U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, JULY 19, 2011

The Committee met in the Congressional Ballroom, Bethesda Marriott, 5151 Pooks Hill Road, Bethesda, Maryland, at 10:00 a.m., Thomas Insel, Chair, presiding.

PARTICIPANTS:

THOMAS INSEL, M.D., *Chair*, National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary,* Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

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

LINDA BIRNBAUM, Ph.D., National Institute of Environmental Health Sciences (NIEHS)

ELLEN BLACKWELL, M.S.W., Centers for Medicare & Medicaid Services (CMS)

COLEEN BOYLE, Ph.D., Centers for Disease Control and Prevention (CDC)

PARTICIPANTS (continued):

HENRY CLAYPOOL, U.S. Department of Health and Human Services (DHHS), Office on Disability

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

ROSALY CORREA-DE-ARRAUJO, M.D., Ph.D., U.S. Department of Health and Human Services (DHHS), Office on Disability (representing Henry Claypool)

GERALDINE DAWSON, Ph.D., Autism Speaks

CHRIS DEGRAW, M.D., M.P.H., Health Resources and Services Administration (HRSA) (representing Peter van Dyck, M.D., M.P.H.) (attended by telephone)

LEE GROSSMAN, Advance Enterprises, LLC

ALAN GUTTMACHER, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) (attended by telephone)

LARKE HUANG, Ph.D., Substance Abuse and Mental Health Services Administration (SAMHSA)(attended by telephone)

YVETTE JANVIER, M.D., Children's Specialized Hospital

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

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

PARTICIPANTS (continued):

SHARON LEWIS, Administration on Children and Families (ACF)(attended by telephone)

CHRISTINE McKEE, J.D.

ARI NE'EMAN, Autistic Self Advocacy Network (ASAN)

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds

DENISE RESNIK, Southwest Autism Research and Resource Center (SARRC)

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

MARJORIE SOLOMON, Ph.D., M.B.A., University of California, Davis and M.I.N.D. Institute

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PROCEEDINGS

10:02 a.m.

Dr. Insel: Good morning everyone. Let's take our seats and we'll get started. We have a very full agenda today, and I want to welcome everyone to the July full IACC meeting.

For those who are joining us by webcast, since some people are just getting plugged in now, let's just go around the table and make sure they know who is here and then we will get started with a formal agenda.

So I'll begin by introducing myself. I am Tom Insel, Director of the National Institute of Mental Health, and I serve as Chair of the IACC.

Mr. Grossman: Hi, I'm Lee Grossman. I am a public member of the IACC and co-Chair of the Services Subcommittee and proud dad of a child with autism.

Dr. Battey: I'm Jim Battey and I am the Director of the National Institute of

Deafness and Other Communication Disorders.

Ms. Singer: Hi, I am Alison Singer. I am the President of the Autism Science Foundation and the mother of a beautiful 14-year-old daughter who is doing great at summer camp, and I also have an older brother who is diagnosed with autism.

Dr. Koroshetz: Hi, I am Walter Koroshetz. I am the Deputy Director of the National Institute of Neurological Disorders and Stroke.

Ms. Redwood: Hi, I'm Lyn Redwood with the Coalition for SafeMinds, and I have a 17-year-old son who is also in camp this week too.

Dr. Janvier: Yvette Janvier. I am a public member. I am the Medical Director of Children's Specialized Hospital, New Jersey. I am a developmental behavioral pediatrician.

Mr. Ne'eman: Ari Ne'eman, Autistic Self Advocacy Network and I am also an autistic adult.

Dr. Solomon: Marjorie Solomon, an Associate Professor in Department of Psychiatry and Behavioral Sciences, a public member and representing the MIND Institute.

Ms. McKee: Christine McKee. I am the mother of an 11-year-old girl with autism.

Dr. Boyle: I'm Coleen Boyle. I am the Director for the National Center on Birth Defects and Developmental Disabilities and represent CDC on the Committee.

Ms. Resnik: Denise Resnik, co-founder of the Southwest Autism Research and Resource Center and mother of a 20-year-old son with autism who just came back from his first sleep away camp.

Dr. Birnbaum: I'm Linda Birnbaum and I am Director of the National Institute of Environmental Health Sciences and of the National Toxicology Program.

Ms. Blackwell: I'm Ellen Blackwell, Centers for Medicare and Medicaid Services. I am also the mother of a 24-year-old son with autism. This is my son, Robert. He had some time on his hands today and since it's our last meeting I thought that because Alison just said I talk about Robert all the time, it might be nice to have Robert with us for just a couple of minutes today.

So we have an extra person with autism with us today. So welcome Robert. What do you say?

Mr. Blackwell: Hello.

Ms. Blackwell: Okay.

Dr. Daniels: It's wonderful to have you here, Robert. My name is Susan Daniels and I am Acting Director of the Office of Autism Research Coordination at NIMH and I am the Executive Secretary of this Committee.

Dr. Insel: Well welcome to all of you. We have got a lot to do today and we are going to jump right into the agenda. First order of business --

Dr. Huang: Tom.

Dr. Insel: Yes, who is with us on

the phone?

Dr. Huang: Tom, this is Larke Huang from the Substance Abuse and Mental Health Services Administration. I am the senior adviser on children, youth and families here and I am also here with David de Voursney who also works in the administrator's office of policy planning and innovation.

Dr. Insel: Anyone else on the phone?

Dr. DeGraw: Hi, this is Chris DeGraw from HRSA.

Ms. Lewis: Good morning Tom, this is Sharon Lewis, the Commissioner at the Administration on Developmental Disabilities.

Dr. Guttmacher: This is Alan Guttmacher. I am the Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development and a member of the IACC.

Dr. Insel: And Geri Dawson, who can introduce herself.

Dr. Dawson: Hello, I am Geri Dawson, chief science officer, Autism Speaks.

Dr. Insel: Anybody else with us on the phone or have we got the whole crew? I know Francis Collins is not able to attend today. Normally Josie Briggs sits in in his place but she has to be out of town today. Francis did send a note saying -- this morning -- he said he's sorry he won't be able to make it because of another commitment, but he encourages us to go ahead and change the world so he is here in spirit anyway.

Okay. First off, can I have you take a look at the minutes of the last meeting which are in your packets and let us know whether you have any suggestions for changes? Any suggestions? Can I get a motion to -- Ari?

Mr. Ne'eman: Just a relatively minor one. On page 4, it says that I asked about the degree to which people with ASD were included in the HHS National Health Disparities Plan. I actually asked about people with disabilities in general.

Dr. Insel: We can make that change. Is there anything else that people want to see changed in the minutes?

Ms. Singer: I would like to make a motion to approve.

Dr. Insel: Second?

Dr. Battey: Second.

Dr. Insel: In favor? I think the minutes are approved and we will go ahead and launch into the rest of the meeting.

Let me start, as we have done in the last few meetings with this quick update of science based on the -- what's coming out in the literature that we'd like to think is a reflection of the IACC Research Strategic Plan.

Of course it's impossible to summarize everything that has been published since our last meeting. Let me also take a moment just to welcome Henry Claypool, who has just joined us, from the Office of

Disabilities in the Department of Health and Human Services. Welcome Henry.

But I wanted to very quickly just take you on a very rapid survey of some of the major papers and recognizing that some will not be -- we won't have time to go through everything and we will have a lot more time later in the meeting to hear about some of the higher profile findings.

But to the extent possible, let me just give you a quick overview of what we have seen and heard in the last two to three months since we last met.

Under When Should I Be Concerned, there are actually a couple of interesting projects, both in fact from the same group at the University of California San Diego, one of the Autism Centers of Excellence.

This first project, from Karen Pierce, in which the communication and symbolic behavioral skills developmental profile, a five-minute screening test filled out by parents, was given to 127 -- 137 pediatricians in San Diego County and over the course of a year they screened over 10,000 one-year-olds and were able to pick up a relative large number, I think there were 32 positive found for autism or autism spectrum disorder.

There were a few false positives in there but overall the beginning of, the suggestion that we could -- and this is one of the very first things that came up in the IACC strategic plan -- develop a very rapid community-based or caretaker-based surveys that could help to get us a much more rapid diagnosis, in this case at the One-Year Healthy Baby Check-Up.

Same group, but a different group of people within that group, looked at the first potential biomarker for autism. In this case it was looking at the synchronization between different brain areas.

These are children who are a bit

older, I think the mean age was about 29 months, but a very interesting observation that by looking at the way the two sides of the brain are synchronized during sleep in children either with language delay, with a development delay, with autism itself or looking at controls, there were some very significant differences, particularly in areas that are in the superior temporal cortex, areas associated with language development, where it looks like the two sides of the brain are not coordinated in quite the same way in the children with autism. So a potential biomarker of great interest. Jim?

Dr. Battey: Is this pathognomonic for autism?

Dr. Insel: Not yet. It's -- at this point it's a diagnostic -- a potential diagnostic finding but it needs to be replicated. There are only 29 kids in each group so I think we will need to see a lot more evidence.

But as a direction forward, again it goes back to this issue about a diagnostic biomarker that we asked for in this strategic plan, so it's the beginning of something like that. Yvette?

Dr. Janvier: I just want to say that the tool that was utilized was actually developed by Amy Wetherby in her group at Florida State, so it wasn't the California group. They just implemented that screening tool.

Dr. Insel: The Pediatrician's tool.

Dr. Janvier: Yes.

Dr. Insel: Right, yes, so this was -- these are two quite different projects but absolutely, so the screening, the five-minute screening tool, which has been around for a while, I think the contribution here is saying that this could be actually reduced to practice and could be put in place and to be able to do 10,000 children in a year, 137 practices.

And interestingly, as I understand it from Karen, that pediatricians have continued to use this after the study was over so it is actually being implemented. Geri did you have a comment?

Dr. Dawson: Well, I was just going to say, it's also important to note that that is a screener broadly for autism and other -- and language delay and cognitive delay and then you would go on for a referral to get more of a diagnostic-specific evaluation.

And one of the interesting things in that study was how few parents followed up on the referral. So it just shows us how important dissemination science is. We have to really think through all the steps that it takes to get parents to get the treatment services, and somewhere there's a barrier. What is it? Why didn't parents follow up when they did get a positive screen on that?

Dr. Battey: Geri that's a general problem.

Dr. Dawson: Yes, but it -- exactly.

Dr. Battey: It -- it follows hearing screening failures and follows just about everything -- screening tests that I am aware of in the pediatric population.

Dr. Dawson: Right.

Dr. Battey: Follow-up is the big problem.

Dr. Dawson: Well, I was just talking to a Jose Cordero about this and he was saying that they did a study that showed that a simple phone call after the positive screen makes a huge amount of difference in terms of just enhancing the number of people that go on. Anyway sorry to derail --

Dr. Insel: No, it's a great point and it's -- I think the contribution here is not that this is going to completely become the diagnostic screening instrument of choice, but it does tell you that even at 12 months, if this was put in just as the pediatricians have recommended at the American Academy, have talked about the nine-, 18-month, 24-month opportunities to screen for autism, there is an opportunity here for developmental delay in general but also for autism.

So it's doable and it's been interesting to see the amount of acceptance of this and it's simply done in the office as parents come through anyway.

So it's the kind of thing that we had talked about in the plan and it's great to see some of these things actually rolling out in different places.

Let me go on to the next question in the plan, How Can I Understand What is Happening. This has been a very active few months for questions of prevalence. I think all of you know about this, which is actually summarized by Cathy Lord in this editorial in Nature, but what she was talking about was the paper from the group that looked at the first, really, population-based study, whole population-based study in South Korea.

This was 55,000 children screened between ages seven and 12 to look at the prevalence of Autism Spectrum Disorder, Autism Disorder itself.

The numbers, I know all of the people on the committee have seen this before, but the number of 2.64 is significantly higher than the prevalence we have been talking about before.

About two-thirds of these children had not received a diagnosis and they were in mainstream general population kind of samples. Question about whether they really would require care and whether they really are in any way showing signs of disability were raised in the manuscript and raised by Cathy Lord in the editorial in Nature.

But it's certainly an indication of an approach which has not really happened yet in the U.S., which is a kind of whole population surveillance approach which I think we will talk more about as the day goes on. But interesting observation. Coleen?

Dr. Boyle: So I just -- I was going to just say that I mean we have a lot of population-based approaches. I think the difference here is that they attempted to screen all children so that's I mean, just -- it's a little misleading to say it's not population-based because we have a number of different prevalence studies that have been population-based.

Dr. Insel: But is there anything in which -- this kind of an attempt where 55,000 children, everyone in this community was screened. Have we ever done anything like that?

Dr. Boyle: They attempted to screen everyone.

Dr. Insel: Yes.

Dr. Boyle: But no, I mean, it's a

really -- is a remarkable study but I just wanted to make the difference between what we mean by population-based.

Dr. Insel: Great, okay. Thanks for that correction. At the same time there were a couple of others that are sort of intriguing, one from the UK where again, it was an epidemiological survey of in this case adults looking across the lifespan.

It came up with the conclusion that rather than there being this huge surge -- we have often talked in the committee about how 80 percent of people with a diagnosis of autism are under the age of 18 -- they actually found about the same prevalence, roughly one percent in every decade of life, going through the 60s and 70s, raising a question about how much of this is just ascertainment, how much of what we have been talking about is ascertainment.

And then, I won't go into detail on the paper that Coleen is the first author on that was published in Pediatrics. Actually I'm not even sure this is out except online, Coleen, I think it's just been released online.

But we will have -- you are going to talk more about this later today and just to give you a quick preview for those of you who may be thinking about leaving early, notice that the numbers are really quite striking. This is again a very large sample looking at developmental disabilities in the United States across a decade looking at trends over time, and a really interesting observation that while some of the diagnostic categories go down, like intellectual disability, others, like autism, have gone up very very significantly and it's not the only one that has gone up but the only one that has gone up almost 300 percent.

So I won't steal your thunder Coleen, I'll let you talk more about this later, but a preview of coming attractions for later in the day.

How Can I Understand What is Happening, again it's not that often that a journal has a kind of overview of each of these -- each of our questions but Nature also did a very interesting essay on this as well because there have been so many papers that have come out in autism and looking at type of physiology and in this case this was a little essay that was published in Nature Genetics maybe a month ago suggesting that we now are beginning to look at converging models for the neurobiology of autism.

Really two major papers but there are several others that contribute to this concept, the first being that -- from Dan Geschwind and colleagues showing that when you look at RNA expression, because you remember DNA makes RNA makes protein, that's the basic pathway for cell biology, and if one looks at the way that the various species of RNA are arrayed in the brain, there are huge differences across different brain areas generally.

And this paper from Dan Geschwind, which looks in post-mortem tissue from autism subjects as well as from controls that are age-matched, shows that surprisingly, the differences that are normally found between frontal cortex and temporal cortex for instance, are not apparent.

There are 174 genes which were significantly different in the controls. None of them were different in expression in the subjects with autism.

So if you look at what that tells you, they seem to mostly come around what he calls two modules, one of which is suppressed, that is it's a module that has to do with synaptogenesis and neurite outgrowth.

And one of -- one module which seems to be actually overly activated, which is the module -- a module that's much more important for genes that have to do with immune activation and immunity within the brain.

So really interesting set of observations. It's not conclusive but it points us in some new directions, as does a second, very large scale study like this done by Huda Zoghbi's group at the University of Texas -- I'm sorry, University -- she's at Baylor.

And what Huda's group has done is a technique called yeast two-hybridization which is a kind of discovery tool, which is if you know that a particular entity's important, what is it connected to?

So we talk a lot about genes. The Geschwind paper has to do with RNA. This has to do with proteins, so this is the real, you know, the final deliverable of that, that pathway.

And she looks at the proteins that are the products of genes known to be associated with syndromic autism -- in this case she is using SHANK3 and I think the other one is PSD-95 -- and says what do they relate to?

And she pulls out some 350 other proteins that they seem to link to and oddly enough, this is what she calls an interactome, it's a whole network that seems to work together.

And there are other anchor proteins in this and one of them turns out to be tuberous sclerosis, the TSC1 gene which is the gene for tuberous sclerosis.

So it begins to tell us, in a really unbiased discovery way, that it's not an infinite set, that there you know is a fixed number, a few hundred proteins that seem to be really critical in leading to the pathways that are associated with autism in those children who have Fragile X or tuberous sclerosis or Rett syndrome which is what Dr. Zoghbi works on.

And it gives us -- it kind of

shines a light on where -- on new places that we ought to be looking, new proteins that could be of interest. Jim?

Dr. Battey: Yes. So does that suggest that the synapse is a sort of final common pathway for many of these developmental disorders of the brain?

Dr. Insel: Yes, I mean it does, but the synapse has about 1,300 proteins in it that we know about and this says that not -- maybe not all 1,300 are really important.

But she comes up -- she starts with about 26 and ends up with something like 539 that are really kind of critically involved and you can't see it all that well with the lights on, but that there are all those little green points of light that seem to be in this interactome.

This is an approach and it's a way of trying to look at function not simply looking at genetic variation. So having mentioned genetic variation, I think the --

get this -- the slides are not -- there.

This has been also a period when there's lots of discussion about this particular paper, which was the largest twin study ever published, and it involves looking at monozygotic and dizygotic twins.

This has been an area of some debate now in the community, so this is from Joachim Hallmayer at Stanford and Neil Risch who is at Kaiser and UCFF.

And the fundamental finding here is that, as we have known for some years, that monozygotic twins, who share 100 percent of their DNA, have a fairly high concordance: if one child has autism the other one does as well.

Dizygotic twins, who have 50 percent of their DNA, just like siblings, if one child has Autism Spectrum Disorder, 31 percent of the time, the other -- the brother -- well, this is male twins -- looking at a more tight definition of autism it goes down to 21 percent.

So it's much less than the monozygotic twins, so having 100 percent of your DNA really matters, but it's actually more than siblings, and that suggests that there's something about shared environment, particularly environment in the womb in this case, that might contribute more to concordance.

So lots of discussion about what this means, the way that the -- this is interpreted and I think Matt State will talk more about this in a few minutes, is that this group felt that it indicates that environmental factors may be even more important than genetic factors because of the effects here of shared environment relative to siblings in general population.

That comes out of the modeling they do which a lot of us don't quite understand, but Dr. State will speak to this in a few minutes and help us to understand how we might interpret these kinds of findings.

One of the environmental factors that has popped up, and it was in the same issue of the Archives of General Psychiatry, but got much less play in the news, in fact it was an adjacent paper, it comes from the group at Kaiser in northern California led by Lisa Croen, and suggests that antidepressant use may be one of the factors early in gestation that could be important.

And actually in this case, looking at this large birth cohort in the late '90s, 88,000 births, they discovered that those moms who had been on an SSRI during the first trimester had nearly a fourfold greater likelihood of having an offspring with autism, which is quite significant relative to other environmental factors that we have looked at.

So epidemiological needs replication, needs further research, but really intriguing as one of the factors that we should be thinking about, particularly because of the connection between SSRIs and serotonin and the evidence that from at least one of our ACE centers, that serotonin may be fundamental to the neurobiology of autism.

Just to go through a few more of these very quickly, I don't want to take the whole morning and you will have -- we will hear some of these in more detail later.

There's been at least one large meta-analysis of both prenatal and neonatal, perinatal risk factors for autism so it goes -- it doesn't mention the antidepressants, that wasn't actually in the literature.

But this was a very large-scale effort to sort of say what is out there. It might be a good thing for anybody who is going to be reviewing this area to look at this meta-analysis.

They looked at over 40 studies and these 60 different variables. I must say that there was nothing that comes up with an odds ratio of three, four, five or six. This is really -- these are very, very small effects.

But there were small, slight effects of low birth weight, respiratory distress, and children who had had a serious medical problem under one month of age, and also should mention that from the CHARGE study and the group at UC Davis, Irva Hertz-Picciotto has had a couple of interesting papers in the last couple of months, one on the importance of prenatal vitamins, that there's an effect there of Moms who didn't get prenatal vitamins having a somewhat higher likelihood of having a child with autism, and winter conception being slightly -- it's a very small effect but a statistically significant one, as has been reported in a few other disorders as well.

Huge amount -- Walter?

Dr. Koroshetz: Just to clarify the issue of the antidepressant use because in terms of the interpretation it could have repercussions.

So I guess the question is depression itself could have a significant effect on the fetus. So was it clear that it was antidepressant use, control for depression, which would be quite new.

