they must be used for that beneficiary, they can seamlessly be rolled into ABLE accounts without tax penalties. They are still subject to that

$15,000 annual contribution limit. They might need to be rolled over in subsequent years.

People can fund these accounts through electronic transfers between their bank accounts. They can write paper checks and some programs also have payroll deductions.

There are states across the nation that also offer contributors to the ABLE account's income tax deductions. There are income tax benefits for contributors to ABLE accounts. Not all states offer this and so this is an incentive for some people to select the states that they select to enroll in.

What can those monies be spent on? I think this is another huge benefit of an ABLE program. It is such a wide array of expenses that you can use it for. IN the law, it talks about things that contribute to the health, independence, and quality of life for the person with the disability. These are just some categories of things that are considered qualified disability expenses for the person. If you think about many of the challenges that you have talked about here today and even Stuart mentioned the cost of supporting someone with autism throughout their lifetime. You think about the co-pays for medical expenses, the non-covered medical expenses, the assistive technology perhaps, all of the things that might be necessary to support someone. If you have an ABLE account, the ABLE account can be used to pay for these things.

Housing and rent is something to support someone. Housing and rent is one expense that has a special caveat and that is it must be expended in the same month in which it is withdrawn from the account. Other expenses can be withdrawn and not spent in the same month and still not count it as an asset as it relates to Social Security as long as you can show by your receipt it was spent on the qualified disability expense. Health and wellness. Think about the different kinds of things that people do to support their health and wellness. Gym memberships, those kinds of things to help them. Legal fees. Education. Maybe non-traditional educational kinds of opportunities. Transportation. All the different kinds of things that people might need.

It gives people a lot of opportunities to be independent and to be part of their communities to increase their opportunities and empowerment as they utilize their ABLE funds.

If expenses are used, if monies are used for things that are considered to be non-qualified disability expenditures then there is a penalty. They could incur penalties which would include taxes plus a 10 percent penalty on any of the earnings for the money in an ABLE account. And any monies that were not spent on qualified expenses would be considered assets and counted as a resource when considering benefits like SSI.

People can withdraw money from their ABLE account in many different ways. They can transfer it back to a linked bank account whether it be a checking or savings account. They can request a third-party check be issued and sent to them. And many of the programs either have a debit card or a preloaded or prepaid Master or Visa Card kind of thing.

It is important that as people are using these accounts and spending this money that they maintain receipts because if they are ever unlucky enough to be selected for an IRS tax audit, they would need to be able to show

how they have this money to show that they have been used for qualified disability expenses. They could be asked to support those expenses in terms of redeterminations with SSI or just to show that those expenses truly were used for qualified disability expenses especially if the monies remained in an account beyond the end of a month and exceeded that $2,000 limit.

I am going to let Colin give you a little bit more information about how ABLE accounts interact with trusts and how they can all be part of a bigger package.

MR. COLIN MEEKS: Thank you. In my practice, we do personal financial planning for families. Now with ABLE accounts in the mix, the question always comes up as to whether I should have one or the other because does the ABLE account replace a special needs trust or is there any situation where I should have one or the other or both. We always tell people that it is probably a good idea to consider having both because there are distinct differences with the ABLE account. There are limits as to how much money you can put in. There are lifetime limits. There are restrictions as to what the money can come out for. But all that being said, the ABLE account is still a very useful planning tool. It is very inexpensive. Almost nothing to start one. You can fund it very little amount of money and it covers more of the masses whereas with a special needs trust, there are upfront costs. There are different types of special needs trust. I do not want to get into all of that here, but there are different ways to set up that special needs trust. It has to be administered by a group of people. There are significantly more costs to set it up and also keep it going.

There are distinct differences between the two. There are disadvantages and advantages to both of them, but in a perfect world, we are trying to help families plan for their financial planning. We try to incorporate both.

MS. MOBLEY: We often say they are just another tool in the toolbox for financial planning. This is a big question that has come about since the ABLE Act was passed and that is what happens if the person passes away. The account administrator has to be notified by the estate of the person who is overseeing the estate. If there is no designation for the transfer, it just becomes part of the overall estate of the person. If there is no designation by that person, it will go through the normal probate process as it would for anyone who did not have any will or anything there.

Within the law, there is a provision that says when a person who has an ABLE account passes away that Medicaid has the ability to file a claim against the money in the ABLE account for any services paid by Medicaid since the person opened the ABLE account. That is a payback clause that is part of the federal law.

There are some limitations to that clause and that says that the payback can only occur since the account was opened that any outstanding bills or commitments from the ABLE account would be paid first and that if there were any premiums paid for Medicaid buy-in that would come out first and funeral and burial expenses would also be paid.

There are several states who have taken a step to pass legislation within their states related to this payback clause. Oregon, Pennsylvania, Maryland, Illinois, Delaware, Kansas, and California have all passed state laws. Those state laws have minor differences based on their state. I can speak directly to what Maryland state law says. Maryland state law just says that Maryland Medicaid will not seek repayment for Medicaid services, for Medicaid claims in Maryland for Maryland residents with Maryland ABLE accounts unless federally mandated to do so. It says that there is the opportunity to transfer it to an eligible beneficiary or to the estate of a person who has the ABLE account.

If you have questions or you want to learn more about ABLE, NAST, which is the National Association of State Treasurers, is there to help. Chris Hunter who is with NAST – this is his email address at the State

Treasurers Organization. You can go on the website. If you go on the NAST website, make sure you put this forward slash ABLE to get to information about ABLE.

There is also the National ABLE Resource Network, which will have information about states. You can compare up to three programs at a time. You can click on a state and learn about the ABLE program in a state that you are interested in looking at.

With that, I am going to turn it back over to Colin to speak to some additional financial planning and information about his personal experience.

MR. MEEKS: Thank you. Do you have slides for me? You guys are on it.

You will be happy to know I only have 45 slides. Just kidding. I have boiled it down to just five. I am going to try and hit the high-level stuff here. Sitting here this morning since this morning, listening to everything in this room, I have never been to one of these meetings before. This is really cool. I am a financial advisor up in Baltimore. I was lucky enough to meet Susan within the last month. It is just really cool to be here to know as an autism dad that there are committees like this doing this kind of work that really helped us out as a family. Just really neat. Thank you very much for that.

To talk about just the basics of special needs financial planning. We got some disclosures there. I sit face-to-face with families every day. We try to help them reach their financial goals, write financial plans, invest their money the right way, whatever it is that is on their mind at that time trying to take the stress out of their life when it comes to money. Obviously, as you know, when you have kids or grown adults in your life that have special needs, it requires a lot more.

I just want to go through three things that we try to address with every family. There is a lot more to it than this, but I will just try to hit the high-level stuff. The first thing we look at is we want to make sure that each family has their updated legal documents. We talked a little bit about trusts and things like that with one of the ABLE slides, but there are just a handful of legal documents. I am not an attorney. We refer the workout to local attorneys and depending on whether the person is in the country that we are dealing with. We try to hook them up with a good attorney. There are some networks of ones that just deal with this type of planning.

The second thing and this sort of goes along the lines of using an ABLE account. We want to make sure that there is liquidity in place and that there is a protection plan. That has to do sometimes with insurance. It has to do with, there could be a trust document in place. We want to make sure that the person that we are planning for has – the family has that liquidity in place.

And then just like everybody's family is different, every plan that we put together has its differences. Not everybody wants the same things. Not everybody is trying to reach the same goals. Not everybody wants to retire at the same age. Not everybody wants to save X amount of dollars for college, plan for a wedding, go on vacation, whatever those goals are. We try to map those things out.

When it comes to planning with a family, and most of my experience is parent initiated. We deal with moms and dads that have either a child with special needs or a grown adult child in their family with special needs. It is way different than just when you are dealing with one lifetime because when you have a child with special needs with autism, you are planning for two lifetimes. Most families are worried about what happens when I am no longer around to take care of my child. What happens when they are 50 years old and I cannot take care of them? Who is going to step in and take care of them? That is where the legal documents can come into place. That special needs planning – it does add an entirely new perspective to the question what happens when I am gone.

We do want to focus on letting our kids not just survive in those times. We want to make sure that everything is in place so that when you are no longer able to take care of them that there is something in place to provide for that.

Some of the benefits that we have seen in our practice and we have heard from families, benefits of planning, and obviously financial planning in and of itself can relieve a lot of stress in your life, but especially when you have something in your life as an unknown such as a child with autism or any other disability. It hits on all these things.

The big ones that we see or we want make sure that the means tested public benefits are there when they need them. We do not want to do anything to disqualify a family from getting those SSA benefits or the Medicaid benefits. That is where something like an ABLE account can really help. If it comes to the fact that we need something more than an

ABLE account, we can use some sort of special needs trust to do that.

Provide ongoing system for advocacy. Make sure that there is something in place to make sure that somebody is there to advocate for your child when you are no longer there to do it or you cannot do it.

Protect beneficiary from predators. We see a lot of cases where – even in our practice where there is no kids with autism or special needs is to make sure that when somebody passes away and passed money onto their heirs that somebody is not sitting there waiting to try to get them to get rid of their money. To separate them from their parent's money. All kinds of benefits that we try to listen to from our clients and help them plan.

This is the most powerful document that we will do with a client. This is just called a planning timeline where we will lay out over the course of – this is just a sample family with a husband and wife on the top and two children on the bottom. The highlighted yellow areas are James-2 diagnosed with autism and these are what we call the pressure points in his life. This is really easy to do if you just – we have a template for it that we can – it is on our website. You can check that out. We try to hit and just lay this out in front of somebody and show them here are all the things that you have told us are going to happen in your life. Here are the things that are definitely going to happen as James gets to be older. We want to put together in those planning documents definite plans of action so that – as we are reviewing their plane very year that we want to make sure that we are doing that.

There is also a child, Hannah, she’s 9. She is a typical child. We want to make sure we are planning for – at this point, how much money do we need to save for college and a wedding fund? But then we need to also do all these other things up there to make the plan work. This could be a situation where there is not enough resources to hit all these goals, but at least we have them laid out and we can set a plan in place to work towards them.

I will just finish up with some common misconceptions of planning. We hear this a lot and we deal with families across the economic spectrum. I do not have an account minimum. We are not looking for people with X amount of dollars. We will help somebody that has no money saved. We will help somebody with $5 million. We are just looking to help the right people at the right time.

It is a common misconception. Planning is expensive to go out and hire an attorney, to hire a financial planner. To do all these things takes money. Sometimes, yes. If that is the case and if money is the issue, there are plenty of online tools that we are more than happy to show families that they can do it on their own or we can help them and walk them through it.

The other one is somebody will be there to help both financially and with the processes and benefits. That runs into the question of do you really want that free help. There is somebody out there that is always willing to help you for free. What is that advice really worth and what will it get you? Planning is only for the wealthy. Not the case. Siblings will be there to step in. With my situation, I do not want to put that on my oldest son. He is going to be the one to take care of our younger son if something happens. We do not want that to be an issue.

A lot of times we will hear people say I have life insurance. I have a will. That should pretty much cover it. And that is a lot of times not a very good planning strategy either.

That is it with financial planning. ABLE accounts are something we are really excited about. It has been around for the last two years and in Maryland, it has been a year. It is one of those neat little tools that we have added to our toolbox. It has really helped our practice out. It helps us help a lot more people because of just the pure simplicity and cost of it. Thank you. Turning it over to Phoebe.

MS. PHOEBE BALL: Thank you so much Colin and thank you everyone for having me here today. I am here on behalf of Neil Romano, who is our chair, who lives in Florida, and he had a prior engagement so he could not make the meeting today. They sent me in his stead. Hopefully, I will be able to fill his shoes a little bit.