Dr. Insel: They can't -- there's no way in that study to look at whether -- what's the effect of depression itself, and they can't tease apart the difference.

There's also a question about the use of antidepressants even before, so one year prior to pregnancy also increasing risk a bit.

So the mechanism is unclear, the effect itself, whether it's antidepressant, whether it's SSRIs, it's not clear that any particular one of the compounds has a bigger effect than others.

The sample, even with 88,000, it's still a very small sample. But the value of having a project like what you can do at Kaiser is you can -- all the records are there so you can begin to tease out these effects.

And remember, we have another project now with a very large HMO network, 17 million covered lives. So we will have a chance I think very quickly to be able to replicate and to look at this and to see whether it emerges in another set.

It would be fantastic of course to look at whether you can separate this out from the effects of -- there are lots of things that go with depression, from changes in diet, changes in activity level, a whole bunch of things that one might worry about.

And one could also ask what are the complications of having untreated depression, which we know is a really severe risk factor for lots of downstream effects.

So it's not as simple as saying stop the antidepressant use and you will lower your risk. You may increase your risk for other problems that we do know about. Jim?

Dr. Battey: I think this

underscores the importance of moving towards a universal electronic medical record so that we can get the sorts of numbers that will begin to reveal some of these realities, and I think the United States has been very, very slow to adopt that, and the epidemiological studies will be far more powerful when we have that in hand.

Dr. Insel: Yes, it's the other thing that we may be able to see in the Norwegian sample and the Danish sample which I know CDC has been working with. Coleen?

Dr. Boyle: Yes, we are actually looking at the SSRIs and other antidepressants in relationship -- in the SEED study so we should have hopefully really soon some information coming on that.

And just to mention, SSRIs are associated with a number of structural malformations and there's fairly good evidence now, so it would be interesting to sort of put the pieces of that puzzle together relative to, you know, whether or not they are indicated in autism and other neurodevelopmental disorders as well.

Dr. Insel: Yes, early days here but I think it's -- seeing this emerge in the, again, you know, it fits in with -- I see my role here as kind of the accountability agent. I wanted to make it clear that these are the very things that were in the strategic plan that I said needed to be nailed down, so we are beginning to see them emerge. It's kind of exciting.

There's a lot more here and I don't -- I think rather than taking the time from our speakers, let me whip through this very, very quickly, a series of papers in Neuron which you will hear about these because Matt State, who is the senior author of one of them, is going to be speaking in half an hour and will take us through much more of this.

This is all from the Simons Simplex Collection, it really deals with the most thorough study yet of copy number variation or structural variation in the genome, incredibly important and it goes back to Jim Battey's question about the implication of synaptic genes because that is what comes out of all of these really very rigorous, sophisticated projects.

Where Can I Turn For Services -- very quickly, there have been a couple of papers worth looking at and we can make sure you have access to all of these if you haven't seen them.

One is coming from this look at the unmet needs and suggests that importance of really focusing on specific needs of children with autism, which are somewhat different, particularly on the medical domain than other populations of developmental disabilities.

And I want to also highlight this paper which came in through public comment as well, from Cathy Rice and colleagues and

Coleen is on this as well, on looking from the National Survey of Children's Health, which suggests the importance of the medical care -- again it's an issue we have brought up in the revision this last year of this strategic plan.

But it points out that for children with autism relative to other developmental disabilities, one of the things that parents seem to be most concerned about is general healthcare and the importance of the Medical Home model for kids with autism. So another one worth factoring in as you look at the strategic plan.

What Does the Future Hold? A study -- one of the first studies actually of cognitive function in the elderly with autism. This is aged 69 on average and here showing that a somewhat different pattern of cognitive loss with aging with greater problems, with visual memory, and actually less problems with certain aspects of verbal memory, which is kind of intriguing.

And then a couple of issues around how services are provided. This report on sheltered workshops suggesting that they actually don't work as well as we might have thought for those with autism, at least they don't -- they don't enhance employment relative to what you see in other groups.

And the survey that has been done on kids on the spectrum in college and the kinds of health needs that they have which was published last month. So Ellen?

Ms. Blackwell: Just a quick comment on sheltered workshops. This is not a model that CMS supports for anyone with a developmental disability, so I'm not surprised. I haven't seen this paper but generally there are other new, much more progressive models for -- to help people with autism and other disabilities increase employment. So --

Dr. Insel: Yes, I think that was

really the point that these authors were trying to make, is that sounds good but it was yesterday's approach and -- Ari.

Mr. Ne'eman: I just wanted to add to that, actually in the next -- I think it's either next week or the week after that, the Senate HELP Committee is going to be marking up the Workforce Investment Act and there is an effort within that to very specifically address the issue that the sheltered workshop model is largely an obsolete one and there's a need to move towards creating an infrastructure for supporting individuals with disabilities in competitive integrated employment. So that's a broader trend I think we are seeing.

Dr. Insel: Great, well thanks for adding on to that and let me just finish up here in terms of the research update by our last item, which was added in one of the revisions of the strategic plan, about infrastructure and surveillance.

A lot is going on. I am just going to mention one, which is NDAR, just to give you a very quick update, we are up to 106,000 records, about 17,000 subjects who have data now that are populating this, and about 62,000 GUIDs at the last count.

So they are well on their way to the challenge of getting 90 percent of all research subjects onto NDAR and populating this by federating with IAN and many other sources including the Simons collection.

So we hope this will eventually be the one-stop shop for all things related to autism research. It's not there yet. It's going to be another year at least before much of the data populates those GUID records, but we are already beginning, and with 106,000 there is already something for people to begin to work with. So this is a work in progress but we are pretty excited about where it's going.

Let me just take -- oops, so there

should be another set here but it looks like -- okay we will do it later, okay.

So the last thing I'll say but this is again by way of a preview of coming attraction, we'll talk about it later, this afternoon, is to give you an update on where we are with the legislative process.

And again, for those of you who may not be around in the afternoon, it's the elephant in the room today, is whether this is our last meeting.

You I think all know that the IACC is chartered by the Combating Autism Act for 2006. That same act calls for the sunset of this committee on September 30th, 2011, which would make this our last meeting.

There is a motion under way in the House and there's a mark-up planned on August 3rd in the Senate to reauthorize the Combating Autism Act, but that hasn't happened and as all of you know, the events in Congress are not happening on the schedule that many people might have thought. There may be a last-minute effort to get this done before September 30th, but if not, this will be our last meeting.

So we will circle back to this this afternoon to talk further about what the options are, and what the consequences of this would be. There is other legislation in the hopper relevant to autism that I want you to know about, and we will do that after lunch.

So let me see if there are any other comments about the science and then we will move on to the first presentation from one of our outside experts. Geri?

Dr. Dawson: So I thought this would be a good opportunity, especially having just done this review of the science and kind of almost a look back in terms of where we have been and where we have come, and to just point out how successful the Combating Autism Act and its authorization of something like the IACC has been in terms of developing the strategic plan, in terms of focusing the ARRA funding on autism and a special RFA, and then you know, getting to see the science that is coming out of it.

So it's just, you know, let's all hope that the reauthorization does go through so that we can kind of keep up this momentum and you know, keep seeing the progress that we have seen so far, because we still have a long ways to go.

Dr. Insel: Yes, absolutely, and in trying to put this little presentation together, as I do every meeting, it gets more and more difficult every meeting to come up with a summary of what's been published in the last four months, because you can't do it, as you can tell, you can't do it in 20 minutes anymore.

There was a time that I could do it in five and that was in 2006, so in five years, we have just seen an explosion in research and an explosion in the number of people engaged in this area across the whole spectrum of all of those questions in the strategic plan.

And I must say there are a number of important papers which I didn't even mention. You will hear about one of them from Geri in a little while, on mortality, that was published in the last couple of months.

So this is just you know, a select sample. I guess if we are reauthorized and we keep meeting like this, and I keep doing these kinds of surveys, we are going to put an hour aside in the morning to cover just all the material that is coming out.

But I think it is useful for you to hear that there are some real outcomes. There's a lot of excitement. This field is moving very quickly. For a journal like Nature to have now these sort of summary editorials about findings, you don't see that in any area of cancer, heart disease, diabetes.

Autism is really becoming one of the most exciting areas in biomedical research and that doesn't mean that it's, you know, that there's a clear deliverable yet that is going to make a difference in the clinic, but we know what kind of impact that sort of excitement has had for heart disease and cancer, and there's every reason to think that this gives us real hope for coming up with new biomarkers, diagnostics, therapeutics, a whole range of opportunities for people with autism.

With that said, let's move into the first presentation, which again, we are already a little bit behind schedule. But I wanted to have Matt State join us to talk about autism genetics, because that has been one of the areas where there has been the most activity in the last year.

And I put up that slide with that range of papers that came out of Neuron in May. In one issue there were three real landmark papers. Matt was the senior author on one of them.

Dr. State is the Donald J. Cohen

Associate Professor in the Child Study Center and Associate Professor of Psychiatry and Genetics, and co-director of the Yale Program on Neurogenetics, a Deputy Chairman for Research in the Department of Psychiatry at Yale, but is probably most well-known to us because he served on the expert panel that helped us with the autism strategic plan back in 2008. So welcome back Matt.

Dr. State: Thank you so much for having me. I want to thank the committee for inviting me back and I am really delighted to be able to try to do the seemingly impossible, which is to try to give you an overview of genetics now in 20 minutes.

I think it's a perfect segue, you know, I think Tom you are going to need a couple of hours, not an hour, I mean even just trying to stick close to gene discovery efforts in autism, it's a daunting task.

So I want to start with the caveat that I am not going to be able to do justice to all the recent work that has been done, certainly not since the last meeting that I was present at, but probably not even for the last four or five months in autism, which is clearly great news.

What I do want to do today is really try to give you a 30,000-foot overview of where we are in genetics and where I think we are pretty clearly headed.

And I am going to do that by first addressing the sort of fundamental question why genetics. I think it's worthwhile to revisit the issue of what's the value of ongoing efforts in gene discovery in autism; then to address I think a really important question, why has it been so hard to find genes involved in autism spectrum disorders, although also really to highlight the fact that quickly this is going to be a section of my talk I think which is going to disappear -- the pace of research in gene discovery and our ability to do this reliably is really being currently fundamentally transformed and I'll talk to you about why that is taking place.

By the way that is not just for autism. That's across I think all of medicine at this point.

So then I will give a quick overview of some of the recent data, trying to distill a couple of key points from the most recent literature and then have that drive a discussion about where I think we are headed.

So in terms of that first question, why genetics, you get five geneticists they might give you five different answers.

But really what I wanted to stress is that I think when you look at the value of genetic inquiry across all of medicine, contemporary medicine, that this first point I think really stands out, that the value of genetics has been as an entre into biology, that it's been the illumination at the level of the molecule and the cell, of pathogenetic mechanisms that's really led to the most dramatic advances across all of medicine.

And when we look at what has happened in terms of our understanding of the pathophysiology of Alzheimer's disease, where that's now headed in terms of therapeutics, the development of statins for hypercholesterolemia, a rare genetic finding, one in a million family, cancer, hypertension -- these really have been fundamentally altered because we now have begun to understand what is going on as I say at the molecular and cellular level.

And I do want to point out that this is already, you can see how this is beginning to transform our understanding of neurodevelopmental disorders.

I think it's hard for us to remember sometimes, you know, history is moving so fast, but 10 years ago, these were considered static encephalopathies. These were set in stone. They came out, whatever the problem was, was the problem, and the notion of thinking about targeted treatments for these disorders was not really in the discussion and gene discovery leading to an elaboration of molecular mechanisms has fundamentally transformed our understanding of these conditions, from static processes to clearly dynamic ones that involve synaptic plasticity.

It doesn't mean that we know how to treat yet. What it does do is give us possibilities to think about intervention that would have been impossible given the old model.

So there are a variety of other things, clearly, that genetics can do. It can help identify population risks, it can be important for clinical diagnosis, early intervention.

Increasingly, as more and more of the genetic substrate is understood, being able to tailor treatments and think about personalized medicine becomes important.

And then I'm going to come back to this point, because really, fundamentally, gene discovery plays a very role in allowing us to begin to dissect the complex interaction of genes and environment.

So clearly because of what has gone on in the last few weeks in terms of the discussion about this issue, the heritability of autism spectrum disorders, I wanted to take a minute to just mention the study by Hallmayer and Neil Risch at Stanford, and to try to place this notion of heritability in context and what it means for us in autism.

So the first thing I want to remind people about is that heritability is the proportion of variance of a phenotype or disorder that is explained by genetic variation.

And the important thing here is that what we're not -- it's not a measure of how many people in a population have a disorder based on that thing. So if you say something is 80 percent heritable it doesn't mean that 80 percent of people have a genetic factor and 20 percent of people do not.

It means that when you look at the entire population and you look at a variety of factors that contribute in that population, you can parse out or try to parse out using twin studies the overall proportion.

What that requires is mathematical modeling and what it requires is kind of taking everyone with a condition or disorder that you are interested in, and sort of putting them all together and homogenizing that and I'm going to talk about why that has an important impact on our understanding of this finding for autism.

So the other thing I want to point out is that heritability is not inheritance. They are just two slightly different concepts.

Inheritance refers to the transmission of genetic information from generation to generation, and heritability is just concerning a population about how much of the overall risk can be accounted for, the variance in that risk by genetic factors.

So that means that things like new mutations, de novo mutations, which turn out to be an important contributor to a subset of individuals with autism, contribute to this idea of heritability but genetic does not necessarily mean transmitted from one generation to another.

All right. So the context for this most recent study, the Hallmayer study, is really there have been about 30 studies overall that have looked at some aspect of the autism phenotype and heritability using twins, but eight of them have really focused on clinical diagnoses since 1977.

And prior to the most recent study, not everyone attempted to look at the heritability or to model this mathematically, and just look to see whether monozygotic twins were more likely than dizygotic twins to share diagnosis.

But the estimates came out at about .73 to .93, about 70 to 90 percent of the variance within the population etcetera.

So the Hallmayer study was notable in part because of the eight, it showed the lowest overall heritability, around .4 or so.

One of the things I want to point out is that this is an estimate in a population and that they, you know, were clear that there was a wide range of potential estimates from their data, from less than 10 percent to 84 percent so kind of square in the old range.

But they did come up with their best guess or I shouldn't say guess, their best estimate was about 40 percent. Okay.

So the first thing that I want to say is that every study has its strengths and weaknesses and they are a very strong group at Stanford and they did things that other studies had not been able to do.

They had a relatively large sample, certainly large for twin studies, not large for gene discovery but large for twin studies, 202 pairs. They used careful direct clinical diagnosis. Those are two very important things.

But like every study, there are weaknesses in studies and one of them I think that a lot of folks within the field sort of focused on is that in looking at a population and trying to this mathematical modeling and estimates, you really want to get as close as possible to ascertaining the full population.

And there were about 1,156 twins that were -- could have been included in their study, through no fault of their own, I mean they worked very hard. But they were able to ascertain about 17 percent of the available sample.

And all that that means is that when you are making an estimate, when you are sampling from a population, you have to be concerned that a low response rate reflects that there are certain people with certain characteristics are more likely to participate in the study than other folks.

We don't know exactly how that plays out but I just want to point out that it can have an impact on what these estimates are. And ultimately the major differences between what we see here and what we are seeing previously really come down to the second point.

So previous studies had shown a very slightly higher rate of concordance for identical twins but really no fundamental difference.

The difference really rested in one calculation, which is the degree to which dizygotic twins shared risk. That was higher than previously estimated and that led to in the end their mathematical modeling, this different conclusion.

But I think it's really important to point out that this is, as I said, one of eight studies, gives you a broad range and there certainly is a possibility that despite being as careful as they could, that there was -- that the ascertainment in their study may have slightly driven up the rates of dizygotic concordance which would have an impact on their estimate.

But I do that just to give you a sense that whenever a new study comes out, there's a tendency to sort of jump on the study and say this is a game-changer. But I think it's also important to point out that this does fit into a body of literature.

But what I want to say is that they -- you know, so now there's a range, goes from .4 to .9 and if -- what I wanted to do was sort of do the thought experiment and say well if their estimates of heritability turn out to be replicable over time, what does that mean for us in autism spectrum disorders? Does it give us an idea that we should be studying one thing versus the other? And I think it's very important to talk about really a false dichotomy between genes and environment.

Now fortunately this is not one to which the IACC ascribes, when you look at the strategic plan, their gene environment, looking for biomarkers and thinking hard about what scientific foundation will be necessary for gene environment studies.

But I think beyond that, it's really important to point out that it's very difficult to think of any common medical condition in which there is not an important interplay of genes and environment.

And to place these recent findings in context, the heritability of high blood pressure is almost exactly what it is, that the lowest estimate of heritability in autism now is, and breast cancer less than that.

And I think that there's just no question that genetic studies in these disorders have played a fundamental role in moving the field forward and answering very important questions.

And along those lines I think that what we really need to keep in mind is that there are different types of knowledge, all of which can be fundamentally important to help children, families, adults with autism, that genetic studies, gene discovery and environmental studies are complementary and have a tendency to give different types of insights into important problems.

So genetic studies typically offer a more direct path to elaborating molecular and cellular mechanisms. It's not always the case, but most of the time you are already at the level of the molecule and then can interpret the results in a way that allow you to begin to understand mechanisms, think about treatment targets, and to give you an ability to study more complex processes that involve genes, like gene expression or epigenetics.

Now environmental studies clearly have the possibility, and a very important possibility of identifying modifiable risks, and it will always be easier to modify the environment than it is going to be to modify the genetic substrate.

But the issue is is that the two together are really what the field needs to address in order to answer what are the really important emerging questions now about the nature of risk, which we are getting at clearly in recent studies of gene discovery, about how trajectories differ for different individuals and why, and then how intervention plays out.

All right. So I want to move on to talk about -- it's couched in why has it been so hard, but I think the major take-home point is why that's fundamentally changing.

So there are three issues that are clearly important and again this is not just for ASD, but for really every common medical condition.

We know now that it's highly genetically and phenotypically heterogeneous. Until very recently we all, in human genetics, had a very limited ability to actually search through the material that we were most interested in, and we know that this is not a simple problem.

As for most common disorders it is not a single gene. It is not a one to one relationship between genetic risk and outcome.

So to give you sort of more of a conceptual feel about what those three things mean -- I am going to apologize for my failings as an artist here and just point out that my circles here are to represent individuals -- but to give you an idea about what this kind of conceptual underpinning is of gene discovery efforts.

So essentially it's really pattern matching, when you cut through kind of all the genetic jargon, what we are trying to do is to identify a group of affected individuals to design a study that differentiates them from individuals who are not affected and then to sift through their genetic material in order to find the thing that makes this a coherent group, okay?

Now if this is what obtained in autism or other common conditions we would be done with gene discovery. The technology is there already. It's been there for quite a long time.

And in part because we don't have that answer, there are a variety of other lines of evidence, but it's clear -- again I'm sorry that I'm not able to do this in a more kind of nuanced way -- it's clear that this is what's going on at the level of genetics. No matter how we define our study group based on the diagnosis of autism or research criteria etcetera, we end up with the genetically heterogeneous group.

And then when you ask the

fundamental question we are asking, what makes these individuals similar at the genetic level and differentiates from this group, the answer is there is no one thing, and that's what geneticists have been dealing with over the last 10 to 15 years, now, once we understood that this was the issue.

So I want to point out that this, you know, the current model is clear that there will be people who have genetic risks absolutely who will not develop the disorder, which is quite important, and that there will be people who likely have no identifiable risk, who will end up in this group, okay?

So that's taken as a given. So the issue is, confronting this, how have we been able to deal with it, and I'm just going to highlight three conceptual approaches, the first which I think has been tremendously important, is it became clear that if you could drive up the number of individuals that you could have in studies, that your ability then to beget some meaningful information, to separate signal from noise, would help.

And this has been, you know, the fundamental contribution of parent advocacy groups, AGRE, the NIH repository, a culture of now data sharing and sample sharing in the autism community has been fundamentally important in moving in this direction, and it's turned out that it's been extremely valuable and I'll get to some recent studies I think that demonstrate clearly that larger numbers are very helpful in answering the question given the heterogeneity of autism.

There are very important approaches that look to try to draw better circles using endophenotypes. I'm not going to spend time addressing them but just wanted to point out that that's another valuable approach.

And a third that my lab has been particularly interested in has been to look for rare mutations. This is not to try to explain necessarily something common about a substantial subgroup, but to find one thing or a small number of things that go back to the first point that I made, that give you particular traction in understanding molecular and cellular mechanisms, so that you can then begin to be able to find common neurobiology that can inform what we are doing.

Now, two final points. One is that -- you know this is going back to the Risch/Hallmayer paper -- the first thing is that remember that what Risch and Hallmayer were doing is taking essentially this circle and trying to give you a summary statement about the contribution of, you know, to genetic variance, of everyone in that circle, and then there are just fundamental limitations to doing that in a highly heterogeneous disorder.

The second is is that putting more people in this who may have no genetic risk, doesn't fundamentally alter the conceptual approaches that we are taking, that it is the same process and the same answers obtained, rare examples, larger samples, doing a better job of finding homogeneous phenotypes.

I think it does suggest an important future direction that the IACC has already anticipated, which is to think about looking at gene environment interaction by getting rid of the clinical part of this, the idea that you could take the entire population, for instance the Korean population, Young-Shin Kim's at Yale, and we are working in collaboration now to move away from clinically defined samples, to looking at an entire population of individuals and asking about genetic risks in an epidemiological sample.

One minute on genetic variation. The only thing I want to point out is that sometimes when people think about gene discovery, it's hard to remember that what we are really talking about is genetic variation.

There's not a new gene in the genome. We are looking at how the sequence or structure of DNA varies.

I also always love pointing out that we are 99 percent identical at the level of our genome, everyone in the room. Fortunately for geneticists who are interested in gene discovery only about one percent of the genome varies and that's what we are interested in, because in the variation is what's going to tell us something about the molecular mechanisms of risk.

The only other thing I want to point out because of the -- just to make sure that the jargon doesn't get in the way, is that this genetic variation can be at the level of the individual constituents of DNA, called base pairs, or it can be in larger chunks.

And when it's in a larger chunk that's gained or lost it's called a Copy Number Variation, and just like the other types of changes, these are a normal part of the human genome, everyone has losses and gains, everyone has changes in individual base pairs that differentiate us from the person sitting next to us, about one percent of our genome.

Some of those play a role in disease risk and finding out which ones is obviously what we are most interested in.

What has been critical in addition to these conceptual advances and the increasing sample size and sophistication, statistical sophistication of the approaches to thinking about discovery, has been really a technological revolution starting at about 2001 and now really ramping up.

The first was microarrays. When I started working on autism genetics in 1997, it was typical for us to get about 150 to 400 data points per person in an effort to find genetic variation that's relevant.

There are three billion bits of

information in the human genome, so picking out 150 to look at was a limited strategy. The first thing that happened is microarrays came along that now allow us to look at several million spots in the genome simultaneously in every individual and give us information not just about individual bases but also about these chunks of DNA that may be lost or gained, deletions or duplications, again, in everyone's genome, but we are interested in whether certain ones of them are involved in disease risk.

This is the thing that now is really moving so quickly but will clearly transform the field. This is the cost of sequencing a million bits of DNA in an individual, okay?

So when I started in this game $100,000 to get a million bits of the three billion in each individual person, impossible to think about getting the full data set on an individual in 1997.

It's now seven cents for the same amount of information and what that means is that for $4,000 per individual, we can get the entire genetic code for each individual person.

This is still a little bit high unfortunately, but what this shows is that with the pace of decline, which is actually faster than computers, so faster than Moore's Law, this will be getting a chem panel when you walk in to see a patient in a hospital. The cost will drop so much that it will stop becoming a major question about whether or not the full genetic code of individuals will be available to look for disease risk.

All right. So, based on this vastly increasing ability to get genetic information out of the genome, and a better understanding of the kinds of strategies that we will need in order to find genes, I'll give you a quick summary of where we are.

One, we know now that individually

rare mutations contribute to autism risk. This is not a hypothesis any longer. There are replicated, multiply replicated findings that rare variations contribute to ASD.

There is an open question about the role of common variants in autism spectrum disorders because there's not been a clearly replicable common variant yet.

But I think that this really suggests more about where we are in the clear trajectory of the development of technology and methods.

When you look at what is happening in schizophrenia and in other common medical conditions I think it's a very safe bet that with larger samples, in order to help address this issue of heterogeneity, that we will begin to confirm and find alleles of small effect.

Now, I think one thing that is very important to point out is that I think there's been some dismay about this idea, about rare mutations, I think because that when people hear about that they think oh well, if it's a different mutation in everyone, what does that mean for our ability to do anything about it? Are we going to have to -- if there are 1,000 different genes contributing to autism, do we need to have 1,000 different treatments?

And the fact is is that so far, as Dr. Insel pointed out at the beginning of the talk, it is becoming increasingly clear, from a whole variety of studies, from gene discovery to RNA to proteins, that mutations are not -- it's not a random set.

And if you look both at syndromic and idiopathic autism, the first place that they point us, it will probably not be the only place, but the first place that they pointed us is to the synapse.

And you know, I think again, being in this since 1997, when we had absolutely no idea what to say about the molecular mechanisms underlying autism, I have to tell you, I always -- I was so jealous in other areas of medicine, when they were able to stand up and give you a pathway, say this is what we understand about the molecular mechanisms of cardiovascular disease or -- and so this is really such an outline because there's 1,000 proteins here and we need to understand really exactly what the connections are.

But you really can't underestimate the importance of now knowing that there are particular molecules that bind with each other, that live in a particular type of synapse, in a particular region of that synapse, to help us begin to think about how we are going to understand the pathophysiology of ASD.

So we know that rare mutations are important. It's very likely that common mutations are important as well. I realize now that given the time, that going through all of the CNV data is not going to work. Obviously this is near and dear to my heart. It was our paper and that -- one of the recent ones, that was the largest study so far.

But I'll just give you a couple of highlights. Dr. Insel has already pointed out now that we know with, I think with -- that the range of de novo, large de novo, new mutation CNVs in simplex autisms of between six and 10 percent, now there are six, seven, eight studies that show that that is the case.

There are particular risks for these when they are large and when you look at the overall risk for that, it is very significant.

So you know, we saw that a large environmental risk, an odds ratio of 3 for common variance, and they can be very important, the effect sizes may be 10 or 15 percent, I'm talking about a six-fold, essentially, increase in risk for carrying a large de novo CNV.

We -- one of the things that was important about having a study that was as big as our study -- we had about 1,000 families -- is that we were able to begin to ask the questions we really want to ask: what's genotype-phenotype relationship once you know what a genetic risk is. We can clearly identify that the risk factors were not a risk for idiopathic intellectual disability as some people have guessed CNVs might be, but that they were risks, bonafide, for autism spectrum disorders; and we got very strong evidence from both papers that girls are protected against these risks.

Now, I think, you know, that probably doesn't come as a surprise to anyone in the room, that there's some -- a lot of thinking about the possibility of protection.

But to bring that, again, to a molecular level, where we can begin to ask questions about why this particular CNV has greater expression in males versus females, is going to be very important for the field.

In terms of -- this slide I'm not going to through the data, I just -- Stephan Sanders led this analysis. You saw that cast of thousands but he's a brilliant post-doc who was able to manage huge amounts of data to do this.

And I just wanted to point out that the study design was -- allowed us to look at affected siblings versus unaffected siblings which gave us a very nice comparison group.

I won't belabor the specific regions. I do want to tell you that we were able to strongly replicate a previous finding that's present in about one percent of cases of autism. I think there was some uncertainty about this. I think after this study, there are enough convincing replications that I think there's no question this is a risk for autism spectrum disorders, both deletions and duplications, at this region of chromosome 16.

One of the new things we found was that a region that causes Williams syndrome when it's lost, increases risk for autism when there's excess material there.

And again, what that's telling us is within a very small section of the genome -- there are about 22 genes in that region -- there's something in there that has a profound influence on modulating social behavior, and the next step for us is to begin to understand what that is.

I have a list of other regions that have very strong evidence across multiple studies now, and I have included little stars. I'll explain them to you in a second.

Overall we were able to estimate, we had two different, independent estimates. Both converged. This is just for de novo CNVs. We estimate, both papers, around 300 separate regions of the genome that are carrying risk for this type of variation, not for other types of variation.

And these stars suggest that these are also regions that have been identified in schizophrenia, or other developmental disorders which I'll come back to in a second.

Again, I really want to stress this point, that these individually rare mutations does not mean now that we need to be thinking about 300 different treatments.

What they give us an opportunity to do is to begin to fill in the dots, at the synapse, because as Dr. Insel pointed out, another companion paper began to do that, to see that this is not chaos, that there's a coherence to it at the level of neurobiology.

I think what this suggests, and this is really the big question, how do you go from multiple variations to multiple disorders and what does that mean for where we are headed in disease studies?

So, this is just one idea about how this is likely to play out, but here, the notion, as I have already pointed out, is there can be multiple mutations in the genome losses or gains or individual point mutations. Again this is just to reflect that they began to result in coherence at the molecular level. It does not mean that everything lives at the synapse but a lot so far has.

But then the question that we really need to answer, and that this lays the foundation for, is what happens? How does it go from here over to here, where some people will have the genetic variation, be unaffected, some people will have the genetic variation and have autism spectrum disorders, others might have schizophrenia.

This is the challenge for the field, to understand how this takes place, and it will clearly be a combination of initial insults or initial vulnerability and common genetic variation, epigenetic stochastic events and environment.

And so thinking about how we study these interactions is critically important. It also means that knowing what these are specifically as opposed to generically is going to be tremendously important and we are making good progress on that point.

So, what's next? The first thing I want to say is that replication may not be as exciting as coming up with the next big thing, but it's a huge milestone for our field.

So again, in the late '90s, no two laboratories doing anything in psychiatric genetics could come to the same answer about any variation.

To have six or seven studies now coalescing on a given answer that gives us bedrock, even if it's an eight to 10 percent of the sample, is a major milestone and it's one that the IACC, parent advocacy groups and researchers I think can really be proud of together.

I mean, it goes back to that issue about how do you get from knowing that something is heterogeneous to now being able to say we know, 16p11 is a genetic risk for autism in one percent of cases.

Common variants still I think are something the can provide us important information about risk course and particularly about gene environment interactions, and this leads to a second false dichotomy in the field: we are wasting time talking about common versus rare, just as we are talking, I think, about genes versus environment. We need to understand all of it.

There's still much more to discover I think in rare CNVs. I have already pointed out that the move now is to be able to rest on this bedrock, to begin to look not only at molecular mechanisms, but at genetic epidemiology, to look at gene-environment interactions in an informed way and next generation sequencing is going to transform our ability to do that.

We now have the ability, which we would not have before, to begin to think about prospective cohort designs based on genetically homogeneous or similar samples.

Why do kids -- we can take a group of kids, say with 16p11, and begin to ask very specific questions about things like environmental exposures.

How -- what -- is there a neuroimaging signature of the child with the 16p11 duplication who is affected versus not affected?

We are going to need to tackle multiple variations contributing simultaneously and it's going to be tough, but we have already taken I think the first step in doing that.

And I think there are a number of other challenges to combine the genetic information with other sorts of information, again, epigenetics and neuroimaging etcetera.

Where I want to end up though is sort of back where I started, which is that we -- this really is an extraordinary time. It's been a long haul but we finally have the tools in hand and the methods to attack the key, underlying problems to gene discovery.

This is not the total answer to autism. Far from it. But to the extent that it gives us those clues on molecular mechanisms play a key role in moving the field forward.

We know how to approach heterogeneity. We now have the ability to look at the entire data set. We understand that there's not a one to one relationship and have now worked out studies that can reproducibly and reliably agree, over time, at different institutions and come up with the same answer.

So while the pace is slower as a clinician, than I would like -- certainly I know that anyone in this room would like things to be faster -- but the progress, there's no question, has been substantial, and the pace is accelerating extremely rapidly in the directions that I have pointed out. So thank you very much.

Dr. Insel: Thanks Matt. I know we are a little behind schedule but I want to take five minutes for questions and comments. We'll go around this way. Jim?

Dr. Battey: Would you care to speculate how it's possible that females are protected against copy number variants and males are not?

Dr. State: So, no. And one of the things that I want to say is that it's great that I don't feel like I have to, because as opposed to simply saying well, generically I think this is the case, we now have specific risk factors, so we can go back and ask that question and begin to try to figure it out, the level of gene expression, protein, etcetera.

So, I mean I think it's very exciting. If we understand that, we will be miles down the road, and we have some traction in beginning to address that question.

Dr. Battey: It seems to me like

it either has to be something where the difference is two copies on an X loci -

Dr. State: Yes.

Dr. Battey: or -- although there are very few genes on the Y chromosome -- something on the Y chromosome.

Dr. State: Well, so, actually, what I want to do is I want to take you back to something, because I am not sure that that's the case.

So the first thing I want to say is that the notion that anything on the sex chromosomes has been ruled out, I think, is a bit premature.

We are not finding a tremendous amount there but it's not impossible that there would be something. But the signal is definitely not strong, and it's not strong enough to answer the question that you are raising.

But there's a ton that goes on between really the simplest level of organization. There are three billion bits of DNA. It's a finite set. That's 10 to the 6th. There are 10 to the 14 -- what is that, eight orders of magnitude more connections in the human brain than there are positions in the human genome.

There's a tremendous amount of complexity going from here to here to here and there are lots of things that influence that. Genetics influences that. Hormonal environment influences that. Other kinds of environmental things will influence that brain development.

And so my guess is -- and now you've got me because I am going to speculate -- but my guess is that it's not going to reside simply in the genetics, that it's going to reside in sort of how the entire system is put together and how that creates protective factors.

Dr. Insel: Yvette.

Dr. Janvier: I just have a few questions sort of together in one. I mean I --

over the past few years I have seen and heard a number of presentations on these copy number variants -

Dr. State: Yes.

Dr. Janvier: and I always, as a clinician, I sit there and wonder, why now, where are they coming from, what is the cause of this?

One of the thoughts -- I have been working with Dr. Arnold Levine on a study looking at multiplex families --

Dr. State: Yes, I know.

Dr. Janvier: and he has done work on the p53 gene and I heard him talk about that being the quality control gene and you know, it not allowing implantation of the fertilized egg and you know, is it reproductive technology that is coming into play here.

You know, certainly I see many older parents, that's in the literature, is that part of the factor here?

And you know, another question is you know, what is the incidence of these increase in copy number variants in the general population? I don't know that we know that. I mean I don't think we are seeing a rise in schizophrenia as we are seeing in autism. I could be wrong. It's not my field. So I think that covers it.

Dr. State: Great, those are -- I wish that I had included all of that in my slide presentation. Okay. So, the -- the first answer is that what you said about the overall rate of Copy Number Variation in the population remains an important question.

It goes back to what I said about study designs. We have studied clinical samples. You ascertain people because they have a particular characteristic. You look through their genome and you find a quote unquote increased rate of things.

We know that Copy Number Variation is a normal part of human genetic variation.

You have them. I have them. Everyone in the room does.

There is a fundamental question we need to answer: is the rate of Copy Number Variation increasing? Is that related to changes in prevalence?

Or is it that by doing clinically ascertained samples that we are just simply going out into the population and finding the people who have the CNVs that landed in the spot that was most vulnerable? It doesn't give you disease but it certainly increases your vulnerability. So that question needs to be answered.

It does -- I mean again, I think it gets back to why gene environment questions are so important. The issue here is that once we know, which we do with certainty, that Copy Number variation plays a role, again we can -- you know, that these are now, instead of you know, kind of theoretical questions, practical questions.

So you can take an epidemiologically-based sample, look at the distribution of traits within that population, begin to ask whether or not they are just -- the CNVs are in a different place but overall the same number, or whether or not it looks like there might be an increase in vulnerability.

Our data so far suggests that it's where, not whether, that when we take a look, about one to two percent of other -- you know controlled populations have this, we did not see an increased rate of the de novo CNVs themselves in older parents. But the sample was not designed to be able to do that.

But these are all questions that we can now I think go back and begin to answer, and we will learn a lot about the interaction of genes and environment I think.

Dr. Insel: Last question. Marjorie.

Dr. Solomon: Thank you for a

great presentation. As I watch presentations, I think as a field we tend to be kind of a silo, and in looking at your slide that's right up there now, I see that you are looking across the disorder schizophrenia, and I was wondering if you had any thoughts or comments on how we, as a field, might be able to work across multiple disorders to help disentangle what's autism and what's not?

Dr. State: Another fantastic question. I think there are -- so this is something that actually is conceptually quite challenging, this notion that -- of -- really a challenge to phenotypic specificity.

I mean there has been such work in autism to be able to define phenotypes that are reliable, and the fact is they are, you know, a child with autism is not a child with schizophrenia. That's not the issue.

But then when we begin to look at the genetic substrate and find that there's a convergence there, it really -- we are going to have to really think hard about what impact that has for psychiatric diagnosis, and for studies.

I think the simple answer is that we need to be talking to each other. That's already happening. There's a Psychiatric Genetics Consortium that NIMH and other NIH institutes I believe are supporting, and that's explicitly asking the question, you take your large schizophrenia samples out there and there are thankfully very large samples out there available, and the autism samples, and begin to say okay, we are going to take a new look at this and ask, without preexisting you know kind of conditions on this, what does it look like if you take those things and put them together?

It's challenging from a statistical standpoint, to not, you know, overwhelm yourself with an unlimited number of possibilities, but I think that that's where the field is headed.

We are going to -- so the two answers are, at the level of kind of the current studies, we can rely on other collaborators in other fields.

I think in terms of where the field is headed is that to be able to study prospectively, once we identify a genetically relatively homogeneous group, whether it's CNV 16p11, a common variant that we find, that that too will allow us to, if we can identify that early, then we can begin to ask questions, as I say, like why does one head in one direction and one the other.

So prospective studies and then from a clinical standpoint, cooperation which is already beginning to take place.

Dr. Insel: We are way past time.

Dr. State: I'm sorry.

Dr. Insel: This is a great presentation and I know there's still some questions. Matt, can you stay around for a little while so people can catch you hereafter at lunch or something like that?

Dr. State: Yes.

Dr. Insel: Great. Sorry Linda, Walter and many others who had their hands up. I know there's a lot more to discuss here but we are about 20 minutes behind and I want to try to catch up some time.

It's a pleasure to introduce the next speaker. Actually this is thematically I think right in line with what we have been talking about, which is how you make the jump from biology to therapeutics.

Randy Carpenter is President and Chief Executive Officer at Seaside Therapeutics. He has had a very rich scientific and medical background as a physician who has cycled through many different aspects of healthcare, and for the last few years has been the person really leading the charge on coming up with new interventions, initially for Fragile X and now for -- potentially for autism.

Randy, great to have you here.

Dr. Carpenter: Thank you Tom, and it's a real pleasure for me to be here. I want to thank everyone for their attention, and obviously I co-founded Seaside Therapeutics, I work in this company, we are developing novel therapeutics for autism.

But also, the other part of full disclosure is my -- I have a sister who is three years younger than me who has an intellectual disability.

She requires -- she's relatively high-functioning but she requires constant care and she cannot live independently.

So when I -- I know there's different -- people have different ideas about what we are talking about when we talk about developing new therapeutics. I'm talking about developing new therapeutics that can help these individuals learn better, help their brain learn better from experience so that they can be more functional.

Because if my sister could add and if she could read, she could potentially live independently. But she doesn't have the ability to do that, and so when we talk about therapeutics, it's all about helping the brain learn better so that people can develop the skills to live independently in life, and I think that that's really what our -- when I talk about treatment that's what I am talking about. So I just wanted to make that clear.

Also, Mark Bear and I started working on this, in this area 10 years ago. Six years ago we started Seaside Therapeutics.

You haven't heard much about us up until the last couple of years and that was purposeful. We didn't feel it was fair to parents, to families, to raise hopes about novel therapeutics before we actually had some inclination and some ideas that our drugs were actually working.

Now that we are actually doing trials in autism, people with autism spectrum disorders and people with Fragile X, we need to have a little bit higher profile so people know who we are, they want to be in our studies, so that pharmaceutical partners may eventually partner with us and think about this area and invest in this area, and so that we can actually raise money going forward, because we have had the great fortune and the privilege of being funded by a family that's largely interested in developing new treatments up until recently, and now we are out in the large parts of doing Phase 3 clinical trials where we really need to raise a large amount of money.