Just a little bit about the National Council on Disability so that you know who we are and what our role is in all of this. The National Council on Disability is a nonpartisan, independent, federal agency that advises the President and Congress on disability policy issues. We have been in existence for almost 40 years and became an independent federal agency in the '80s. We started out focusing really on education and moved to other issues.

We are very proud to have written the first draft of the ADA. I cannot really say I shared anything in that. I was in high school at the time. That is something that certainly we put forward as something the National Council on Disability is very proud to have done.

Also, the ADA Amendments Act, which was passed in 2008. We had a big hand in working on those issues and making sure that the ADA met its potential to help people achieve their goals.

We like to say that we try and further the goals of the ADA which are equality of opportunity, full participation, independent living, and economic self-sufficiency. Those are all areas that we work on.

With regard to ABLE, we have been calling for changes to the asset restrictions in SSI and Medicaid and other means tested programs since the early 2000s. Stuart was talking about how ABLE was the newcomer after ten years. I very much feel that. I, myself, was working on asset development in the early

2000s back when they called them individual development accounts and that was sort of the in vogue thing at the time, which I think has sort of become ABLE.

I am very happy to see ABLE passed. When I first got here, I started working at the National Council on Disability in 2014. ABLE was really one of the first things that I worked on when I got to DC, which was a little bit - I think somehow, I was fooled a little bit because since then I think that was a great big achievement. Since then things have ground to a bit of a halt in DC in terms of legislative accomplishment, but certainly as Stuart mentioned and I think others also, this is something that when I talk to staffers on the Hill and when I talk to representatives and senators on the Hill, folks that were involved in ABLE see this as one of the crowning achievements of their legislative careers. They really see this as I did something good. This is the kind of thing I came to Washington to do. I think that that is something that is very important for us to remember is really how important this is.

I think also as I will talk about a little further, one of the things that NCD is trying to do and all of us are engaged in I think is trying to make ABLE better going forward and make it a real opportunity for more and more people to take advantage of.

For myself, I just wanted to mention really quick. Part of my experience with it is I was born with spina bifida. I actually got through law school using a PASS plan, which was a Plan to Achieve Self-Support through Social Security. I mentioned that because it has some similarities to ABLE. It is a way of saving money so that you can achieve the goal of becoming self-sufficient. For me in college that was very empowering to say I could start working. I could save my money to achieve the goals that I had. I really want to emphasize that and Bette mentioned this very eloquently.

Empowering people with disabilities to save money to achieve their goals is so important and the fact that people with disabilities are the owners of the ABLE accounts is so critical because it is that ability to – even if there are other folks in your family making contributions to that account, you can really see this account growing as something that is going to help you do the things that you need to do in life and basically pull you out of the entrenched poverty that we see with folks that are on programs like SSI and Medicaid.

I would direct your attention to our progress report from 2017, which talked about poverty and disability and that sort of intractable connection. I think ABLE is a really important way out of that that we have identified.

Bette mentioned people worrying about losing their benefits and lacking trust in federal programs that say you can go back to work or you can do this or that. I used to be a protection advocacy attorney in the State of Florida. We dealt with a lot of issues around people having overpayments for SSI and SSDI. There is real fear and there is real – within the disability community, folks that live on these means tested programs and families that have worked very hard to make sure that their grown children – I kind of hate that term, but I cannot think of a better one – with disabilities have the supports and services that they need going forward. There is a real fear that those will be threatened by trying to move beyond that. We really do need to try and help people get passed that fear so that they can work towards something greater than just a lifetime of poverty.

When I started on SSI for myself, it was $450 a month that I had to live on. You had to pay rent. You had to all these other things out of that. That is very little money. It is now $750 a month. It is not much to live on and ABLE can provide a way out of that and improve the quality of life and the ability again to meet your goals so tremendously. That is my little soapbox about how important it is.

There is some concern that ABLE accounts and this has been touched upon as well that are not being used perhaps as much as we would like. I think that goes back to the fear that folks have about losing their benefits if they take advantage of these kinds of programs.

But we do need to start bringing more people in to using ABLE accounts to make these programs more sustainable in the states that have adopted the programs and also to encourage the few states that have not taken up ABLE to do that.

If you build it, they will come. It does not seem to work with disability policy. I can say that because I am from Iowa. I get to make those references to The Field of Dreams. It does not seem to work with disability policy. We have seen some disappointing things. I mentioned PASS plans earlier. Those have not been used as much as folks would have hoped. That always makes me sad because again for me it was life changing. We do not want to see that happen to ABLE.

As part of that, the National Council on Disability was charged by the House Appropriations Committee in this most recent budget that was passed, the 2019 budget. I will just read the language because I think it is very eloquent about what our role in all of this is going to be. They said the committee is concerned about the inconsistent guidance provided to ABLE beneficiaries from various federal agencies that administer needs-based assistance programs. As a consequence, participation in state ABLE programs suffers. The committee strongly encourages NCD when convening stakeholders to conduct information sessions on ABLE accounts. In addition, the committee directs NCD to serve as an interagency coordinator to ensure consistency across federal agencies and programs.

NCD through its work with disability organizations should also raise awareness on the eligibility and benefits of these accounts. We have basically three charges within that. One is to provide information to folks as we go throughout the country. We have four quarterly meetings a year with our council members and with staff who can interact with people. Our next one is going to be in Jackson, Mississippi. After that, we are in Las Vegas. These are opportunities to meet with people throughout the country and hold information sessions and try and provide more information about ABLE accounts to work with folks like Bette on making sure that this information gets out there.

But also to provide interagency coordination. We have a really interesting role here in DC as the National Council on Disability and an ability to interact with folks from other agencies who have a role in making sure that ABLE is a successful program. Some agencies have really taken up that charge. I will talk about that in a minute. Other agencies – maybe we would like to bring them on board a little bit more and get them to issue guidance that is helpful. That is what NCD is going to try and do going forward.

And the other thing is to raise awareness within the disability organizations in DC. There are a lot of national organizations here in DC, some of which obviously Sam is already very involved in these issues. Some of the organizations here in DC – we want to talk to them about ABLE and make sure that they are doing what they can to make sure folks are aware that this is an option.

After this nudge from our appropriators, which is always poignant, we have taken several steps already. We did an initial assessment of the guidance issued by various federal agencies whose programs may be impacted by ABLE. We found that the IRS issued fairly detailed guidance early on. To Bette's point, this is essentially a tax program, which I think is sometimes why it does not get the attention within the disability community that perhaps it deserves sometimes. Also, CMS issued guidance in 2017. And also the SSA has included guidance within the POMS, which is their guidance.

We have seen a lot of really good input from federal agencies, but we have also heard nothing from the Department of Education on ABLE in terms of guidance, very little at least, and also Housing and Urban Development has been silent on the issue. I was speaking with Bette before this about some of the confusion around whether – if you are on a housing voucher and you have an ABLE account and whether that should count against you in this means tested program. Obviously, it should not. We need to clear that up. We are definitely going to try and reach out to those agencies as well as others to make sure that they are issuing helpful guidance that is consistent across federal agencies.

We recently hosted a meeting with our federal partners, which Stuart was there, and I think a couple of other people that are in the room. We were pleased to see SSA, CMS, ACL, and other agencies along with many disability groups whose members may access ABLE accounts to discuss where the gaps are and what we can do going forward. We are in the early stages, but we are going to try and play a really valuable role in moving ABLE forward.

We also plan to do information sessions, again, as I mentioned, as we are traveling around the country. I, myself, will be going to Ohio to meet with Bette's counterpart in Ohio. As she mentioned, they were the first program in the country. We would like to see with their longer history with ABLE what has been successful and what has not and try and make sure that we know the program really well so that we can provide helpful guidance in that role.

From a legislative perspective and this is more in my wheelhouse, the council will also be supporting the ABLE Age Adjustment Act, which is Senate Bill 817, and educating staff on the Hill about the need to make ABLE more fair by raising the age of onset that

Bette mentioned, a limit from 26 to 46, which will not only make the program more fair, but it will also increase by an estimated 6 million, the number of people who are eligible ABLE account holders. There is hope that that will enable more people to not only use the program and become ABLE account holders, but also that that will make the programs more sustainable because you will have more people who are able to invest their money. We hope that that will improve the long-term outlook of the program.

Those are all the things that we are doing so far. Again, we are early in this process in terms of our level of involvement with ABLE, but we are very excited about it. We are certainly going to be looking for ways to be helpful in this conversation both in DC and again throughout the country. Thank you.

(Applause)

DR. GORDON: Thank you. That was really informative set of presentations. Are there questions? I see Sam already has her hand up. I have Alison next.

MS. CRANE: I wanted to thank the panel and I really also wanted to apologize that we do not have a self-advocate on the panel. Susan and I work together. Pretty hard to find people who were ABLE account holders who could come. We did identify a few people who had ABLE accounts, but none of them were able to make it today. I wanted to just preemptively say that attempt was made and it did not work today this time.

But I want to pass along some concerns that we have heard from the self-advocate community on ABLE because I think this is an incredibly important and valuable tool that could be used, but we are not seeing the uptake that we would like to see. One is that doctors do not know how to certify people who did not have a diagnosis before age 26. We can keep saying over and over that certification is possible, but doctors do not seem to understand what the standards are. We are hearing people being told by doctors that you do not have an intellectual disability. I cannot certify you for an ABLE account even though you are on the autism spectrum or you were not qualified for SSI before age 26 or you were not diagnosed before age 26 so I cannot say that you have a disability before age 26 - clear that autism - it does not start at age 26. Many people who should have been on SSI before age 26 are not because it is a very difficult process. Some people for one reason or another they had a lot of support. They did not SSI or they had a job. They lost that job as a result of a disability and they should be able to get on

ABLE. But we are not seeing people who are really understanding how to get that population of people onto ABLE.

It is one of the reasons why we have advocated for raising the age limit entirely because it would be easier in my mind to just get rid of the 26-year-old cutoff and educate every doctor in the country about this.

Expenses. This is a high stakes account, which means that if you do not track your expenses right and you get audited or Medicaid agency investigates you, you could lose benefits. This is seen as so risky that a lot of people are afraid of getting the accounts.

We have worked with some ABLE administrators to try and develop apps so it can be used to track expenses. I think that could be really valuable and important because a lot of people with disabilities lose stuff and are very bad at being organized. I know that I am very bad at being organized. If I had to save all of my receipts or else lose my health care, I would be out on the street with no health care. It is really important to make sure that there are apps and stuff that can help remind people and prompt people to upload their receipts.

We need more accountants who are not only familiar with ABLE, but able to help with that kind of a task. We are being told that accountants are not familiar enough with ABLE to give advice on this. I know that that outreach is happening, but obviously it needs to keep happening because there has not been that much market penetration into the world of accountants. People are getting inaccurate advice from accountants about whether they are eligible. People are not able to find accountants who are able to support. Even if they know that accountant is wrong, it means that they cannot get that accountant to help support them and make sure that they are actually tracking their expenses and doing everything that they need to do.

Finally, we need better education of Medicaid social workers because I have encountered several people saying I know that I would be able to track all of my expenses right. I know I would be able to get everything right, but my Medicaid case worker does not understand it. I am really worried that my Medicaid case worker will get something wrong and no matter what I do, they will think that I have done something wrong and they will cut off benefits and then it will take months for me to appeal it and get my benefits back. Those are - basically, I wanted to just summarize the concerns that we have heard.

DR. GORDON: Alison.