And so these are all the reasons that we are raising our profile right now and I want to be right up front about that, that we are committed to this area, we were founded to develop treatments for this area.

And I don't really need to tell this audience that this is a huge, unmet medical need. You know, a lot of people had been quoting the CDC number as a prevalence number, but it actually looks like that's more of a diagnosis rate, diagnosis in a chart, and the prevalence may be much higher.

And there's no question that if you need lifetime care and you are not able to work, you need support, that there's a tremendous cost associated with this too, not just to the individual and their family, but to society as a whole.

We have heard, you know, my talk couldn't be set up better by Tom and Matthew for this, and I really don't want to go over this in any detail because we heard about it: it's that this is a daunting task. It's complex and it's very heterogeneous, and you know, it's a spectrum disorder, and we all are aware of that, that there's broad variations in manifestation, severity, comorbidity.

And still, to date, for the vast majority of cases, we really do not know what causes it. It may be more than one cause.

There's a strong genetic basis but it's complicated, and then we have the contribution of environmental factors, which we know are there, but are again hard to quantify and it makes scientific analysis very challenging.

But I'm here to tell you today that this is a time for real optimism, and I think that progress will soon be realized.

First, as you heard, there are a number of genes that have been identified that are highly, in the terms of geneticists, highly penetrant: if you have this mutation, you have a much, much greater risk of having autism.

And we have identified a number of those genes, as you saw. They have been reproduced in animal models, so the same sort of genetic mutation, and it allows you then to understand you know, if you have a mutation, you don't make an effective protein, how does that interfere with how the brain learns from experience?

This is, as you have heard, and I was going to try to make this point but I don't have to, that a lot of this evidence, whether it's from the bottom up, with syndromic single gene mutations, or the top down, from broad screens of the genetics of autism, has focused on synaptic functions.

So how do the nerves communicate to each other over these trillions of synapses in the brain, the connections we term neurons which allow us to learn from experience?

And as we understand how these mutations lead to impairments, so the ability of the brain to learn from experience, we have identified novel therapeutics and these have shown promising preliminary results in human trials.

So I think this is very, very encouraging, and as we go on to the second one, you also heard today about how we can now start to diagnosis earlier and I think everyone in this room believes if you can diagnose earlier and treat earlier, and get the brain tuned so it can learn from experience better, that you will have a bigger effect, the younger you start.

And finally, I think even more importantly, and hope for me even with my sister, is that treatments, these are not static, that treatments that are introduced in adult animals and in, hopefully in adult humans, will still provide significant benefit, so that this is something that, still, there's tremendous ability of the brain to learn. We are all learning today. We are all adults. We could learn a new language if we had to. We may not have a perfect accent. But we could do that and we could function.

So there's tremendous ability of the brain to change even in adulthood and I think that's very encouraging.

So you know, the model that we have is you start out with a human, identify the gene, animal model, understand when that mutation is present, how does that interfere with how the brain learns from experience, everything that brain learns: how to see; how to talk; how to do mathematics; how to read.

And then identify potentially treatable targets and then take these targets into humans and see if they can provide benefit.

Now we -- this is an article from my co-founder Mark Bear, and I am going to credit him as the scientific genius behind our company. I have been working with him for 10 years and this is a publication from about three years ago, where they raise the question, you know, is this a synaptic problem and a synaptic problem related to protein synthesis?

And they actually identified these highly penetrant single gene mutations: Fragile X; tuberous sclerosis; PTEN; neurofibromatosis; Rett; all the ones that we have been talking about here today, and of course we started with the most common one.

So if you have this mutation and you are a male, 15 to 30 percent of the people will have -- meet the full diagnostic criteria for autism, but the vast majority will be on the spectrum somewhere.

So it doesn't matter whether you are vaccinated. It doesn't matter what diet you are on. It doesn't matter how good your parents are. If you have this mutation you are going to have an impairment.

And so this is a, I think, a really strong way to take a scientific approach to try to understand what is the role of that protein.

And just a couple of facts for those of you that aren't as aware of Fragile X. It's the most common known genetic cause of autism and it's the most common inherited cause of intellectual disability.

And it's a single mutation in a

single gene, and what this means is it makes a -- there's clear that you do a blood test or you do a genetic test, and you either have this mutation or you don't, and then you can be in a trial with a very selected population that's more homogenous than I think the broad autism spectrum disorders.

And so we are using this as our initial effort and our initial focus to validate this single gene approach.

Now I don't want to belabor this, but we are standing on the backs of thousands, if not tens of thousands of scientists in their whole entire careers to get to where we are today.

This was not possible a few years ago. These discoveries have really changed things and we have a convergence of research that's been -- that's occurred in genetics and molecular biology and we have heard a lot about the genetics today, and also basic neurobiology and pharmacology and I am going to point out a couple of things.

I mean, this usually starts with very astute clinicians -- here, Martin and Bell, who described an excellent pedigree of intellectual disability.

So they said there's something genetic going on here. It looks like it's related to maternal transmission and then, you know, we really couldn't start talking about DNA without the Nobel Prize-winning discovery of what is the structure.

And as we move down, we have -- it's not until '91 that this actual mutation was identified, quickly generate an animal model and that sort of sets the stage.

On the other side, another Nobel Prize-winning discovery, the first time that someone conclusively showed that the brain is modified by experience.

This is an experiment where if you prevent the eye from seeing, in a critical period, it's functionally blind. So it needs to have experience. It needs to have the right types of experience to learn how to see. You can have all the wiring there, but if you don't get the right experience, the brain doesn't interpret it properly, you won't develop vision.

And then this all worked down to a discovery, largely in an area where my scientific founder was working, Mark Bear, that actually determined that one of these major mechanisms for how the brain learns from experience is this signaling through a glutamate receptor, metabotropic glutamate receptor, that regulated protein synthesis.

And it's only when those two paths converged -- the Fragile X knockout mouse and this idea about how is experience-dependent learning regulated in the brain -- that the discovery could be made, which is saying when you don't make this protein, when you have the Fragile X mutation, how does that interfere with experience-dependent learning.

And so this is where Mark made this -- had this insight. Things didn't work out the way he planned. It wasn't the way he thought when he designed the experiment.

And what he found out is that these were the -- these synapses we have been talking about, there's trillions of these in your brain, this is the glutamate that's released, it's an excitatory neurotransmitter -- when, you know, information comes in, so you see something, it stimulates this, glutamate is released, you have these ionic channels here that allow the electrical impulse to pass.

The brain decides, is this important information, and if it is, it makes this connection stronger. It puts more of these ion channels on the surface. Or is this noise, background noise, and if it is, it makes it weaker, and it takes these receptors off.

And what he found is that this

metabotropic glutamate receptor, this specific receptor, regulates the stabilization of taking these receptors off the surface and drives this in this direction.

And what the Fragile X protein does, is it is actually a brake on that system, and when you have the mutation, you don't have the brake, you have got your foot on the accelerator, and you drive everything to this side.

So another way to think about this, is that there's a balance in the brain, it has to be tuned. It has to be tuned to tell important information from noise, discriminate between important and unimportant information, and that balance is from glutamate, promoting protein synthesis, and the Fragile X protein putting a brake on that.

And when you don't have this protein, when you have the mutation, you are out of balance. The brain is not tuned properly. It's having a hard time to learn from experience. It doesn't learn as efficiently.

Fragile X -- children with Fragile X still learn things. They just don't learn as efficiently as people that don't have this mutation.

And so our treatments are really to target two things. One is we inhibit signaling through the metabotropic glutamate receptor with one of our compounds, and with our others, we upstream, we inhibit release of glutamate, and we try to shift things back into balance, retune the brain so it can learn better from experience, and that's really our scientific approach.

And this has been profound, profoundly effective. If you look at the abnormalities that you can define in molecular models, the Fragile X mouse model, that is missing the protein, you can say okay, how is this brain learning from experience differently than the wild type brain that has the Fragile X protein, and you can identify a number of things that are different.

One is, the experience-dependent learning here is abnormal in -- and whether it's in the visual cortex, how you see, or the hippocampus, which we think helps you make long-term memories; whether it's in the amygdala, which controls fear; or -- and then other things like seizure disorders and even anatomical abnormalities.

So you have a lot of these small, immature neuron synaptic connections, like we showed, because this whole system is biased towards eliminating connections rather than making them stronger.

All of those can be corrected, so every abnormality that you can find, or everything that's different in the Fragile X mouse, can be corrected by downregulating signaling through mGluR5, and I think that's profound and it's very exciting for an animal model, because it could just -- that rather than just treating symptoms, like giving an anti-psychotic or a major tranquilizer to control irritability, we are actually trying to target the fundamental molecular pathophysiology, and it's all enabled by this convergence of this huge amount of research that's going on at NIH and in academic centers around the world and it's really an incredibly promising time.

And so, you know, to look at this, we start out with very astute positions, identifying an X link pedigree of intellectual disability, ultimately identifying the exact mutation that is underlying that syndrome.

Animal models, novel therapeutics and there are now three drugs in clinical trials that target the metabotropic glutamate receptor and we will soon know.

I mean, if you read the New York Times, Novartis has already published positive data there, on their trial, and it looks very, very promising.

So, you know, what's next? That's interesting. That's Fragile X. We then looked at what are the next, you know, three most common, single gene disorders that are highly penetrant, that are associated with autism.

And what we -- what Mark found, and again this is from the publication in 2008, is that, whether it's neurofibromatosis, PTEN hamartoma, tuberous sclerosis or Fragile X mental retardation, these are all important -- in the signaling pathway that controlled -- when you stimulate the postsynaptic neuron and how it controls protein synthesis.

And so this was 2008 and to just reiterate the explosion of data that Matt State was reporting to you, this is 2011, another publication from Mark Bear, and it's a bit of an eye chart, but what I want to point out to you, is that if you take -- this is again the presynaptic neuron releasing glutamate, stimulating the metabotropic glutamate receptor, and controlling protein synthesis.

These are some of the other proteins in these pathways that link glutamate release to controlling the protein synthesis that controls how the brain learns from experience.

And what you see is, whether it's all of these syndromic disorders, with an increased risk of autism spectrum disorders, rare mutations, or even structural variants, we are looking at populating this in signaling pathway and it's pretty interesting that there's -- we believe this suggests there's a convergence.

And what this means is that you know, all of these mutations that -- a preponderance of these really highly penetrant mutations, so if you have this mutation you are much, much more likely to have autism, with synaptic structure and function, suggests that if we have a treatment, say, that we develop for Fragile X, it may very well work for a large number of people with idiopathic autism that have that same dysregulation of that signaling pathway as the cause for their autism.

And so that we think that there's a potential that, you know, it's probably not going to be like hyperlipidemia where you have a single family and you develop statins and they lower cholesterol in everybody. I don't think it's that. I think it's going to be more complicated, clearly.

But it raises the potential that each one of these new therapeutics we get for each single gene disorder is going to work much more broadly than in that disorder.

And along those lines, I would say that you know, if you look at the mGluR5 antagonist, and you say look in the animal models, if you take the inbred mouse strain that has all these behaviors that are reminiscent of human autism behaviors, it's rescued by an mGluR5 antagonist.

So we don't even know what causes these abnormal behaviors in this mouse, but the social impairments are rescued.

Similarly, if you look at environmental toxins, so valproic acid, if you -- if there's prenatal exposure of the mother to valproic acid, your risk of developing autism is seven to 10 times higher.

So this is a clear factor that's associated with autism. If you look in the animal model, this is again rescued by mGlurR5 antagonist.

So whether it's idiopathic, an unknown cause, or -- so this is -- the data that we are seeing is really encouraging. And the other thing I'd point out is that the valproic acid model actually reduces this protein expression in the mouse, so that we can actually link it to a reduction in protein expression, that if you have that mutation, you also have autism.

So I think it's a very, very

interesting and exciting time. There's a wealth of research going on around the world. And our approach, then, was to start out with Fragile X, but other groups have looked at Rett syndrome in the same way, neurofibromatosis and tuberous sclerosis, and they have also advanced compounds into clinical trials for these indications.

So there's -- it's an exciting time to be in this field and I think there's a great opportunity.

So I would present this strategic vision and focus, that we believe that the path forward is to focus on the science. What do we actually really know? Where is the science leading us? Where is it pointing us?

And then prioritize treatments that actually target the pathway that's dysregulated and get it back into normal balance, try to improve the ability of the brain to learn from experience.

And then the big advantage for

drug development, which is a challenge, you know, with the next step, is how do you get this approved, is that if you are working in these single-gene disorders, you can clearly define who they are.

We may all debate about is this person on the autism spectrum or not, and do they meet the full criteria for autistic disorder, but you either have the mutation or you don't, and it's a very clear study population then.

And then we believe that once you get these drugs approved, then you also, at the same time, test them in the broader idiopathic autism population.

And so we think this is the way -- this is the path forward, and it'll be a portfolio of personalized medicine. That's the vision that we see for this field.

And this is the vision that we are pursuing in our company, where we have our lead compound in registration trials. If these are positive, we will get this drug on the market, and it'll be available within a couple of years.

We are doing a large trial, these -- ongoing, in autism spectrum disorders. Our mGluR5 antagonist -- this is a GABA-B agonist, our mGluR5 antagonist, we are going into phase 2 in autism and in Fragile X.

And then we have other, you know, other single gene disorders and other programs that we have identified through our basic science research.

But I am going to point out that it is not going to be quite that easy, you know, we have been part and we have been trying to help to move this, a biomarker consortium into the pre-competitive space.

So why biomarkers? You know, I think that I showed you that if it's Fragile X, and you can slow this down, you can improve function.

But we have evidence to suggest

that at least some of the Rett mutations are on this side, where there's insufficient protein synthesis, and if you give the same medication that you would give to someone who has Fragile X, you might actually make this person worse.

And so what you really need to do is to give them a medication that does just the opposite for this population, and this isn't new. I mean, this happens in all of psychiatry. I mean I don't know if any of you have ever given Benadryl to your child for a plane trip, and had them become hyperactive instead of go to sleep, but it's not a very fun thing and you probably won't do it again.

And so there's drugs that work and some -- always one way, some that have these idiosyncratic reactions, and some that don't work at all for certain people and they need a different medication.

And so although we are focused on this one pathway that controls protein synthesis, it may be -- it's likely, in fact I'm certain there are other pathways where these compounds won't work at all, because that's not the problem.

And so what we need, then, is we need to have a big effort, also, I think, into autism biomarkers, if we really want to go from the single gene disorders out into the broader autism population.

And that is, we need them for to say does this person have the same dysregulation that someone with Fragile X does, yes or no?

If it's yes, then we'll put them on a medication that you would use -- that we discovered through the Fragile X approach.

And so we need them to -- so we are not putting people on drugs that only cause toxicity and provide no benefit for them, and that we can enrich the population, that it will actually respond.

But we also need our biomarkers

that say we have actually engaged this circuit, this signaling pathway, and we have made it function more optimally.

Because if we can tune the brain so that it learns perfectly, just like a typically-developing individual, from experience, and we are still going to need to combine that with behavioral therapy.

I mean you are not going to learn math on your own just because we retune the brain. You are not going to learn language on your own. You are not going to learn probably social cues.

So you need to have those interactions and you need to have the training still, so that ultimately what we would like to do is put someone on a medication, and three years later say their IQ is higher, they are functioning -- they are functioning at a higher level, they are doing much better.

And so the way to do that is to have an early read that you are in the right dose range and you are actually having the effect that you'd like. So we need two types of biomarkers I think going forward, to really help this field move.

So I thank you for your attention and I mean I am really thrilled to be here, and I'm actually thrilled to be here with some positive news, that I think there's going to be some major advances, and it's really been enabled by the huge amount of effort that's gone into basic science research that none of this would be possible without. So thank you.

Dr. Insel: Randy, thanks for that very hopeful message. We have one minute for questions. Any comments, questions? Denise?

Ms. Resnik: Just a comment. I want to thank you for that presentation. I am a co-founder of the Southwest Autism Research and Resource Center and we have participated in your trials and you are an outstanding organization to partner with.

And I think your presentation

today also underscores the importance of the private sector working with us, as part of this IACC, and moving things forward together. So thank you very much.

Dr. Insel: Great comment. Okay, I think, given the time, Randy thanks for this overview, and I suspect if the -- we are continuing into the next phase of this, if this committee gets reauthorized, we will want to have you back in about two years to actually see where those charts end up, because we will be very interested to know about the results with Fragile X and the results with autism, which are really very exciting.

Rather than taking a break, I'd like to recommend that we just move forward and we will be able to break closer to noon for lunch.

Geri Dawson wanted to tell us about recent work on mortality in autism and the importance of epilepsy in contributing to that. So Geri, thanks for taking us through this.

Dr. Dawson: Sure, yes. I am very happy to respond to this request to talk about this paper and you know, all different kinds of approaches to trying to impact the lives of people with autism spectrum disorder in a positive way, and this I think really speaks to the issue of prevention of high rates of mortality in autism.

So just to give you a little bit of background, there is evidence in the literature that mortality rates are higher in autism than in the general population.

This is a study that was published in 2010 where Gillberg and colleagues have been following 120 individuals longitudinally.

The people they have been following at the time this paper was published were between 23 and 46 years of age, and at that point, nine individuals with autism had died. That's a rate of about 7.5 percent of that sample.

Just to give you a sense of what you would expect at that age, it's more like about 1.6 percent. So you can see that the mortality rate in autism appears to be increased by perhaps as high as sixfold.

So in this paper, they noted that their -- that most of the individuals who had died did have severe intellectual disability. One had seizures and -- but average intellectual abilities.

But most of them had some kind of comorbid medical condition and epilepsy was one of those common conditions. And then, one accidental death due to drowning, which I think, keeping in mind our discussion later in the day about safety.

So what we decided to do is to try to follow up on this by looking at some data that were available through the California State Department of Developmental Services. And part of the reason why we are interested in this is because we had noted in the sample -- thanks Tom -- the sample that is part of the Autism Speaks Autism Tissue Program, that there was a high rate of comorbid autism and epilepsy.

So about a third of the donors to the Autism Tissue Program not only had autism but had epilepsy. So we looked at this much larger data set from the California Department of Developmental Services. And what we found was that indeed having autism plus epilepsy does appear to be associated with a higher rate of mortality.

So if you look at the data here you can see that in this data set, that the death rate for autism alone was about .7, .8, whereas the rate if the person had autism and epilepsy was 5 to 6 percent. And so you know, again, we can see this clear elevation associated with epilepsy.

Now we also, just to show you, this is a distribution of donors to the Autism

Speaks Autism Tissue Program, and you can see that starting at about 11 to 15 years of age, in terms of the donor age, that there is a high rate of autism plus epilepsy among individuals who are donating to the autism tissue program.

Now one of the other discoveries in going into this California data set which we think is also important to point out, was that the data really aren't very good about recording causes of death in these kinds of registries. And you can see here, I've highlighted that in 27 percent of the cases, almost a third, it was just unknown. And so this is also something that we want to make a point of, that we need to do a better job of tracking causes of death so that we can have a better understanding of what some of these risk factors are, with an eye towards preventing these high rates of mortality in autism.

So just to conclude, we did show

that mortality rates are higher in individuals with autism who also have epilepsy.

We also want to underscore the need for better records that are accessible so that we can start to collect data and understand better what the risk factors are that may be contributing to early death in individuals with autism.

We hope that this kind of information in the future could inform prevention efforts. So for example we know that as a person ages with autism, that the risk for epilepsy continues to increase as you move into adulthood, and if this is a risk factor for early death, you know, having better methods of monitoring that and potentially even preventing some of these deaths is very important.

And in general I think just underscoring these high rates of mortality is something that's important for us all to be aware of, and to think about across the life span, how we could implement prevention efforts so that we could reduce these high rates of mortality.

So that's it. A very brief presentation, almost back on schedule for you, Tom.

Dr. Insel: Geri, could you just clarify one thing? Could you go back three slides? One more. Yes. So, why is the rate in ASD with epilepsy less than epilepsy alone?

Dr. Dawson: Well, because, actually the mortality rate associated with epilepsy is quite high as well, so there's a sudden unexplained death due to epilepsy, which is you know, one of the contributions to high rates of mortality associated with epilepsy.