MS. SINGER: In a surprised counterpoint to Samantha, I wanted to present some of the parent's perceptions with regard to the ABLE accounts. I think there is a good understanding in the parent community or there is a sense that a 529 account is for the purpose of saving for college. You plan to put money into that account for 18 years and then it has time to grow and earnings build and you can see that there is a benefit. You can calculate based on your contributions how much earnings you are going to have at the end of those 18 years.

The ABLE account is people think of more as a spending account. They often are confused that is not more like a flexible spending account and they are contributing pre-tax dollars that they can then spend immediately. Because so many of the families are – because in the ABLE account, you can spend the funds right away, there is not enough time for those earnings to accrue. People are not really seeing the benefit of making this investment.

I was wondering if you had thought about trying to reposition, remarket this account to families of younger kids as a way to save for their children's futures when they become adults and try to discourage them from spending down the funds too soon before they have an opportunity to see the earnings - because then they say I am paying a monthly fee and I am not accruing earnings. That is because they are not allowing enough time. I am wondering if you have thought about that.

MS. MOBLEY: Basically, when we describe the program, we talk about it from the person needs to decide how they need to use the program because we do meet some families who need that money and they need it now. And we do meet families who look at this as a long-term savings program. For us as program administrators, we do not tell people exactly how they need to use the program. That is a personal decision based on their family situation.

The benefit of having accessibility to the account now might be the fact that they found themselves in a situation of constantly exceeding that $2,000 asset limit. And in order to maintain their SSI benefit, they need to be able to put money into the ABLE account in order to not lose the SSI benefit. That is one of the reasons why they need the ABLE account. For other people in the case of young children, we do meet young families who are looking at it as a long-term savings.

It is hard to market it one way or the other because each family situation is so unique and different. I can speak at least to what we do when we do outreach here in Maryland. We talk about all those different scenarios and talk about how each family makes a decision about how this account could best benefit them as a family or as a person as a beneficiary of this account. It does get confusing because there are so many ways that it can be applied and can support a person in their life.

DR. GORDON: You just elucidated one way that I guess a low-income family might be able to benefit from having an account and that is that they have some assets they can keep the other assets out from affecting their evaluation for SSI.

But you mentioned an aside about maybe another way and I am not really sure. You mentioned that Florida has chosen to "fund" their efforts. Are there other states that do that and what does it mean to fund? Does that actually mean that the state gives money to families with disability or does it mean that they pay for the upkeep or how does that work?

MS. MOBLEY: They pay for the administration of the program so that the program does not need to charge any administrative fee in order to run the program.

DR. GORDON: Absent resources coming from the family or from the individual with the disability, there is no mechanism to use these things to actually provide additional support for folks with disabilities. Is that right?

MR. SPIELMAN: yeah, but one of the things that Bette Ann and I have talked about is that in the 529 space, employers are making contributions to ABLE accounts. There are some states – I have not looked at this - while Phoebe, you may be familiar, familiar with this as well. I believe, I am going to say it is Nevada and Maine, actually do seeding for 529 accounts. There may be other mechanisms by which wealth can be created in families that would use ABLE accounts.

MR. MEEKS: I would also say that with the limitations of ABLE accounts and as a long-term savings tool it probably if we listed all the things at least from my experience, it would not be the best long-term savings tool. If we are trying to find a vehicle that would accept an inheritance from a grandparent or somebody names their IRA their beneficiary or their life insurance, we want to make sure that in case an ABLE account probably would not be the best tool because of only being able to put $15,000 per year in the well. We might recommend a special needs trust in addition to the ABLE account. Maybe it is a more of short-term goal.

MS. CRANE: I have heard of cases in which people have done a special needs trust that deposits money into an ABLE account as well. That is something that I have heard people doing.

MR. MEEKS: yes, it is complicated, but it works.

MS. CRANE: You get $100,000 from your grandfather. The special needs trust gets that $100,000. It then gives you $15,000 a year into your ABLE account until that money is out and that is the way that people sometimes do it.

MR. MEEKS: Would you like a job?

MS. CRANE: Talk to me afterwards.

DR. GORDON: Are there other questions or comments for the panel? John.

MR. ROBISON: I guess I would make this observation not meaning to just seem like an ungrateful lout, but I think that we should remember that as great as this plan is and as great as the work all you did on behalf of disabled people, this is very much a tool for the 1 percent. You tell us up there that there are some 25,000 people who have opened these accounts. That is a tiny fraction of the autism community. We talk about how we can roll over 529 accounts into an ABLE account. The average 529 accounts from what I just looked up have $220,000 in it. The average American does not have $220,000 in entire net worth to their name. Again, we are talking about a 1 percent account for one group into another kind of 1 percent account. I am all for that for people with disabilities. I have no criticism of what you have done in that regard.

But I would draw particular attention especially to Stuart because I do not know the others' work. But Stuart, you have worked to get federal legislation so that other therapies cover autistic people so that therapies are available to us around the states. If we want to do something meaningful for autistic people, help the people who do not have any money who are the vast majority. That means give real tax credits to employers to hire us. Make more services available to us. You and government agencies. This is not something to pat our heads over. This is a fundamental failure of delivery of service to the average American.

MR. SPIELMAN: John, if I could respond to that. I am going to take issue of your last comment. This is not a perfect solution to an incredibly complex problem, but it is one way to make things better. We have to continually try to put more wealth into the pockets of people who face severe challenges.

We - all of us on the panel – I am going to speak collectively because I know all the people a little bit. All of us on the panel are aware of the limitations of ABLE. But I think it would be unfortunate if we were to emphasize that this does not solve all the problems in the world. It never was intended to, but it was intended to make things better.

We are continually exploring ways to get more funds into the system, to get more contributors into the system, and to have a broader economic effect so that the people who have the most difficulty savings, the most difficulty making the monthly payments and weekly payments we all make that those people are going to have some benefits.

ABLE is a start. Historically, and Phoebe, you can comment on this, we have seen not a tremendous amount of movement in the financial empowerment, financial wealth space in government for a very long time. This is one of the significant impacts of ABLE. Yes, it is far from the one single – it is not a Swiss Army Knife kind of financial solution. I am going to push back on criticism of ABLE. It is definite progress. We just continually have to do better.

MR. ROBISON: Stuart, I should not have I guess criticized ABLE so much as saying here in your presentation just brought out my great frustration about how I feel that we in government service are failing to help the American people. While I think what you have done is good, I do not think it is going to help the people to the degree they need help. I guess that is it. I am sorry for maligning you unfairly over that. You know I appreciate what you all do.

MS. CRANE: A slight rebuttal. One of the things that was really fascinating to me in the statistics is it was either Stuart or Bette Ann Mobley was presenting that the average account size for an ABLE account is $4000. That to me suggests that this is not necessarily a 1 percent account. It instead helps people develop a little bit more of a bridge between the dire poverty that is enforced by a $2000 asset limit for most government benefits including the home and community based services, et cetera that we need in order to get jobs. A bridge between that level of poverty and a little bit more of a cushion. A lot of people are never going to get above $10,000 in their ABLE account.

But that money in the ABLE account is going to really help them if they need it as a cushion if their benefits are interrupted, if they need to move, if they need to make a major purchase.

I do think that there could be real use to these accounts for people who are not necessarily in the worst poverty. They have to have over $2000 to their names in order for it to make a difference. But for people who are trying to achieve moderate financial stability I think that it could be very useful.

MS. BALL: Sam, I would like to add to that a little bit. I completely agree with everything you just said. I also just wanted to point out. It is not even that you have to have $2,000 to your name. Part of it is aspirational. Opening up that ABLE account with $50 and saying someday I would like to have the problem I have more than $2,000 and maybe I will lose my benefits. That is a good problem to have if you are not going to actually lose your benefits whereas if you have that hanging over your head that you could lose your benefits if you earn and retain assets then it makes you not even want to try.

I would also like to point out that ABLE does not exist in a vacuum. It works in conjunction with other programs. There is 1619(b) through Social Security. There are other ways of - I worked. I was on SSI for 12 years before I got my first real job out of law school and got my last check from Social Security. It is very powerful to work and save money like I said to get to the next place in your life you want to be.

When you are only getting $750 a month to live on, it does not take much to improve your quality of life. You do not have to have a whole lot of money in that account to be able to buy a new TV or whatever the thing is. It is probably not even approved under ABLE, but maybe that would allow you to have money elsewhere. You could use the money in the ABLE account for something and then you would have money for something. It would improve your quality of life because again when you have so little money and when we are talking about as Stuart referenced, the entrenched poverty of people with disabilities that has persisted and persisted and persisted over decades. I personally have been doing this work for 25 years. I feel like I am having the same conversations over and over again and the needle does not move on employment of people with disabilities, on asset development for people with disabilities, on so many of these kinds of issues.

ABLE Act is not perfect. I think it is open to the criticism that you cannot save money unless you have it. I totally get that. But it not being perfect is not really a problem. Nothing is perfect. And all of these programs work in conjunction with each other and we need to try and advance in small ways everywhere we can. I see that all the time of that criticism of this program is not perfect; therefore, I am not going to invest my energy to advocate for it. I think the disability community cannot really afford to do that. I think we have too many issues that need to be addressed too urgently.

MS. MOBLEY: One of the examples, which I thought was incredible in one of the presentations I did, was a woman who said I have been struggling as a brand new home owner because by the time I think about paying my mortgage and saving to pay my property taxes and I pay my expenses for the month, she is a person who gets SSI benefits, who has a part-time job and is really struggling to make those expenses. She said my monthly expenses are far exceeding $2000 in assets. I am not always able to get all that money out of my account by the end of the month. But with ABLE, I can do that. I can put this money into my ABLE account and then when I am ready to make those payments for my mortgage, transfer it out, this saves me from struggling to lose these – I am going to lose these SSI benefits because I am going to constantly exceed the $2000. It has given her a tool to be able to feel some sense of security as now a new home owner as a person with a disability. I think about the empowerment that it is creating for many people as well.

DR. GORDON: That is great, but wouldn’t it have been better if we could raise the damn limit from $2000 to $10,000 or something reasonable in this day and age. $2000 will not pay the average rent in most American cities.

MS. MOBLEY: You are absolutely right. We haven't gotten that accomplished. Now we have ABLE so we at least have a tool to help.

MR. SPIELMAN: You cannot always get what you want, but you try.

DR. GORDON: Sometimes. Alright, other comments? Okay. I want to thank the panel for really wonderful presentations. I know people on the committee of course learned. Maybe many of you knew about ABLE. Maybe many of you did not. But I know out there listening on the web and to the broadcast and the audience, I am sure there are lots of people who did not know about it and now will know about it. It is really important for you to bring this information not just to the committee, but to the audience that tunes in. Thank you very much.

Next up we have a break. We are running early. We are going to keep going with that earliness. We are going to take a 15-minute break. We are going to return here at 3:35. Twenty-five minutes to four.

(Whereupon, the Committee took a brief break at 3:17 p.m. and reconvened at 3:35 p.m.)

DR. GORDON: The last item on the agenda is the Round Robin where each of the committee members reports out to the group on goings on that they would like to announce for the benefit of either the committee members or the public viewing. We will go ahead. We will start with you, Alice.

DR. KAU: I would like to share one piece of information about what is happening at NICHD. NICHD is in the midst of a collaborative process to revise or to edit our scientific research strategy, our strategic research plan. There are ways that the public can help shape NICHD research agenda. You can find more information NICHD's website. You can send your questions or ideas to NICHD strategic plan at NIH.gov or you can attend the NICHD strategic plan webinar on October 31, 2018. If you need information or have questions, let me know.

DR. GORDON: John.

MR. ROBISON: The things I have been thinking about with adult issues, I think that my ideas are not fully enough formulated yet to present here. David and I talked about publishing them as a commentary in Autism. I do not want to just preempt the whole peer review process by presuming to tell you that now. I think I should wait until January and therefore contrary to my nature, I will just be quiet.