So yes.

Mr. Ne'eman: But just to -- actually I had the same question. To build on that, I mean, I understand there's a very high rate for epilepsy, but why would it be lower for autistic people who also have epilepsy?

Dr. Dawson: Yes, that's a good question and I'd want to hear other people -- because I'm totally speculating here.

Dr. Koroshetz: One possibility is that the total epilepsy in children includes just unbelievably terrible developmental disorders with, you know, 50 seizures a day type of thing.

So mortality is associated with uncontrolled seizures.

Dr. Insel: So these are kids in status, who would probably have had status, Walter, is that --

Dr. Koroshetz: Yes, uncontrolled seizures, yes.

Dr. Dawson: Right, and you also think, very kind of along the same lines, about the fact that you know, many people with autism don't develop epilepsy until later in life.

So you also have kind of the

cumulative effect of having epilepsy throughout the life span and how that would then contribute to increased mortality rates across the life span.

Dr. Boyle: I was going to say, these are crude death rates, they are not age-adjusted so that may be part of the explanation.

Dr. Dawson: Right.

Dr. Koroshetz: And NINDS has put out a major initiative to try and understand the sudden unexplained death in children with epilepsy. It usually occurs in nighttime and people who have had seizures.

It also occurs in diabetics, juvenile diabetics, again unknown reason, usually at night. So it would be good you know, for everybody to kind of hit this problem together.

Dr. Dawson: Right, and I do know that there are efforts under way among advocacy groups. So for example, Autism Speaks is working very closely with the advocacy groups that are focused on epilepsy to be able to leverage some of the underlying science that is common there. Some of the genetic risk factors are similar. Some of the issues, for example, related mortality are similar.

So it's just another example where partnering together can be helpful in understanding you know, both causes and treatment.

Dr. Insel: Lyn and then Yvette.

Ms. Redwood: Along those same lines of partnering together, I am wondering whether or not we could also look at the University of Maryland Brain and Tissue Bank to see what they have in their database with regard to cause of deaths in their ASD cases. I think that would be interesting to also do that and something we could probably easily replicate fairly quickly.

Dr. Dawson: Right. So now, I would have to check for sure and you know, Jane, I don't see anyone from the Autism Tissue Program here.

But the Autism Tissue Program tracks brains not only in the Harvard brain bank, which is you know, what we oversee, but also in other brain banks.

So this very likely does include the information from Maryland, but I will double check on that. Yes, so the autism tissue program kind of has two parts of it. One is an actual brain bank, which is a subset of the data that is in the Autism Tissue Program portal, where we try to track brains that -- not only in the United States but in the UK.

So if an investigator for example wants to have access to tissue of a certain age or a person with a certain background, they can look broadly across all the different autism tissue banks.

Dr. Insel: Yvette.

Dr. Janvier: On a couple of

slides ahead, it says -- the heading is cause of death is often unknown, and on the ASD group without epilepsy, it's 35 percent, and the ASD group with epilepsy it's 40 percent. So that doesn't look very different to me.

And also to comment on Walter's issue, one of the programs that my hospital has is a pediatric long-term care unit and I was the director of our unit with 25 beds for 10 years, so -- and also was a consultant to many of the multiply-handicapped schools.

And even though many of these children have, you know multiple congenital anomalies, or severe neurological disorders, and intractable epilepsy, we you know, these are children under 24-hour care.

So they didn't necessarily die of a seizure per se. They were known to have epilepsy and seizures, but I mean it was a very common scenario, the child seemed fine and during the night, they passed away and were found. I mean I heard that in schools and in my own institution.

So just some clinical experience.

Dr. Insel: Thank you. Any final comments or questions? Ellen?

Ms. Blackwell: Just a quick comment about the California data. California is the only state that serves everyone. So unlike other states where the sample might just be the people who are served with developmental disabilities, everyone in California is served through DDS.

So this is a really -- it's not just a large group. It's a giant group compared to what you might get from other states.

So I like to look at the -- I do a lot of work with California and the DDS data is really good.

Dr. Dawson: They just need to do a better job of putting into the records the cause of death. That would be really helpful.

Dr. Insel: Linda.

Dr. Birnbaum: Just a quick comment tying together the past two talks, which is I just remembered that Dr. Carpenter talked about the efficacy of his antagonists in the animal models of valproate-induced apparent autism syndrome in the animals. So potential issue for therapy.

Dr. Insel: Because it's an anti-epileptic compound.

Dr. Dawson: Exactly.

Dr. Birnbaum: Yes.

Dr. Insel: Interesting. Okay. As they slide suggests here, we are the time for a lunch break. We are at noon. We will take a one-hour break, for those joining by webcast or phone, we will reconvene at 1 o'clock with public comment and then get on with the rest of the agenda. Thank you.

(Whereupon, the committee recessed for lunch at 12:00 p.m. and resumed at 1:09 p.m.)

AFTERNOON SESSION

1:09 p.m.

Dr. Insel: Okay. It's a little slow here getting people back from lunch but we are going to go ahead and try to stay with the agenda.

We do have a quorum at this point and we have got people on the phone with us. So let me just remind the committee that in addition to the statements in your folders from each of the people who are giving oral comments, there also are statements under the written comments section.

And as we have done in other meetings, we will circle back under committee business to make sure there is discussion of public comments towards the end of the day.

So with that as an introduction, let me start with the first public comment, from Dan Burns. Welcome very much to -- delighted to have you here.

Dr. Burns: Thank you, Tom. I am

glad you are here. I am a parent of a child with autism, a 23-year-old. I know other people in here have children on the spectrum who are older, aging out of the school system, Alison and Lyn and others with older children.

Tom is one of the few people in the medical establishment who is talking about prevalence in terms of what's this going to do to our economy and our society and our ability to care for these adult children as they age out of the school system. So I thank you for that Tom, and I hope to hear more about prevalence and updates on that later this afternoon.

So in response to this need, I am working with Polly Tommey in England to establish the Autism Trust in the United States, Autism Trust USA, and we are doing it in Texas.

We are building our first Center of Excellence in the Austin area. We have -- we are in the conceptual phase now, the planning phase, the fund-raising phase.

Our idea is that we will put together residents, wellness, treatment, vocational, training, outreach and an agricultural community.

So we are taking the best of these areas and putting them together in what we call a village.

The wellness center is -- touches on this group in that it could be an opportunity for research. We want to put an autism trust everywhere. That might even be one in every state and several in Texas.

So this gives you a group of people that we can work with, you can work with, as we research the needs and possible treatments of adults with autism.

We are a parent-driven group. We are revising our business plan right now based on input from Autism Society of America, national association, all the parents getting together and saying here's the way we want to see this trust work in our community.

So it's parent-driven. It's entrepreneurial in the sense that we would like to be funded, self-funded, to whatever degree is possible.

Now that doesn't mean that we are not going to seek Medicaid funds and other kinds of funding. In fact, I hope that this committee is successful in soliciting for the rights of adults with autism to be federally-funded and state-funded, because we are going to need that too.

But we also want our adult children to be able to give back to the community, and we see that happening through agricultural and horticultural pursuits and retail, including cafeterias.

The residential piece of this is quite interesting, because when you ask parents, you know, what's the greatest need for your child who is aging out of the school system and you are looking at your own retirement and eventual death along the line, they say it's housing.

So we are examining and experimenting with residential models. One of the things that's happened is we've found that developers of senior living centers are becoming interested in developing centers for developmentally disabled children, adult children.

I think of them as children. Maybe you think of them as adults. To me, my son will always be my child.

And of those DD folks, some of them may be interested in funding a center for autism. So we are very interested in the market, if you will, for residences, and we would like to know more about prevalence, prevalence by age group, prevalence by geographic area.

Tom has made the statement several times and we have quoted him as saying 80 percent of the individuals with autism are under age 21. But what does that really mean in terms of actual numbers, and how many of them are going to be graduating this year and next year and the year after that?

So we would like to have some detailed information that could be used to sell our concept to investors.

So we want to work with like-minded -- and I see that my time is up -- I want to respect the time boundaries that I have been given because I do appreciate this opportunity to present, and would like to say I'd be glad to meet with anyone who wants to discuss possible common interests between the committee and the public and our endeavor.

So thank you for your time.

Dr. Insel: Thank you very much and we will, again, circle back to this later in the day. I'm sorry that Denise Resnik wasn't in the room but it would be important to include her in this discussion because SARRC is doing something quite similar to what you are describing and I -- okay, so you will have a chance later today if you can stick around. So thanks very much.

The next comment is from Jim Moody.

Mr. Moody: Thanks. Good afternoon and thank you to members of IACC and Dr. Insel for the opportunity to make comment for the National Autism Association.

In our last statement to you, NAA Board Chair Lori McIlwain discussed with you what our organization refers to as our autism.

We represent thousands of families across the country who are in crisis on a daily basis. A quick look through news headlines of just the last few weeks highlights the level of urgent need facing those affected by severe autism.

Autistic boy dropped off, abandoned in hospital. Mother of autistic boy with autism, quote, overwhelmed. Autistic teen killed by police. Special needs kids tied down, blindfolded on bus.

Mother killed autistic son with coat belt so, quote, no one could point fingers at him, close quote, when he was in heaven.

Autistic child found wandering along I-17 access road. Missing Indiana boy found dead. John Berman, aged 7. Parents tell tales of restraint and seclusion.

Young Portland man, 17, who has mental disabilities missing since Tuesday. Police report missing child wanders into stranger's home.

Naked child found alone at convenience store. Teacher probed for hitting pupil. Abbotsford dad devastated that autistic daughter is removed from home following a wandering incident.

Police ask for public help in finding autistic man. Mother trying to build fence for autistic son. Police hunt for missing schoolboy.

Families are overwhelmed with the level of care required for their loved ones. For many, just keeping their child safe from potential harm caused by restraint, abuse, bullying and wandering is an exhausting, 24/7 job.

In addition to safety issues, many individuals with autism are often diagnosed as suffering from other disabling health issues, including painful, chronic gastrointestinal issues, seizures, sleep disorders, self-injurious behaviors, aggression, paralyzing anxiety, crippling OCD and more.

Families are struggling under the weight of incredible stress, with little if any respite, effective treatment options or financial assistance.

Adults and teenagers rapidly aging out of our school system face a lack of opportunities, support, services, employment opportunities and supported living arrangements.

With one percent of America's children being diagnosed with an Autism Spectrum Disorder, we stand in the midst of a national health emergency, a crisis deserving the utmost attention, resources and urgency that we can summon as a society.

While the IACC strives to address the autism epidemic as best it can with the resources provided, it is simply nowhere near enough.

You do not have the manpower or the funding necessary to effectively meet the many diverse and significant needs of this community that require and deserve around the clock attention.

Among the major issues that need urgent attention are prevention, medical care, residential services and support, insurance coverage for medical care, therapies and safety equipment, employment, training and support for adults, targeted, meaningful research aimed at prevention and treatment, safety issues including wandering, bullying, restraint, seclusion and abuse, higher education for individuals with ASD, training, education and support for caregivers, training for first responders and law enforcement personnel, focused research on children during the process of regression into autism to determine in real time the actual mechanism of this disorder, a specific commitment to a national epidemic deserving of a crisis level response, a program of research to determine which cases of autism are caused by vaccines and the mechanism of injury, use of a strategic plan to significantly increase the research resources devoted to autism, greater reliance on targeted funding opportunities and program announcements administered by special emphasis panels as a way of getting at the specific objectives of the strategic plan.

As an advisory committee you are tasked with making recommendations to our government. We ask that you consider the recommendation of a Presidential Task Force on autism.

Such a task force would identify the full scope of needs of individuals affected by autism and their families, be an effective liaison between the autism community and government conduct, oversight of the federal research funding and a significant increase in that funding focusing on need to know rather than nice to know spending, develop a 20-year strategic plan, draft, advocate for and guide relevant autism-related legislation, oversee, integrate and streamline autism efforts of all federal agencies, and especially in this time of severe resources, or scarce resources there must be a prioritization of both research and services to those with the greatest need and with the greatest unrealized potential that can benefit from a prioritized and earnest commitment to prevention and treatment.

Government representative

scientists, researchers and clinicians are simply not aware of, or in touch with, the real-life issues that families face every day.

Therefore, the Presidential Task Force should include significant representation of community stakeholders knowledgeable on each area of need, allowing it to be driven forward by the sense of urgency that only stakeholders can provide.

On behalf of our families and those with severe autism, we ask for your serious consideration of this recommendation and NAA would like to also acknowledge Dr. Insel's testimony last week before the House Commerce Committee, and his strong support for renewal of the IACC and of the CAA.

We at NAA and through the Combating Autism Act reauthorization coalition have been working for over a year to get a clean bill and are now looking at just an extension of the sunset.

Dr. Insel has famously said there

are no epidemic deniers here. But we fear that there are others perhaps in the Administration who are scared to death by the autism epidemic, and we urge everybody in this room, and listening on the phone, to contact your Congressman and your Senator to get the sunset extended.

This is -- the work of IACC has just begun. The needs are extremely urgent. Thank you.

Dr. Insel: Thank you. Let me also point out, as I did a few moments, ago, that you have written comments in your packages that are quite extensive. These were comments that came in over the course of the months since our last meeting, so I would like to ask that committee members give those your full consideration.

We will have a chance to revisit the public comments later in the day. In the meantime we are going to go on with the rest of the agenda, which has to do with, initially, a presentation on the ASD outcomes in adulthood.

I would like to introduce Paul Shattuck. Dr. Shattuck is no stranger to this committee. He served on the diagnosis work group when we were first putting together the strategic plan.

Two of his papers were in the 2009 summary of advances, so he is often quoted, especially some of his more recent work looking at this transition to adulthood. It's a paper that I think has been mentioned in just about every meeting since its publication.

So Paul, good to have you here, and I know there will be lots of questions about your current work. Welcome.

I should also mention, since I didn't, that he has joined the Brown School from the University of Wisconsin's Waisman Center, where he was a National Institute of Health post-doctoral fellow and is currently the Assistant Professor at Washington University in St. Louis.

Dr. Shattuck: Well, I'll get started. Thank you so much. I appreciate the opportunity to speak to you. I am very excited to be here today.

I am going to be talking about some preliminary findings from our work on examining use of services and outcomes in adulthood.

This is a gift for me. It's actually a podium where the mic comes up high enough. Oftentimes I wind up ducking down like this to reach the mic. So thank you for a tall mic as well.

Approximately, if we use the current estimates of the prevalence of autism and look at current population estimates of how many 17-year-olds there are in the United States, we can back into an estimate of approximately 50,000 young people with autism are going to turn 18 years old this year.

Turning 18, you know, arguably one way of thinking about aging into adulthood, you could debate that, whether 18 is really the marker.

But I want to basically take a preliminary look at some answers to the question what happens to young people with autism after they leave high school, and I have got some information about patterns of service use, some information about engagement in post-secondary work, in educational opportunities, and I want to kind of leave you with a few thoughts at the end of the day about that.

So, U.S. law, as most of you know, guarantees access to a free, appropriate public education for children with disabilities, all children with disabilities.

A broad, federal entitlement to supports and services goes away once students leave high school. There is no corresponding, universal entitlement to help in adulthood.

Many families describe this abrupt loss of service like being pushed off a cliff. Once out of high school, the availability of services becomes uncertain and highly dependent on the severity of a person's needs, the family's financial resources and where they happen to live. It can be very idiosyncratic.

Despite this commonly understood phenomenon, we know virtually nothing in specific terms about what happens to youth after they exit high school.

I just finished writing a review of scientific literature, which will be coming out later this year in the Canadian Journal of Psychiatry, about services for adults.

We found over 10,000 articles about autism from 2000 through 2010, but only 23 studies focused on services and interventions aimed at supporting success in work, education and social participation among adults with an ASD -- 23 studies.

Most of these studies included only a very small handful of participants. We are talking almost half of the studies with a number of participants in the range of three to six participants.

We aspire to offer evidence-based services for people with autism and their families, but the sad fact is that the evidence base for adult services is extremely thin and underdeveloped.

As you all know, autism does not indeed disappear in adolescence. The majority of a typical life is spent in adulthood. However the vast majority of spending on research and services for autism is aimed at very young children.

This graph is a visual depiction of my impression of this imbalance. It's not based on a count of articles or anything like that. It's meant to be a visual heuristic.

But this profound imbalance between how life unfolds versus where research is concentrated represents a broader failure to strive for a thorough understanding of the course of autism across the lifespan.

The citizen in me is offended at the unfairness of neglecting adults with autism. But the scientist in me is also upset about the enormous, what I see as an enormous scientific opportunity cost that this represents.

What fundamental discoveries about the nature of autism are we failing to achieve because we are neglecting the study of autism's trajectory across the lifespan?

I want to say it one more time. What fundamental discoveries about the nature of autism are we failing to achieve because we are neglecting the study of autism's trajectory across the lifespan?

There are three other important social trends unfolding as ASD prevalence increases. The demographic makeup of our society is becoming more racially and ethnically diverse over time. Poverty and economic insecurity are becoming more common. And publicly-funded programs for all types are experiencing increased stress due to the economic downturn.

In particular, our field of research has done a very poor job of thinking about how social disadvantage interacts with the course of autism.

This is at odds with two important facts. First, the proportion of the population living in poverty is increasing over time. The rate is especially high among children, with about one in five children living below the poverty line for a total of roughly 15 million U.S. children living in poverty.

Given the current prevalence of autism this translates into roughly 150,000 children with autism living in poverty in the U.S.

Second, some research has shown that socioeconomic status clearly matters when it comes to the developmental trajectory of young adults. Poor kids do worse, not surprisingly.

And as with the neglect of aging issues in general, the unfairness of neglecting poor people with autism in research should shock us as citizens, but also as scientists and supporters of science, we should also lament the scientific opportunity cost this represents.

What discoveries about the interplay between human beings and their environment are we denying ourselves by failing to examine how exposure to social disadvantage influences development and outcomes?

So I have been focusing my research program on trying to build an evidence base that can help improve services in systems of care for adolescents and adults with autism spectrum disorder, and really starting at square one.

We have some very basic descriptive work that needs to be done estimating the nature of the needs of this population, who gets what, what kinds of services are being accessed, what are the barriers to accessing good quality services and so forth, and these are the questions I am very passionate about answering.

I have been very fortunate to receive funding from NIMH through two mechanisms, a core grant to our school's Center for Mental Health Services Research, which helped me launch this line of inquiry, and more recently, an R01 grant to continue building on that pilot work.

My work has also been funded by Autism Speaks and the Organization for Autism Research. I am very grateful to both those organizations for their support.

The main aims I am pursuing in this research, number one, is to just describe and track at a descriptive level patterns of service use and access in this population; number two is to examine young adult outcomes across the board in terms of employment, work, housing, independence of various sorts; and lastly, to examine disparities and inequities, particularly in access to services.

I am pursuing these aims through analyses of data from a large, longitudinal study that was launched in 2000 by the U.S. Department of Education. It cost roughly $20 million to implement.

The overall study followed nearly 11,000 youth who were enrolled in special education and were ages 13 to 16 at baseline in the year 2000.

It's a nationally representative and diverse sample. Data were collected from multiple sources and multiple methods. There were parent interviews, interviews with youth with disabilities when they were capable of participating, direct assessments, teacher interviews, IEP extracts, transcript extracts.

It's a really rich source of data, and the initial sample included about 900 youth with autism.

Now in the U.S., autism is one of several categories used for eligibility determination in tracking enrollment in special ed.

It's important to note this is a study of youth who are enrolled in the special ed autism category.

Schools do not necessarily make these classifications using standardized clinical guidelines. As many of you know, where you live really matters when it comes to your experience with schools.

However we do know from other research that the vast majority of those enrolled in this category also meet clinical case guidelines for autism. In other words, the special ed designation of autism is very specific.

However, the special ed autism

label is only moderately sensitive. So not all children with autism are actually served under this special ed label of autism.

Many children with autism are enrolled in special ed, but are tallied under other labels like mental retardation. Some with autism are not in special ed at all.

My findings, just to be really specific, generalize to all special ed students who are in seventh to 12th grade as of the year 2000 in the autism category.

The sample frame included any youth for whom the public school had administrative responsibility, even if they were going to a private school using public funds.

Response rate at wave 1 was 84 percent. All reported estimates have been weighted. So my findings are representative of the roughly 14,000 youth who were in that autism category in that age range in the year 2000.