DR. BALL: First, I just want to thank Dr. Scott for being here today, representing the Autism Society's Panel of Professional Advisors. We set about eight months ago to look into this issue. He has been very passionate about it for a very long time. He authored a book, which will be coming out I think in the next month and a half to two months on the topic so just very timely for us.

The Autism Society is heavily looking into funding some of the aspects of some of the gives that we even talked about today so that we can make impact for families immediately which strategies and also with help on trying to get this information into individual education plans.

DR. WILLIAMS: Just brief two things. Our application receipt for the autism research program was earlier this month. We are going to be reviewing those over the next several months and we will have our funding recommendations done by after the first of the year, late winter.

And then we also did receive another seven and a half million dollars again for the program this year. We will be coming out with our solicitations, our program announcements probably late winter, early spring for the FY19 program.

DR. LAWLER: I am happy to report that we have wrapped up probably about a year of planning for our revision of a strategy plan, which you all can find on our website. I think when I consider the autism program that NIEHS supports, it hits so many of the important themes in this from individual's susceptibility to considering exposures not one at a time, but in context, bringing big data approaches, continuing and pushing forward with greater community engagement and this idea of a translational framework that is directed at public health efforts as opposed to clinical interventions. It is very good reading. It is not voluminous, but it is great. I encourage all of you to check it out.

DR. JOHNSON: Hi. Within the Administration for Community Living, we have the National Institute on Disability, Independent Living, and Rehabilitation Research. This fall they funded two new research grants related to adults with autism spectrum disorder and community living.

One of those – three-year grants with budgets of about $200,000 each year. One is at Temple University and the title of that project is Enhancing Community Participation for adults with autism spectrum disorders through Peer-Mediated Transportation Interventions.

And then the second one went to Penn State University. And the title of that project is Increasing Community Participation in Young Adults with Autism Spectrum Disorder.

We also provide support to the president's committee for people with intellectual disabilities. That committee will have a meeting on November 8 and 9 and a focus of the meeting will be on employment. Those are our updates.

DR. GORDON: Continuing around the table.

DR. MAMOUNAS: I am sorry. We do not have anything.

MS. SPENCER: From Social Security, we have just awarded a new five-year task quarter with the Health and Medicine Division of the National Academies to help us as we consider policies we want to change in the disability arena. Generally, we have a standing committee that just advises us every quarter over a period of five years and then consensus committees that we gather to help us form an evidence base on a variety of subjects. We have not issued the task orders yet. That should be coming pretty soon.

MS. CRANE: We recently released two important tool kits. One, I do not know if I brought up at the July meeting, but I do not think I did. It was a white paper on how supported decision making can help adults transition from institutional settings to the community.

We also released just the other week an easy ready toolkit on employment policies. This is a toolkit that is accessible to people including people with limited literacy on the importance of competitive integrated employment, helping people understand the employment policies that affect their lives and helping people be more effective advocates for access to employment.

We are working with NCD on two white papers, one on discrimination in organ transplant contexts. Another one on the use of quality adjusted life years in ways that might lead to discriminatory health coverage decisions. And we are working on a paper – we held a summit of self-advocates to discuss the definition of what they considered important to the idea of community living. We will be releasing a toolkit on that that includes a self-advocate definition of what community means to them and what community living is.

And also I will get yelled at if I do not say that our gala is coming up in mid-November. I think it is November 15. Everyone is encouraged to buy a ticket to our gala and attend our gala. It is always really interesting. It is not like any other gala that you have ever been to because this is a gala full of autistic people and run by autistic people. We are now allowed to clap at this gala. The lights are on. There are seats. There are communication cards that you can use to avoid people that you do not know. It is a fun time. Everyone should come.

DR. PEÑA: I really want to go to your gala now. I am the director of the Autism and Communications Center out of Cal Lutheran

University. We just had our annual conference last week. And the theme for this year was preparing autistic students for higher education, post-secondary education programs. Our keynote speakers were actually AAC users. They are augmentative and alternative communication users who are college students at four-year universities so two from UC Berkeley and one from Cal State Channel Islands. They provided the keynote panel. They were awesome.

In addition to that, our center has started a transition program, which is a four-day workshop for autistic students who use augmentative and alternative communication to prepare them for college in post-secondary programs. We offer that in California and another one is going to be happening this weekend in Maryland. Thank you.

DR. SHAPIRA: From the CDC, the next cycle of funding for the Autism and Disabilities Monitoring Network will start in 2019. Applications in response to the funding announcement were due by October 1. They will be reviewed shortly. We will hopefully have information in the near future.

And now, fresh out of the oven, the Spanish app for Learn the Signs. Act Early for iPhones and Android devices was launched this week. It is live. It will be promoted starting next week.

And then the third area is there are frequently studies published from CDC's Study to Explore Early Development or SEED and updates on SEED publications are included in newsletter that are posted several times a year on the CDC website. I would like to give the web address for the minutes for individuals who would like to look that up.

It is www.cdc.gov/ncbddd/autism/seed.html. I will review that in the minutes to make sure it is correct. Thank you.

DR. WEXLER: Good afternoon. At the Department of Ed, we do not have specific grant programs really that focus on autism. It was the end of the fiscal year. Those of you who are in the grant business in the federal government understand what that is about.

But we fund about 15 doctoral training grants every year and a number of them have an autism focus. We also have a master's program and some of those had an autism focus.

But the thing that I think is the most fun thing we have been doing – we did not fund it this year. It is in its fifth year. But it is a data center. Basically, what happened was about seven or eight years ago, I was asked how many kids with disabilities are also on free and reduced lunch. That was the question. I supervise all the special ed data. That meant going to free and reduced lunch people, which is the other data system in the department. They came back with an answer for me. It was great. They said 22 million, which is a big number, but it is especially big when you think that there are only 6.2 million kids with disabilities. We knew we had a big problem in terms of data streams talking to each other.

The federal government – we are not allowed in our department to have those streams interact with each other, but states can. We funded a center for – it is about $10 million or $12 million center. With the work scope of developing software to help states and to make it free, have their federal data streams talk to each other so you are talking special education kids. You are talking free and reduced lunch, homeless, English learners. There is a whole litany of kids. They have developed it and they are beta testing in many states and the states are lining up for this. What does it relate to us about? It will mean that you could go to a state and say how many kids with autism are also on free and reduced lunch and are English learners and are between the ages of 6 and 12. That was sort of our fantasy with us. It actually is going to come true.

I think for researchers out there it will be terrifically interesting, but also we talk about there is a lot of kids who have autism or have intellectual disabilities who are also coming from very poor families, but we do not know that. Now, we will be able to know.

MR. ROBISON: I would like to suggest that we have had a remarkable thing happen. It is 4 o'clock. We have discussed the public comments. We did not have in-person comments. We have reached the end of the agenda and I suggest perhaps for the one time in our existence we could adjourn before five.

DR. ELAINE COHEN HUBAL: So are you going to take from the telephone too on the round table?

DR. GORDON: Yes, we will.

MR. ROBISON: Pardon me.

DR. GORDON: You are jumping the gun a little bit, but I promise. We will be out of here before five. On the phone first. Who is that on the phone?

DR. HUBAL: This is Elaine Cohen Hubal with US Environmental Protection Agency. I just wanted to mention a couple of things. Our Children's Health Protection Advisory

Committee, CHPAC. It is the Office of Children's Health Protection. It has an advisory committee. They did meet last week. There materials and things are posted if people are interested in that.

The EPA Administrator also posted a memo last week affirming EPA's commitment to children's environmental health. As somebody who has been in the Office of Research and Development for over 20 years, I appreciate that.

I just want to kind of throw this out as a resource and just something for people to maybe look into and think about, but the Office of Children's Health Protection at EPA jointly with CDC or ATSDR sponsor, Pediatric Environmental Health Specialty Units. There are ten throughout the country in the different EPA regions. Directors are pediatricians with specialties in environmental health. They develop and provide a lot of community and science translation resources that are I think extremely good and something that maybe we can think about as a committee tapping into or expanding on. That is it for me. Thank you.

DR. GORDON: Thank you. We have one more around the table.

DR. RING: Yes, sorry. I returned late to the table and missed my spot. I thought it would be worth mentioning. There has been in terms of the translation of scientific findings into devices and medicines that might have a real impact on the community. There have been two clinical developmental programs that have kicked off advanced studies in the past quarter that I think are worth tracking as a community in terms of their potential and the exciting science behind them. Roche just launched their balovaptan Phase 3 study for social deficits in autism, which is what most advanced industry trial in this space that has taken a new chemical NRD or a brand new medicine, and moved that forward.

Janssen has also kicked off a large Phase 2 proof of concepts study with a FAAH inhibitor, fatty acid amide hydrolase inhibitor, which works on the cannabinoid system of the brain and has also been evaluated for social anxiety and is now in a very significant Phase 2 study in autism. Both of these, I think, are probably the leading edge of medicines development in this space and are worth tracking as a group moving forward.

DR. GORDON: Thank you. Are there any other announcements on the phone? I have one myself. I guess we will close with a couple of announcements from the NIMH. One of them is just to announce the two latest funding opportunities. As many of you know, in response to the recommendations from this body, NIMH has been now for a few years trying to establish a body of research to support interventions that help individuals with autism as a transition from schools into the community, from youth into adulthood. We have been frustrated with the pace of applications in this area.

We went through two different rounds of calls for applications. In the first round, we got very few. In the second round, we got a few more, but not enough – high quality. We recognized that we actually – there is not enough people in this field studying that group, the transition-aged individuals with autism at the transition age.

We have actually created now a career development opportunity so that people who have trained in other areas of science, autism or otherwise, of clinical psychiatry research to spend some time retooling themselves to be able to study this population. We have two announcements, one specifically for those who want to engage in clinical trials in this group and then another for those who want to address other issues, but not through clinical trials. We are very excited about those two opportunities which again grew out of our continued efforts to meet the recommendations of this committee.

The last piece is less about recommendation for the committee, but any time I get the opportunity to talk to researchers, I want to make sure to announce it. It just opened up last week, a request for information on proposed provisions for a draft data management and sharing policy for NIH. As many of you know, we recognize more and more the need for individual investigators and groups of investigators to share data to make their data publicly available for other researchers to ask their questions with, to maximize both NIH's investments and also the possibility that we could see returns in terms of public health impact. We have been pushing more and more towards that, but we are now requesting that investigators look at some proposed provisions. They are not even really at this point draft policies, but they are proposals for what kinds of policies we might want to put in place. We are encouraging researchers to look at those proposed policies and to provide comment. The RFI was released on October 10 and will close on December 10.

That is it unless there are any other announcements from OARC.

DR. DANIELS: I just wanted to mention that earlier we had Colin Meeks here as a part of our ABLE panel. I did not have a chance to help him mention his project called the Special Needs Connection podcast, but it is listed in your agenda under his name. This is a podcast series that he does as a parent of a child on the autism spectrum to help educate people around the country about especially financial planning for people with disabilities, but he has expanded beyond that and has been doing interviews around the Maryland area and beyond to try to help people learn more about different types of opportunities and resources in the autism community. I just wanted to let you know about that. And the website is on our materials links for this meeting. If anyone is interested, you can find that there.

I believe I do not have any other announcements. Thanks so much for coming. We really appreciate everyone's input and the interesting discussion we have had today.

DR. GORDON: John, do you want to make any final remarks?

MR. ROBISON: No. I think I made the final remark and then you un-finalized it.

DR. GORDON: Alright, thank you all.

(Whereupon, at 4:00 p.m. the meeting adjourned.)