Most of the findings I will be presenting today are based on wave 4, which was conducted in 2007. The response rate there was 74 percent of the wave 1 participants, a pretty good response rate, not too much attrition.

We have information from about 400 parent interviews about patterns of service use, and we have a combination of responses from youth and parent interviews which we pooled together to come up with estimates about postsecondary work and school outcomes.

First I will present some findings about rates of service engagement, basically what services are U.S. youth using after they leave high school; what are some of the correlates of service engagement.

This is summarizing work that was published earlier this year in the Archives of Pediatrics and Adolescent Medicine.

As of this wave 4, when these young people are no longer in school, about 80 percent are living at home with the parents, 86 percent male. Most of them have been out of high school for at least two years at this point. About one-fifth are nonverbal and about almost 10 percent are uninsured.

So we have measures of over a dozen different kinds of service use, but we chose to focus on four in particular in this paper: case management; mental health; medical evaluation for specialty medical evaluation; and speech therapy.

The variables come from a sequence of questions that are asked of parents whether the youth had any service during the prior two years.

So this is not, you know, have they gotten this service in the last month or so, this is during a two-year period, has your kid ever had any service in the past two years.

A list of services was then read and includes psychological mental health services or counseling, medical services for specialty diagnosis or evaluation, speech, language therapy or communication services, and then we also created an indicator variable that indicated whether none of those four was received.

So we find not quite half, 42 percent had some kind of case management during the prior two years. About a third, 35 percent, were engaged in some form of mental health counseling. About a quarter had received some kind of medical evaluation related to their disability. Just under 10 percent were receiving speech therapy. Almost 40 percent were receiving none of these four services at all during the prior two-year period.

That displays pretty clearly there. Here I am comparing the rates of service access after high school, which are these dark blue bars on the right, and with the rate of service use among the same youth while they were still in high school six years previously. Those are the light blue bars on the left.

So there's a decline of access to services for each type of service, most notably speech therapy, which also happens to be the most commonly-received form of help during the school years, and is the hardest to obtain service after high school exit.

So that's one of the more noteworthy findings I think, in this research, you know, difficulty with communication and communicative interaction is a core, hallmark feature of autism spectrum disorders.

There is no other type of service or intervention that is accessed more commonly during the school years than speech therapy. It's the most needed and the most frequently engaged-in type of service and support during the school years, and it's the most difficult one to obtain after these young people leave high school.

Controlling for a variety of other factors what we found is there was an elevated risk of not getting any services among African Americans and among those with very low incomes, incomes less than $25,000 per year: a six-fold increase in the odds for the low income category; a three-fold increase in the odds among African Americans.

With respect to not receiving case management, again, the very low income group -- this is controlling for severity and a variety of other factors -- at a much higher risk for not receiving any case management.

So the socioeconomic and racial disparities in service engagement documented in our study clearly indicate a need for further research into barriers to accessing services after high school.

A second research question we are just taking a look at now, in a paper that's -- oh, it's almost baked, not quite ready to go out the door but almost there -- you know, we kind of expected to see a drop in service access after high school and I am really just putting some nationally representative numbers to what we have known all along.

But how are these young people doing once they leave high school? Are they getting jobs? Are they going to college? Where do they live and so forth?

The good news is I could stand up here all day and answer those questions with a whole series of bar charts but we don't have all day.

So I am going to share some preliminary findings that have not yet been published, and in order to focus the rest of my talk, I have decided to flip the question around and ask how many young adults are totally disengaged after leaving high school? This is the first six years after high school.

By disengaged I mean they had no kind of -- no job of any kind, no job training, no sheltered or supported employment, no technical or vocational school, no community college, no university attendance, and the news is pretty disheartening I'm afraid.

Thirty-three percent of young adults who had been served in the autism category while in high school had no engagement in employment or postsecondary education during the two years prior to this 2007 survey.

That's one third, that translates into thousands of young people in their early 20s who are totally disengaged.

How does that compare to youth from other special education enrolment categories? Remember, this is from a study of over 11,000 young people nationally who are enrolled in special education, so for any given outcome, we can compare, how are the young people with autism doing compared to young people who are enrolled in other special ed enrollment categories at the beginning of the study?

Here we see that, indeed, young people who were enrolled in the autism category are faring the worst after high school. The rate of disengagement in work and postsecondary educational opportunities is the highest of any group of young people who are enrolled in special education, highest by far.

So is the risk of disengagement the same for all young adults with ASD, or does it vary among subgroups? Well one way it varies is by how long people have been out of high school.

So remember, this survey was conducted in late 2007, it was late summer and the fall of 2007. We can look at that rate of disengagement and say how does that rate of disengagement change as people get further and further away from their date of leaving high school.

And what we see here is that in the first few months of 2007, the rate is especially high. Nearly 60 percent of young people are not engaged in any kind of work or educational opportunities.

A year to a year-and-a-half out it's still at about 50 percent. You know, it gets a little bit better as time unfolds.

I don't have charts to show you but I can just tell you verbally that this compares very poorly to young people in other categories.

There seems to be an extended period of disengagement and kind of floundering in the first three years for the young people with autism.

Even if I had this same chart up here for the young adults from the mental retardation category, we would see a much lower rate of disengagement that first year out, and it would go down faster.

So the rate for the young people with autism is higher right off the bat leaving high school. It stays higher, longer, and it takes longer for it to taper, which means that people are eventually getting engaged in work and employment opportunities, you know, four to six years out of high school but it takes them much longer to get engaged and stay engaged than youth from other disability categories.

How about racial disparities? There are significant differences in the lack of engagement when we sort by race and ethnicity.

Compared to white youths, those who are black or Hispanic are much more likely to be disengaged from any kind of postsecondary work or school opportunities, nearly two thirds for Hispanics and one half of blacks.

Now here, we are stratifying lack of engagement in work or school by family income. Wow. So this is what we call in epi or services research kind of a dose response gradient.

The bar on your left, those are the families who are making less than $25,000 per year. The bar on the far right are those families making more than $75,000 per year.

The rate of disengagement in post-high school opportunities is highest among those from the poor families, and it gets much lower for those who are from more affluent families.

Now without showing another slide I am just going to tell you that in this sample at least, income and severity of impairment are very highly correlated, such that youth with autism who are also poor tend to be more severely impaired compared to their more affluent peers.

So maybe, maybe this income dose response gradient, maybe that's really just a reflection of the fact that young people who are from poorer families, tend to be more severely impaired.

Let's take a look at a few

indicators of severity and stratify by severity. One indicator of severity we have is a functional mental skills scale that was constructed by summing four questions about how well the youth can do following tasks without help: tell time; read and understand common signs; count change; use the telephone.

We collapsed the scale into quartiles with higher values corresponding to greater skills and ability, and what we see here is that the youth with the lower abilities, which is the bar on the left, have higher rates of disengagement.

So what we are saying basically is that the more severely affected young people with autism at the lowest ability level, nearly 60 percent, are not engaged in the first few years after high school in any kind of work or school, but things are less foreboding for those with higher abilities. Those with higher abilities have a much lower rate of total disengagement. That would be the bar on the far right.

Another indicator that we have is verbal ability. We have a variety of indicators of verbal ability that are mostly based on parent report. This one we have collapsed into two categories of verbal and nonverbal.

Again, we see that those with greater developmental impairment are more likely to be disengaged. The bar on the right represents an estimate for those who are nonverbal.

Just over 60 percent of nonverbal individuals are not engaged in any kind of post- work or school opportunity after high school. The rate is much lower, about 20 percent, for those who have some degree of verbal ability.

All right. So, are these driving this income gradient? Remember, we had this income gradient in this previous slide, where the poorer kids were worse off, they are more likely to be disengaged.

Poverty, low income and being more severely impaired is highly correlated, so possibly this is just being driven by the fact that the bars on the left are populated by young people who are more severely impaired.

Are youth from poor families disengaged from work and school simply because they tend to be more severely impaired?

The answer is no. There is a significant income gradient within every stratum of ability across every measure of ability that I have the ability to look at.

In other words, severity of impairment and income are both important determinants of how engaged youth are in the first few years after leaving high school.

The probability of no engagement if you are poor and nonverbal -- that's the bar on the far left there -- 75 percent. On the other hand, if you are from a more affluent family, and have higher verbal ability, then the rate of disengagement is only 12 percent, that's the lowest bar on the far right. That's about a 12-fold difference in risk rates.

So the lack of engagement among youth with low income is not driven purely by their lower average abilities. They are independent and very strong main effects of both income and impairment severity.

I am just going to whip through a few concluding slides. I want to leave some time for questions.

So, limitations, every research project has limitations. I am using secondary data that's -- was not initially designed as a study of autism per se, that we don't have any ASD-specific measures at our fingertips. We don't have any normed measures. These are mostly scales that we construct based on responses to questions that are responded to by parents and the young people themselves.

Relying on parent report can be a

weakness, although we do have kind of the ability to look at convergent validity across measures that we collect from parents, teachers and the youth themselves.

There's some loss to follow up but the attrition rate in this longitudinal study is not nearly as bad as in many other studies.

And the sample frame, you know just remember, the sample frame here is young people who are enrolled in the special ed category of autism. Is that fully representative of all people with autism? We just don't know and we can't answer that question definitively given the data at hand.

On the other hand, we have got some strengths working in our favor. The size of the sample, the socioeconomic diversity of our sample is a huge asset.

The longitudinal nature of our data -- we will be getting wave 5 data any day now. We are waiting for it to be released, and then we will be able to look at a full 10 years worth of longitudinal follow up with these young people and we will be able to start putting some estimates to what's happening to these young people once they are in their mid-20s, which is very exciting.

Some other advantages are the clear relevance for policymaking and kind of telling the story about the needs of this population, again in the absence of information that is in the existing literature.

This kind of descriptive, services epidemiology if you will, is very important for informing policymakers about the needs of this population.

So for the next steps, we will be describing the needs of this population as they continue to age through their early and mid-20s.

With support from Autism Speaks, we are very excited, we are in the midst of launching a set of papers that use a particular technique called propensity score matching where we -- it basically allows you to get as close as you can get using non-experimental data to test the impact of interventions at one point in time on outcomes at a later point of time.

We have a whole set of questions about the impact and effectiveness of school and transition services that happen during the teen years. Do they, do they matter? Can we see a measurable effect on later outcomes in various areas in young adulthood?

So to conclude, I would argue that social context really matters. My research suggests that youths with -- who are racial minorities or from poor families have a fundamentally different experience during transition and young adulthood.

Policy matters very much. There is often a mismatch between the eligibility criteria for many adult DD services versus the unique needs related to social and communicative competence of youths with an ASD struggle with.

Services for this population need to recognize that difficulty with social communication can be every bit as disabling as physical or intellectual difficulties.

Public policies have really not caught up with emerging scientific discovery, and the reality faced by people on the autism spectrum.

I think that's partly what's behind the huge drop in rates of speech therapy after leaving high school. We can talk more about that if you want.

Lastly, I hope my research is a helpful step towards building a population-based research program on what happens to adults with autism, but this is clearly not enough.

I think future advocacy for more research on adulthood cannot hinge solely on the tragedy of being driven off the cliff for service eligibility upon leaving special ed, nor can advocacy refer mainly to the fact of growing numbers of children with autism aging towards adulthood.

Of course these are obviously important facts and they help create a sense of urgency, but they do not really frame a research agenda.

Recently many funding agencies have been promoting the notion of transdisciplinary science, which means teams of people from different disciplines coming together to share ideas and fundamentally rethink research questions in a way that's rooted in multiple disciplinary perspectives from the outset.

We need to challenge ourselves as parents, advocates, clinicians, friends and scientists, to craft a transdisciplinary research agenda about how autism unfolds across the lifespan.

We need to find ways to blend

basic and applied science approaches. They don't have to be, you know, facing off across the street as separate camps.

We need to find ways to speed the pace of discovery and dissemination and translation. In short I propose that we do not just need more research. We need new ways of imagining and conducting research across the lifespan.

Thank you very much for letting me join you today. Do we have time for a couple of questions?

Dr. Insel: We do. We have about 10 minutes. I'll start with Geri.

Dr. Dawson: Well Paul that was a really informative and inspiring talk. I have a question about the longitudinal findings that relate to the relationship between level of intellectual disability or verbal/nonverbal and engagement or employment.

And I'm trying to square it with the work of Marsha Seltzer, where I -- as far as I recall, her findings were that a group that was particularly struggling with finding employment were people with autism who did not have an intellectual disability because there were so few supports for that group, that she actually found there were more supports for a person who had autism with an intellectual disability.

But there seemed to be a huge gap for people who did not fit easily into some of the existing programs, and unfortunately the rate of employment was extremely low for that group.

So I'm just wondering, is it different, or how does that fit with your findings?

Dr. Shattuck: Yes, well I know that work pretty well. So I studied with Marsha, that's where I earned my doctorate. I love Marsha. She's an amazing scientist and great mentor.

So a few differences and maybe not

so much difference as you might think. Number one, this is a much more socioeconomically diverse sample and we see that there's clearly a strong correlation between socioeconomic status and impairment severity.

And number two -- I'm not sure quite how to put this into words -- so if we look at rates of service engagement, we find -- we kind of look -- we hypothesized going into the paper that was published earlier this year that there would be almost a U-shaped distribution of service engagement by income -- by that -- and severity.

By that we mean we anticipated that people who were the most severely impaired would be the least likely to be disengaged from services, because a lot of the adulthood MRDD service systems are -- their eligibility criteria are set up so that they have some kind of scoring basis for scoring severity and they triage. They triage to bias towards the most severely affected people. So most state systems are really designed to help people who are the most severely affected.

So we kind of expected that rates of service disengagement would be low among those folks.

Folks who are not so severely impaired but have moderate to mild levels of impairment, they often don't qualify for those state-funded services.

And so in some sense they are at an increased risk for service disengagement, but their slightly -- their higher abilities in terms of cognitive functioning and verbal functioning also reduces the chances that they are not going to be completely shut out of actual engagement in work and employment opportunities.

So what we see in some analyses I didn't show, even though we have a lot of young people who are very severely impaired, might be engaged in some kind of services, they are still not succeeding in terms of obtaining a job or working in any kind of employment situation, or even getting vocational training.

They might be getting case management but that's just, you know, kind of a -- oh, what are we going to do? I think it's more an indication that we have relatively high rates of service engagement among those severely impaired individuals, but that service engagement isn't translating into positive outcomes.

Dr. Insel: Ari.

Mr. Ne'eman: Two things, one a question and the other a comment. Just a question. What measure was utilized for determining lowest ability, highest ability in the various quartiles within that?

Dr. Shattuck: Sure, so this is -- again, we don't have elegant -- this is not a study that's chock full of highly rigorous, normed measures.

And I can be more specific with my

notes here. This is a scale that's constructed by summing together a series of questions that we have about what are called sort of functional mental skills.

We have four questions about how well a youth can do the following tasks without help: tell time; read and understand common signs; count change; look up phone numbers and use a telephone.

These are from the parent interview, where we basically asked parents for each one of these things. We have got this four-point scale ranging from my kid can't do that at all to my kid has no problem doing that whatsoever.

And parents rate their child on each of these four tasks that are sort of adaptive behavior abilities, and we sum those scores together and it creates a scale that ranges from I think four to 16 and then we chop that into quartiles based on the distribution for this population and we have a way of talking about impairment severity in a crude way.

Mr. Ne'eman: Very interesting. And then the other comment -- the other thing I had, which was a comment, was, if you could move forward two slides.

I was really interested by this slide in particular, most notably the fact that it seems that the outcomes for nonverbal people who come from rich or middle income households are better than the outcomes for verbal people who come from low income households.

And I just -- I think that that's incredibly indicative of something that is so frequently left out of the autism discussions we have been having -- class.

Generally speaking I think you know, even within this committee, the conversations we have been having around severity and so on and need, have really looked at it solely from a health or a functional impairment perspective, so I am just very grateful to you for highlighting this, because I think it really points out the degree to which the outcomes you have are very much related to the social context with which you are born to and live in.

Dr. Shattuck: Well, I tell you, it's definitely a hypothesis-generating research. I mean even looking back in our data when these young people are still in high school, there's a very strong correlation between income and just about any severity measure that we have our fingers on.

Poor kids are more severely affected. So generally speaking there's a couple of different hypotheses for thinking about that. There's kind of social selection and social causation.

Selection would argue that possibly there's some kind of bias in enrollment patterns, that for whatever reason, more severely affected kids from poor families are getting identified in the autism category in school.

The other set of theories has to do with social causation, meaning that you know, being poor is bad for you and that over time, being poor means that your developmental trajectory is going to be worse than someone from a not poor family and that by high school, we see these big gaps in ability between rich and poor kids.

You know we don't have a time machine for this sample, we can't go back and measure them at preschool age and see if they were equivalent on various measures.

But it certainly, in my mind, begs the question, you know, how can we build a research program around looking at socioeconomic risk as a predictor of trajectories of development over time.

Dr. Insel: Lots of hands are up and we only have a couple of minutes. So Alison?

Ms. Singer: I just wanted to drill down on that. What are the reasons that being poor is bad for you? Is it because you have less access to habilitative services across your lifespan, like early intervention, or is it that the families have less time to focus on their own case management, because we saw there was a relationship between family income and the need for case management.

So what are those drivers?

Dr. Shattuck: We -- I can't say. I mean I can hypothesize and we have from research on intellectual disabilities, on child and human development stemming back 30 years, we have a lot of theories and evidence about why kids who are born into poor families do less well on measures of IQ, on behaviors, on involvement in criminal justice, you know, if you follow them up 10, 15 years later, there's a lot of evidence to show that that is the case.

And there's, you know, there's a

big debate. Some people would argue that it's genetic. You know, parents are poor, because they probably have low IQ, they have got behavior problems and they can't get good jobs and that's why they are poor to begin with and they are more likely to have kids who have behavior problems.

So there's that whole camp of people that kind of build that, it's more of a biological selection argument.

Other people would you know, point to this social causation, environmental deprivation evidence, and there certainly is evidence that you know, kids who grow up in you know, in an apartment with single parents and no books and no toys and you know, no one to play with because they can't go outside because the neighborhood is too dangerous, you know, those kids score worse in high school on measures of academic achievement and behavior problems and so forth and it's kind of this environmental deprivation story that you could build.

I can't -- you know again, I wish I could jump in a time machine and go back and look at our sample of 920 and see what they looked like in preschool, but I can't.

Dr. Insel: I think Yvette and then Marjorie and then we are going to have to move on.

Dr. Janvier: I just was curious, when you -- you have a slide that says secondary school leaving status, that you know, I don't know if you had information about, are these kids finishing at the end of 12th grade or are they staying through 21?

Dr. Shattuck: Yes, so I'm sorry, I blanked out that slide in the interests of time. It's in your handouts but it's not up in the slide show.

So I had a slide in there about secondary leaving status, and I don't have it in front of me. But the short answer is yes, the young people in the autism category are the most likely young people in special ed to stay you know, until they are 20 and 21.

So they are much more likely to stay in high school compared to kids in other groups, and these kind of late-leavers. Does that answer your question?

Dr. Janvier: Yes.

Dr. Shattuck: Okay.

Dr. Insel: Marjorie?

Dr. Solomon: Yes, I was really interested in the propensity score matching study you are about to embark on and was wondering what kind of factors related to high school you are going to be looking at, and then what kind of hypotheses you have about what will predict good outcomes.

Dr. Shattuck: Wow. Yes, that's a big question. I'd be happy to talk to you later. I mean I have a huge set of hypotheses, and you know, it's a blessing and a curse.

This data set, we have tens of thousands of variables, I mean, because we have so many instruments from different sources.

What I'm focusing my energy on first is looking at what I call procedural safeguards. So from a policy perspective, we could ask the question - I'm not a clinician so I think more of a policy advocate because that's my background -- from a policy perspective we can ask what's the low-hanging fruit?

You know, if we could fix one thing through policy advocacy to make life better in young adulthood, what would that be?

So we want to look at things like what are -- you know, kids are entitled to certain things during the transition planning process. It's supposed to start by a certain age. You are supposed to get a transition plan.

The reality is, in our data, not every kid leaves high school with a transition plan. Almost a quarter of these kids leave high school never having gotten any transition planning.

Most of them start later than they were entitled to under the law. The transition plans of those who have transition plans don't have all the required elements.

So right off the bat we are going to look at some of these procedural safeguards. If you don't get what you are entitled to, does that mean bad things are going to happen to you later on?

Because from an advocacy and policy standpoint, it's easier to go argue for enforcing existing rules than it is to argue for funding a creation of new interventions. That's kind of where we are starting.

Dr. Solomon: Great, thank you.

Dr. Insel: I promised Ellen that she would also be able to ask a question and we'll take the time.

Ms. Blackwell: Hi Paul. Quick question. On your services slide, I'm just curious, did you look at whether or not these kids had public insurance or private insurance?

Dr. Shattuck: Yes, we did, and I don't have it in front of me, but as I recall, those did not pan out as predictors of service engagement.

Ms. Blackwell: Okay, because I thought it was pretty interesting because all these categories -- case management, mental health services, physical health services and speech -- they are all -- I'm just wondering if there was a drop off after the kids, if they were Medicaid kids, you know, they dropped out of EPSDT, because that looks pretty typical in terms of what adults would get in Medicaid.

Dr. Shattuck: Yes, the unfortunate thing with the measures of insurance we have in this data, we don't get as specific as whether they had Medicaid.

We have just basically three

questions that are asked of parents, you know, or four questions: do you have insurance; was it private; was it public; was it an HMO?

So it's a pretty crude way that prevents us from drilling down to look at that question.

Dr. Insel: I can't resist. There's a paper out recently from Amy Finkelstein and colleagues looking at the Oregon experiment, where the whole state couldn't -- they couldn't afford Medicaid for the whole state, so they did a lottery, and people were assigned to either get coverage or not, and then Amy came in with others and looked at the outcomes.

And the New York Times did a lead editorial on this yesterday because they were saying this is something policymakers really need to look at, they really -- you now, this is a beautiful experiment of what the impact is.

Could you do something like this

with your data, so if you looked at, out of the 983 or whatever it is, if you could take those who have the most service use and those who have the least service use, you are going to do that obviously for the propensity study for high school, but post-high school, those who don't fall off a cliff, there must be some, there obviously are from these graphs, those who do and actually find out what difference it makes in terms of outcomes?

Dr. Shattuck: Yes, we can probably look at that. Once we get the wave 5 data in, we will have a little more sample size. I think we could -- we could go there, definitely.

Dr. Insel: We are looking at major -- potentially major changes in funding of supports, as Ellen can tell us, and that kind of data makes a big difference when people are trying to make decisions.

So the outcome data could really matter at this point. It would be interesting, if you have access to it.

There's, I think, more questions and more discussion, but unfortunately less time.

Dr. Shattuck: I'll be around all afternoon. I'm going to be leaving around 7 this evening if anybody wants to catch up with me in the hallway during break, I'd be happy to answer more questions. Thank you so much.

Dr. Insel: Okay. Paul, thanks so much, that's great. Coleen, you were going to take us through this recent report on prevalence of developmental disabilities from the National Health Survey. So we've got about 15 minutes to hear about this.

Dr. Boyle: Well thank you and thank you for the opportunity to present, and I think this paper actually tries to put autism in context with other developmental disabilities and actually addresses what was Marjorie's point this morning of sort of taking a look at what is going on relative to epidemiologic patterns for autism relative to other neurodevelopmental as well as sensory disorders in young children.

So just as a way of background, there's really a lack of information, particularly national data on developmental disabilities in U.S. children.

Some previous studies listed there show a range of prevalence in terms of overall developmental disabilities. We know from some of CDC's data as well as other sources of information that there's a suggestion of higher prevalence for selected developmental disabilities, particularly for autism and attention deficit-hyperactivity disorder.

But really, looking from a national perspective, there's a lack of data on trends for developmental disabilities.

So this just tries to summarize for you some of the prenatal and early postnatal factors that might have influenced trends, and one is improved survival.

We know that children born pre-term as well as children with selected birth defects and genetic disorders are living to adulthood, which they hadn't done in previous cohorts, so that clearly can impact survival.

We know there's changes in medical practice and prevention-related changes that could have led to decreased prevalence of developmental disabilities and this includes improved prenatal diagnoses, new infant vaccines to protect against meningitis and other neurodevelopmental sequelae from particular infectious diseases, as well as expansion of newborn screening and the opportunity to prevent some of the adverse consequences of genetic disorders identified through newborn screening.

We know there's shifts in population factors. We have heard here I think in this committee about the role of parental age in autism, and parental age is also involved in a number of other developmental outcomes as well.

And we also know there's increased awareness and improved diagnosis and that's true for autism, but it's true for a number of other developmental disabilities as well, so influencing those trends.

So the objective here was really to examine the overall prevalence of developmental disabilities overall, as well as specific DDs in U.S. children, and we used children aged three to seven -- excuse me, three to 17.

We used a cutoff of three because a lot of these conditions are really not diagnosed prior to age three, and we looked at trends in prevalence over a 12-year period between 1997 and 2008.

And we also looked -- tried to look at how the prevalence and trends in prevalence varied by key descriptive factors, so again giving you a sense of -- that picture, and this relates very nicely in terms of some of the implications from Paul's presentation earlier.

We used data from the National Center for Health Statistics' National Health Interview Survey, and this is the child health component.

Again, that's 12 years of data. They now have 2009 data available, so this could be updated. I mentioned it's three to 17.

Approximate sample size is 120,000 children or about 11,000 children per year. The nice thing about this survey is that it is sampled proportionate to size for the population in the U.S., so it does represent the U.S. population.

The information is actually obtained from in-person interviews, so it's unique relative to other surveys, and it's done by the census, and the interviews are done with a parent or other knowledgeable person.

And again another very remarkable part of this is they have excellent response rates, so their response rates for this in-person interview are around 90 percent, which is really quite remarkable in today's environment.

These are the specific conditions that we looked at then. Some of them are specific conditions. Some of them are functional limitations. But you can just scan down that list in terms of you know behavioral and emotional disorders, sensory impairments, motor problems, intellectual disabilities, and then included issues such as seizures and then speech and language issues.

The definitions varied slightly based on the question that was being asked, but in essence, most of the questions were essentially an affirmative response to a question about whether a doctor or other healthcare provider ever told the parent or the caregiver that the child had a specific condition.

Time frame is somewhat different depending on the condition, but the majority of the conditions asked about whether the child ever had this, assuming that these conditions are chronic conditions and they don't fluctuate.

Again, this is just some of the factors that we looked at, again getting a sense of how these conditions varied by child's age, gender, race, ethnicity, and then a number of socioeconomic factors including the mom's education, the total family income, and then health insurance status.

These are weighted to reflect the U.S. population and they also adjust for a sampling design and we didn't use the entire 12-year time period because the numbers do get small and in terms of stability, so there's really four time periods reflected here in the results.

So quickly, these are the overall

prevalence, and I was just trying to point out here that the prevalence of any developmental disability over that 12-year time period was about 14 percent, so that's 14 percent of U.S. children being reported with one or more of these conditions.

A child could have more than one of these conditions and so it's not a simple sum of the conditions identified here.

And then the highest prevalence condition are, as you might anticipate, attention deficit-hyperactivity disorder and learning disabilities, and then you can see the other conditions really corroborate fairly well with prevalence rates from other studies.

This is the male to female ratio, and I guess the -- I don't guess, but the remarkable observation here is a predominance of males relative to females for many developmental disabilities.

The ones that are highlighted are the ones that were statistically significant and you can see, if you just scan down that column, that males are more prevalent for all conditions with the exception of cerebral palsy, and that autism is really an exception in terms of the male predominance relative to other conditions.

Another interesting finding you will notice, this is just a summary of the race, ethnicity observations, and that autism is not identified here.

So the predominant finding was really that Hispanics had lower prevalence of several disorders, including ADHD, learning disabilities and other developmental delay, but not autism.

Early on in that time frame, in fact, Hispanics did have lower prevalences, but that -- the gap has closed over the 12-year time period.

And similarly, this is the socioeconomic factors relative to the developmental disabilities, and again, our indications of poverty including maternal education were associated with a number of the developmental disabilities but not in regard to autism.

This is the trend data and I apologize for this. I used this in another presentation and so you can't really see the trend for autism, but that just sort of gives you a sense of the relative prevalence of the different conditions over the time period.

And you can see the change in the top line which is all developmental disabilities changed from about 13 percent to 15 percent over time.

And this is the slide that actually Tom showed you earlier in the -- today's schedule, which shows you the change -- these are the four individual conditions that were statistically significant, where there was a significant trend over time, that's autism, ADHD, other developmental delay, and actually then there was a significant decline in hearing loss over the time period.

But you can see relative to the other conditions, that on -- the trend in autism is quite remarkable. But there also was significant increases in -- excuse me, ADHD as well.

So just in conclusion, what we reported was that there's nearly 10 million children in the U.S. reported to have a developmental disability in the most recent time period.

So that's using that 15-percent figure from the 2006 to 2008 time period, that translates into about 10 million children, and over that time period we see a 17 percent increase, which again, translates to about 1.8 million more children with developmental disabilities relative to a decade earlier, and that these changes were due primarily to the influence in the rates in autism, ADHD, as well as this catch-all category of other developmental delays.

So relative to the specific trends, obviously with autism, this does corroborate what we have seen over shorter time intervals both from the CDC ADDM network as well as from the HRSA-supported National Survey of Children's Health. And again, each of those were a relatively shorter time period.

We have limited data in terms of trends for ADHD, mostly office-based visits, so clinical information and education data, mainly the other health-impaired category within the education data, but also show increases over time.

Hearing loss is a little bit of a quandary for us. There's really no other previous trend data so we have a -- we don't have a sense of what's going on there, and with the other developmental delay, again that was a sort of a catch-all category that was asked and there was a change in education category in 1997 which allowed use of this category for children up to nine years of age, which may have influenced the trend in that category there.

So, why increases in ADHD and autism, and you are all familiar with each of these, obviously for both conditions there's the advantages of early intervention.

There's improvements in clinical, parental and the societal recognition of these disorders. There's efficacy, particularly around the issue for ADHD in terms of medications and behavioral interventions, so there's incentive to identify children.

There's increase in the prevalence of prenatal and other risk factors, again going back to the idea that we heard earlier in terms of SSRIs and parental age and other factors that might be influencing at least some of that shift over time.

And then the last one I list here is really sort of a societal shift in terms of both the acceptance of developmental disabilities and the de-stigmatization of many of these conditions.

So, pointing out strengths and challenges, which I think I've already done in terms of the prelude here. Strengths -- this is clearly a national picture so it has importance in that regard. It used the same set of questions over that 12-year time span, and it really has an exemplary response rate, so in terms of thinking about sources of bias here, you know, we can at least exclude some of those issues.

The challenges -- obviously the one key is parent reporting of these conditions, and obviously they are reporting children -- diagnoses either are physician-reported or healthcare provider-reported conditions.

And then the issue of chronicity of these disorders, and we know from the National Survey for Children's Health, in a study that was published two years ago, that when we asked parents whether their child ever had autism and whether they currently have autism, we actually came up with a very different rate. So again, getting a better sense of -- and I know NIMH is actually following up on the children whose parents reported that they no longer had the disorder, to get a better sense of what's going on there.

So just implications, I think this has important implications, very important, in terms of what Paul was just talking to us, has really a direct bearing on the need for health education and social services, including the impact on caregivers.

And I think it's also critical that we continue to monitor and get better at monitoring changes in autism as well as other developmental disabilities, trying to put that in context, both in terms of shifts in risk factors, changes in terms of acceptance and benefits of early services, and continued services. Thank you.

Dr. Insel: Thank you, Coleen. Great.

Dr. Boyle: So questions?

Dr. Insel: Just to clarify, was there an earlier round before 1998? Is there data from 1990 or --

Dr. Boyle: There was -- this was 1997 to 2008, and prior to that there was a -- there were prior -- yes, so National Health Interview Survey was done prior to that, but not all the questions were asked during that time.

So autism is really -- that was the first time autism was asked.

Dr. Insel: Okay, so we don't -- there's no 1990 autism data to compare to.

Dr. Boyle: No 1990 data, no.

Dr. Insel: Okay. Questions or comments for Coleen?

(No response.)

Dr. Insel: Okay.

Dr. Boyle: Okay. Thank you very much.

Dr. Insel: Thank you. We are going to move on to the next item on the agenda, which is a presentation on bullying and students with disabilities and, Ari, you are going to lead us in this. Thank you.

Mr. Ne'eman: Well, hello. Just before I begin, I should clarify. There's a slight error in the agenda. For the purposes of this discussion, I am here in my National Council on Disability capacity, rather than the capacity I typically serve on the committee with.

So just to provide some background, the National Council on Disability is an independent federal agency, and part of our task is to advise other parts of the federal government with respect to ensuring that disability policy is incorporated in the broad scope of areas of public policy with which the federal government engages with.

And although, as of late, in part because of some of the discussions on the Hill, a great deal of our time has been spent on issues like Medicaid and Social Security, we have always made it a high priority to look at other aspects of disability policy in discretionary spending, particularly education.

This particular paper, which is available for the IACC members within your folders, and is available for those listening at home on NCD's website, ncd.gov, was requested by the White House, for the White House Conference on Bullying Prevention, a national gathering looking to address the issue of bullying from the perspective of multiple communities, ranging from the disability community to various other civil rights communities, racial, ethnic, religious, sexual minority groups and so on, and attempted to essentially look at the issue of bullying from the perspective of students with disabilities as a particularly vulnerable population within that.

And in addition to the broad history around special education law that we identified, we noted a couple of issues that came up with respect to our literature review, which had particular implications for policy.

First, and it should serve as no surprise to any of the people here, we know that the students with disabilities are disproportionately likely to be bullied, and a lot of the research that has occurred around this has looked very specifically at the experiences of autistic students.

But even within that, students with disabilities are disproportionately likely to be bullied and for parents to have heard about it not from the school district, and this represented a very concerning trend.

One of the surveys found that less than a quarter of parents found out about bullying from the school and over 80 -- around 80 percent heard about their student's experience with bullying from the student him- or her -- the student themselves.

Obviously this represents a particularly concerning phenomenon in light of the fact that many students with disabilities have challenges with regards to communication, and as a result, are less capable of communicating those particular experiences.

There have been a number of federal policy efforts to try and address this issue, and very often bullying has been looked at simply as a social phenomenon and not as an area for public policy and in part, the recent conversations that have been occurring have been trying to change that.

Two of them have major implications for our discussion. In 2000, the Department of Education's Office of Civil Rights and Office of Special Education and Rehabilitative Services issued a Dear

Colleague letter to school districts and state education authorities talking specifically about the issue of disability harassment, stating that school districts may possess some responsibility to try and stop bullying of students with disabilities that's occurring on the basis of their disability, under Section 504 of the Rehabilitation Act and under the Americans with Disabilities Act.

Recently, last year, in 2010, the Department of Education's Office of Civil Rights issued a more broad-ranging letter, looking not just at bullying of students with disabilities, but bullying of students on the basis of other protected classes, in part based on the concerns raised from the gay and lesbian community.

But the gap that exists with these particular policy letters is that both of these Dear Colleague letters looked at bullying only on the basis of protected class, so they imposed upon school districts an obligation to act if a student was being bullied on the basis of their disability, for example if they were called the R word, or if they were teased because they took medication or walked in a funny way, but didn't impose any basis or any requirement for school districts to act if their bullying was occurring on the basis of any other attribute, say their income status or their name, and since we know that students with disabilities are disproportionately vulnerable, this is concerning.

Now part of the reason for this is because the conversations which occurred around bullying prevention in disability context have mostly been circling around Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, and rights that emerge with respect to that.

And part of the reason for that is that's the broadest definition of disability possible, and so if you are going to be encompassing the broad scope of the disability community, not every student with a disability qualifies for IDEA-funded services and an IEP.

But for those students who do qualify, we put forward in our white paper the idea that school districts may possess a higher legal obligation to not only act on the basis of bullying on the basis of disability, but also to act to respond to bullying more generally arising due to the free and appropriate public education guarantee and the least restrictive environment guarantee arising under IDEA.

I think it's very interesting, shortly after we issued this paper, the second district court for the state of New York cited this paper as the basis for supporting a parent's claim that their IDEA rights for a free and appropriate public education were in fact violated due to a school district's failure to address bullying which was not on the basis of disability.

This poses a couple of potential implications with respect to policy. First, it implies that efforts to inform school districts of their legal obligations with respect to responding to bullying need to go forward not just looking at rights arising under Section 504 and the ADA, but also need to look at the implications of rights arising under IDEA as well.

And in fact, NCD has recently issued a letter to the Department of Education Office on Civil Rights calling upon them to follow up their previous Dear Colleague letters with a third one looking specifically at school district obligations to address bullying arising under IDEA.

But in addition to that, it also poses a number of critical questions with respect to challenges that may emerge with existing bullying prevention efforts and existing IDEA law.

For example, a number of efforts

to address bullying have included zero tolerance policies and things of that nature designed to remove the students who are engaging in bullying from the environment.

That may run afoul of IDEA's Stay Put provision, which prohibits school districts from removing a student with a disability from their current placement on the basis of behavior relating to their disability.

Some states have tried to address this in their bullying prevention laws by proposing to exclude students with disabilities altogether from bullying prevention efforts, which we see as a quite unfortunate measure, and fortunately, most of those efforts have been defeated where they have been proposed in state law and instead most state laws with respect to bullying prevention have instead simply precluded any rights currently existing under special education law from being impacted from state bullying prevention laws.

In addition to that, there exists some conflict between the free and appropriate public education provision of IDEA with respect to bullying prevention and the least restrictive environment provision of IDEA with respect to bullying prevention.

If we looked at a school district's failure to respond to bullying as simply a denial of FAPE, then one of the responses the school district may choose to utilize there is to remove the child from the general education environment in order to try and address the bullying.

That would raise questions under the least restrictive environment provision of IDEA and so, as a result, we have been encouraging the department and school districts to look at bullying prevention for students with disabilities as an issue with implications under both FAPE and LRE with respect to IDEA.

We also think there are a number of significant policy recommendations which relate to this as well. We issued, in our report to the White House on this topic, seven distinct policy recommendations outlining steps that could be taken to advance the situation of students with disabilities regarding bullying prevention.

The first was relatively straightforward, which was simply ensuring that federal research programs on bullying prevention incorporated students with disabilities.

And that's an area in which we have seen some progress. The National Council on Disability and other disability-related federal agencies are now represented on the Federal Partners in Bullying Prevention task force that the federal government has convened to look at this issue.

And in addition to that, the university centers on developmental disabilities have embarked on a number of studies relating to bullying prevention.

A second recommendation was to require parental notification of bullying incidents when they occur, and this is a policy measure which we have seen in states which have adopted it for the issue of restraint and seclusion to have significant positive effects, particularly when dealing with students who, due to disabilities and other challenges or simply trauma, may not be able to report bullying when it occurs themselves.

We feel an expanded role of the IEP is relevant here too. The state of Massachusetts has passed a law which specifically requires for students with disabilities, including the autism spectrum, that are disproportionately likely to be bullied, for bullying prevention strategies to be incorporated into the IEP process, and we are hopeful that when IDEA comes up for reauthorization in the near future, although one doesn't exactly know when Congress will in fact act on it, which is a constant challenge, that this is something that we can see reflected in the federal level.

The issue of data collection represented our fourth recommendation and in fact most national surveys looking at bullying and victimization in the general population do not currently include disability on either the 504 or the IDEA definition.

We also highlighted the issue of workplace bullying, and it's relevant to note here that the Equal Employment Opportunity Commission has pursued successfully a number of cases relating to workplace harassment on the basis of disability, including instances in which the person bringing the claim was on the autism spectrum. And so we think this is an issue with relevance across the lifespan.

Finally there's some relevance with regards to federal hate crime laws, where a bullying incident denigrates to -- reaches the level of physical violence, in which there's a possibility for a claim to be brought under the Matthew Shepard and James Byrd, Jr. Hate Crime Prevention Act.

And we also encouraged Congress and relevant stakeholders to explore the possibility of a private right of action, which some circuit courts have suggested may already exist due to the claims arising regarding -- with respect to Section 504 and the ADA.

But there's a great deal of legal uncertainty on that question and so parents and families are often unsure as to what rights they possess with regards to responding to bullying incidents that occur against their children within schools.

Does anybody have any questions with regards to this?

Dr. Insel: Alison?

Ms. Singer: Yes, thank you Ari.

That was really interesting. You talked about inappropriate and poor responses from school districts to bullying, but what are some of the best practices guidelines for school districts? What would we like to see school districts doing in response?

Mr. Ne'eman: So this is one of the challenges. Because of the fact that up until very recently, bullying was frankly not looked at as a public policy problem and there was sort of a boys would be boys kind of attitude out there, there is not a lot of research on highly effective means of bullying prevention.

There's been a little bit out there that's seen some promise. The Olweus interventions that came out of Scandinavia have some research base to support them.

But in part what's needed here is a more broad-based effort to ensure that these issues are reflected in the federal research agenda both more broadly and with respect to students with disabilities.

We have mostly been looking at this issue frankly as a legal issue rather than as a research issue under the assumption that if school districts have an obligation to respond, and an obligation to show that they are not practicing -- and I believe the legal standard is deliberate indifference -- that that will spark a great deal of innovation as to various options as to how to respond.

But as of the moment, the research literature on this question is frankly very weak.

Dr. Insel: Yvette.

Dr. Janvier: Yes, I just wanted to comment, I mean I work with many, many children on the spectrum on a regular basis, and I notice that they are more often discussing with me bullying that is going on in school, and I thought maybe there's an increase in bullying, but I have a feeling that many of the schools, I know many of the schools have anti-bullying policies, so those policies are not decreasing the bullying. But what they seem to be doing is educating the children who are being bullied that they are being bullied, so that they are bringing those concerns, you know, either to a professional's attention, my attention, and sometimes to their parents.

So it's kind of an interesting way of the right thing being addressed but not necessarily the focus of the programs.

The other thing that's happening, you know, I work in a hospital-based program, and the Joint Commission for Accreditation of Hospital Organizations now has us asking everyone, are you threatened.

And in the population that I'm dealing with, which are children with developmental disabilities, we are getting a lot of interesting answers, and I can tell you, we don't really have a policy as to how to address this.

So you know, it seems to be an emerging area of, you know, development, but I do think it's interesting that you know, so many of the children in my office who are verbal and can communicate and can tell you what's happening in school, they are raising that concern but the schools don't seem to be responding very well, and certainly, it's not affecting the bullies who are continuing to bully.

Mr. Ne'eman: I think that's certainly the case. One of the most frightening statistics we found in the literature review we did was one survey found that as many as 92 percent of families with kids on the autism spectrum had discussed bullying with school officials, but only about 68 percent felt that school officials had an adequate response to it.

So I think what we are getting at here is actually I think a very similar issue to the challenges faced by families that are trying to get school districts to do more around soft skills and other non-academic skills for students with disabilities, which is namely, we need to help schools understand that they possess responsibilities towards their students that go beyond simply the educational sphere and the academic sphere.

Now fortunately, in the context of bullying prevention, it seems like the Department of Education's Dear Colleague letters have stated that quite explicitly with regards to the bullying that's occurring on the basis of a protected class characteristic, such as disability or gender.

But there appears to be, based on recent judicial rulings, an opportunity to expand that to a more broad-based obligation to respond for students who would have IEPs.

Dr. Insel: Denise.

Ms. Resnik: Thank you, Ari. Greatly appreciate that presentation and it's concerning to all of us. Was there anything in the research and in your review on peer supports and peers coming forward, particularly when we talk about vulnerable populations who can't self-report?

And I'd be curious to find out what you learned about peers.

Mr. Ne'eman: That wasn't an area that we looked at closely, primarily because the request from the White House was mainly a review as to the extent of the problem and then policy and legal questions that come up with respect to looking at potential federal and state action.

But it definitely is a relevant one. I mean we know that the problems that emerge here come out of issues with peer victimization and that those are things that are driven by peer pressure, and you know, much of the literature in the positive behavioral supports realm suggests that the response to that can also be found with respect to action by peers.

So I think, you know, that's definitely going to be a relevant area for future research.

Dr. Insel: So I think Marjorie and then Geri and Ellen.

Dr. Solomon: Two sort of clinical resources. Fred Frankel at UCLA has a book Good Friends Are Hard to Find that outlines some of the practices that children and their parents can use to try to help a child prevent themselves from being bullied, and that does include getting peer supports.

I also believe the Department of Education, and I'll go online later and look for it and I can distribute it, has a really nice website that talks about what kids can do when they are bullied.

So it really has become a very big national issue and I don't know that there is any empirical research on it but there are some better resources now.

Dr. Dawson: Thank you for that

presentation, Ari. I was just going to mention that I think that your idea of conducting research in this area is a very important one and, you know, we don't see a lot.

In fact looking at our portfolio, I think for the first time we funded a project last year that was the first one that came in on bullying and it's a project that is looking at both factors that lead to higher risk for bullying for individuals with autism, and as well as factors that can reduce opportunities and reduce risk for bullying, with the focus a lot on this peer victimization. So I'm really eager to see, you know, what comes out of that research project but I'm struck, you know, as we look across the full portfolio, that we really don't have a lot of research in this area and it's an important one.

Mr. Ne'eman: I know it certainly is, and I guess the one thing I would add there is it seems critical to me that as we look at this issue across the various sectors with which it is relevant: research, policy, law, that we not only look at identifying why and when it's happening, but also what we do in response.

And that's really frankly the area where the research is weakest right now. It's also an area where the law is the most conflicted, and you know, again when we tried to address this issue, and you know, as we work to try and get guidance that looks at bullying, responsibilities of school districts with regards to bullying under IDEA, we continue to see sort of a trend, a trend on the part of many school districts, to try and respond to this issue by removing students who are bullied, and from our standpoint that's very counterintuitive and it's very counterproductive.

Bullying occurs in segregated environments and in environments that only consist of students with disabilities just as much as it occurs in integrated environments, and if we are going to try and address the bullying simply by removing the victim, well, certainly, I think there are all kinds of ethical questions to be had there, but there are also a number of very real, practical questions, which is to say, that doesn't change the problem. It simply hides it from view.

Dr. Insel: Ellen.

Ms. Blackwell: Ari, do we know of any states other than New Jersey and Texas that are ahead of the curve in terms of statewide legislation on this issue?

Mr. Ne'eman: Well most states have passed laws with regards to this issue, it's just that you know, frankly, most state laws consist of requiring school districts to have a bullying prevention policy, and that doesn't exactly have the best track record of success there.

There have been some moderate efforts with regards to data collection, but the truth of the matter is, is that the state laws that have occurred here have had a limited impact.

The things that have driven more change around this have been the judicial decisions, which seem to have sent a message on the part of school administrators that failure to act in response to bullying constitutes some degree of liability, and that's driven a lot of change.

That's not limited to the disability community. There's also been a lot of stuff coming out with respect to that regarding gender, suggesting that some of the litigation that's occurred regarding workplace harassment may have similar implications for schoolyard harassment as well.

So you know, again, most states do have an anti-bullying law but the most progress has been coming in other sectors.

Dr. Insel: You had Julia Bascom down on this part of the agenda. Is she here?

Mr. Ne'eman: I think so.

Dr. Insel: And was your plan to have her join you for part of the presentation?

Mr. Ne'eman: I think she has her own presentation.

Dr. Insel: Okay, because we are -- we have used up the time for this segment of the agenda. We can extend it a bit but it will bleed into other items on the agenda. Maybe we can do this rather quickly.

Mr. Ne'eman: Well let's give Julia a chance to speak.

Dr. Insel: Right.

Mr. Ne'eman: And then we'll move forward.

Dr. Insel: Okay. Welcome to the meeting. If you are more comfortable sitting at the table, you are welcome to do that as well, unless you have slides to show.

Ms. Bascom: Do I need to adjust this?

Dr. Insel: No, well I think we can just raise it a little bit. Because the time is short, I didn't realize we were going to have two presentations in this section, I would just encourage you maybe to, let's say five minutes and we'll see if there's conversation or discussion. Thank you.

Ms. Bascom: Hi. My name is Julia Bascom and I've had it easy. I've had it easy. What this means is that in fifth grade I was the smartest kid in the class.

I also did a lot of hiding under my desk and I talked funny and I moved stiffly, so the other kids formed a club. It had only one rule, the golden rule: you couldn't talk to Julia.

I changed schools at the end of the year. I kept breathing, but then, I had to. I had it easy. No one beat me up. They didn't have to. I did a good enough job of that on my own.

I have a friend. We'll call him

Martin. Martin is autistic --

Dr. Guttmacher: Those of us on the phone can't hear right now for some reason.

Dr. Insel: Thanks Alan, maybe we -- Julia, is there a way to adjust the microphone? Or let's just see if we can increase the volume.

It's not on? Okay. Well in the meantime, would you feel okay using a microphone at the table and you could just join us here, and would that --

Yes, yes, well there are plenty of seats and there are plenty of active mics and that way everybody will be able to hear.

Ms. Bascom: Okay.

Dr. Insel: Great thank you.

Dr. Guttmacher: Thanks.

Ms. Bascom: Does that work?

Dr. Insel: That's great, and this mainly was meant as a test to make sure Dr. Guttmacher was still with us, so good to know you are there.

Dr. Guttmacher: Well, I passed. Feel free to do another spot quiz anytime.

Ms. Bascom: I'm just going to start over if that's okay. Okay. Hi. My name is Julia Bascom and I've had it easy.

I had it easy. What this means is that in fifth grade I was the smartest kid in the class. I also did a lot of hiding under my desk, and I talked funny and I moved stiffly, so the other kids formed a club.

It had only one rule, the golden rule: You couldn't talk to Julia.

I changed schools at the end of the year. I kept breathing, but then, I had to. I had it easy.

No one beat me up. They didn't have to. I did a good enough job of that on my own.

I have a friend. We'll call him Martin. Martin is autistic, like I am, although he doesn't identify that way. In fact, nothing would make him happier than being just like everybody else.

See, Martin and I are different. We both know that being different, being autistic, being disabled, is dangerous.

We've both been bullied. We've both had it easy. We've both seen what our alternatives are -- be just like everyone else, or don't be anything at all.

The difference between Martin and I is that I know without a shadow of a doubt that this is wrong. Martin doesn't.

Martin and I became friends because we were both worried about each other. Martin was worried because apparently no one had ever taught me how to pass for normal.

I was worried about Martin and the way he was quietly twisting himself away. I only got more worried when he tried to teach me how to blend in, how to pass, when he yelled at me senior year for looking like that, because don't you know you'll get hurt, you'll die, looking like that?

I have another friend and we'll call her Maria. Maria has also had it easy. She's autistic like me, but she is more visibly disabled than I am.

What this means is that when we went to get ice cream two weeks ago no one would sit near us. What this means is that people think that because I help her count out the change to pay for ice cream, I should be the one ordering for her.

What this means is that Maria is not permitted to just neutrally exist in public. Getting ice cream becomes an act of war.

I work with middle school students with significant disabilities in a mostly self-contained classroom. Some of them have also had it easy. No one will talk to them, the other kids run away when they see us coming, the teachers don't want them in their class room, but no one gets beat up.

Some of them have permanent brain injuries from abuse. Like Charlie. Charlie goes into murderous rages and he has almost killed people.

He's the sweetest kid, but someone decided to beat him enough that he doesn't feel the world is safe for him, and he's right.

Kaley hasn't been to school in two months. The social workers are sent away from the house and the state is content to leave it at that. I don't even know if she's still alive, and no one seems interested in finding out.

Roger, who can't feel or control his tongue, was kicked out of his foster home three days before Christmas because he ate too messily.

He is in an institutional placement now and his foster mom visits him regularly and expects him to call her "mom" and say that he loves her.

And she says she loves him too. And the hell of it is, the world agrees with her.

Here's the thing about being disabled: It sucks. It's horrible in a million different ways, and not a single one of those ways is because I can't do this or because I have that impairment.

That would be too easy. Instead, every single reason translates roughly to: because people are awful.

Sometimes, for a minute, for a day, for a week, I think I can forget that. I delude myself into thinking that the reason I can buy ice cream without five different hostile stares, can be allowed to work in a school, can be invited to the occasional meeting, is because people really are okay, and not just because I learned how to fake being normal, being human well enough to avoid some sort of weird ability-based xenophobia.

I'm wrong, of course.

This is about bullying. And here's the genius behind really good, really effective bullying: it turns the victim into their own worst bully.

I told you I never got beat up for being autistic, but I want you to take a really good look at me. You see my glasses? That's from banging my head in 10th grade.

I have spots all over my arms from gouging my skin out. The scars on my face are the same idea, though a little more recent. Same idea: Self destruct.

I -- there are a million more I can't even show you. I mean even the insides of my cheeks are scarred. I can't tell you how many pairs of sheets I've had to throw away because I woke up covered in blood from trying to pick myself apart while I slept.

And I didn't do it because I was depressed, or scared, or because I hated myself. I didn't want to hurt. But I knew I had to. When I hurt, I was in my place.

And smacking my head against a wall for an hour a day was ultimately less painful than trying to convince myself, let alone everyone else, that I was maybe, possibly, worth something just the way I was.

The thing about bullies is that, although they never go away -- I mean, I went to a different school with different kids after fifth grade, but there were always plenty of bullies to keep me remembering is that they can't be with you every second of every hour of every day.

They can do hundreds of subtle and nasty things to you, and they will, but eventually they will need to pee or go home or at least sleep.

So what they do is they program you so that you can bully yourself in their stead. I mean, I can still hear the chanted "retards" in my head whenever I play with a strand of beads. I still believe, in my stomach and in my pulse, the way you know to run away from a lion or not to jump in the campfire, that I shouldn't be here.

I don't need someone yelling at me to sit down, shut up, stop flapping. I do those things automatically now. No one needs to tell me that I'm worthless. I get that. Message received, message believed, message drilled into my bones.

No one has to threaten me and force me into some version of myself that is less visibly disabled, less obviously autistic, less real and I guess less threatening. I've carved off all those edges of myself into exactly what I need to be.

And that's the only reason I've ever had it easy. Because I could do that. Because I have, or had, the rare ability to pull myself apart and twist myself into some new shape when ordered.

I'm lucky, in other words, that I don't have any glue holding me together. I'm lucky to be broken, because then there is nothing left for anyone else to break.

So what I've just described is called having it easy, and it's actually not easy at all. It's complete and utter psychological and emotional warfare, and there is no winning for us.

They, the bullies, set the rules and the terms and they will always win. Millions of us live like this every day. We have it easy, we can't complain, this isn't something that can be solved with curb cuts or an act of legislation, and so we die the death of a thousand cuts.

I told you about Martin, earlier. Martin always beat me on quizzes in class, but there is one thing I know that he doesn't. I know that this is bullshit.

Here's the secret. There is, in fact, one way to beat the bullies. See, what they want is to work themselves out of a job, to have you doing their dirty work for them. They want you to beat yourself up.

So the way you win is by stepping out of the game entirely. The way you win is by knowing, being absolutely and irrevocably and 100 percent positive, that they are wrong.

It's the tiniest thing. It's also almost impossibly hard. I mean, how do you discover the world's best-kept secret: that despite what you've been hearing since you were two and your parents started dragging you to doctor after doctor and all the other kids stopped playing with you, that you are actually perfectly fine, just fine.

When you are disabled, you are sick in every sense of the word. You are disgusting, scary, dangerous, broken, wrong, lesser. I knew this, I had it memorized and lived my life accordingly.

But one day I met someone else who was sick. "You're sick!" I protested when they insisted on acting like a human being.

"Yes, I am." they agreed. "So are you."

And then one morning I woke up, and I was still sick. And I was also fine.

I was fine.

There is no equivalent to a Gay-Straight Alliance or a GSA for disabled kids. We have to pass it on like a secret. You're okay. We're okay. Everyone else is wrong. We have a right to be here too. We're not just sick. We're not in doctors' offices all the time. We're okay.

And we need that support, we need some sort of physical community. Passing it on like a rumor isn't enough. The moment we realize that the hateful people who fill and control our lives are wrong is the moment when everything can start to change.

That moment shouldn't ever have to happen. It should always just be something we always know. Things won't get better until then.

Good-bye. My name is Julia Bascom, and I am, always have been, and always will be, fine.

Thank you.

(Applause.)

Dr. Insel: Julia, thank you for sharing that with us, and in view of the time we are going to have to move on, but we really appreciate your joining us and there may be a chance for further response during our discussion of public comment as well, if people would like to respond at that point.

In the previous meetings we have had there have been lots of discussions about sort of the face of autism, and the question of heterogeneity comes up over and over again and it's one of the issues that I think has been at the heart of the most conflicted conversations we have had and also some of the most complex ones, because we may each have a very different picture of what we are thinking about when we think about Autism Spectrum Disorder. It truly is a spectrum.

Leading up to this meeting, there

was a suggestion from several members of the committee that one of the things they wanted to do with this meeting was to make sure that there would be an opportunity for the full committee to hear from different ends of the spectrum, and so the next two presentations, which I am afraid will have to be briefer than we would like, because of the time constraints, represent that.

We want to hear on the one hand from Heidi Scheer, who is here to talk to us about the needs of children with severe autism, and from Scott Robertson, who is going to join us from the Autistic Self Advocacy Network.

So, Heidi, welcome to the meeting. I know you have come from far away. We really appreciate your engagement with us.

Ms. Scheer: Thank you for having me. I really appreciate it. Yes, I am here just to give you a few minutes. I'll keep it brief as to what it's like to live with a child with severe autism.

Of course, we know the spectrum is very, very broad and we have high-functioning Asperger's, and then we have the much more severe cases.

So what I'm going to start with right now is just a little look into just the daily morning routine of an eight-year-old with severe autism.

(Pause while video starts.)

Ms. Scheer: Can we make it full screen?

(Video shown.)

Dr. Insel: Is the audio on on the computer itself?

(Video continues.)

Dr. Insel: Maybe you can move the microphone closer to the speaker on the computer. Would that help?

(Video continues.)

Ms. Scheer: So there you have it, just a few moments of a daily task that we all need to do, which is to get dressed.

This actually took two hours to come to conclusion, and that's what we need people to know, that living with severe autism impacts every aspect of your being, as a family, and that's why it's so crucial for research to be done in every aspect of treating autism.

My son, many of his friends that we know through traveling around and meeting people with autism, so many of these children have such severe GI problems that they are in such pain, that they literally whine and cry day and night, all day long. That's all they can do.

And it's crucial that we don't forget about the medical, the physical, the biological aspects of treating children with severe autism so that they can become well.

I also want to share just one more moment with you, as to how severe it can be to live with a child with severe autism.

My child was actually so severe one day that he left the home without my knowledge. This was before we had to install alarms and locks on every door and window in my home.

He left without me knowing and he wandered three blocks away into the middle of the road. He was in his underwear. He was in bare feet and he almost got hit by a car.

I was greeted by four police cars, officers and a whole lot of questions. That is not only the day that I almost lost my son, literally, to death by being hit by a car, but also by questions of law enforcement as to why my son had wandered out of my home and was almost hit because he was in the middle of traffic.

So I just need to share with you that it is imperative that everyone here know the pain of living with severe autism and that we need to make change. We need to make change and we need research to, like I said, dive into every aspect of treating these children with autism.

And I thank you so much for allowing me to be here today and sharing our story. Thank you.

(Applause.)

Dr. Insel: Thank you. Scott Robertson.

Mr. Robertson: So do I need to sit at the table or sit up over here? Is the microphone not working at the podium?

Dr. Insel: You are welcome to do either one. Whatever you are most comfortable with.

Mr. Robertson: I just wanted to make sure I didn't mess up with the technology here. So I'll try to keep this not too long, so if we maybe have a little bit of time for your questions. I don't have any slides. I just have a few remarks.

I wanted to thank the committee, the Interagency Autism Coordinating Committee, for inviting me here to speak today from my perspective as an autistic adult and national advocate for autistic people, adults, youth, and children.

I just want to share a little bit about my background before I dive into services and supports for autistic adults, and the dire need for expanding in that area.

So just to give you a little bit on my background is in the advocacy world, I serve as Vice-Chair on the Board of Directors of the Autistic Self Advocacy Network, as a council member on the Pennsylvania Developmental Disabilities Council, as a member of the Autism NOW National Autism Research and Information Center, which is federally funded, and as a member of the advisory board of the Bureau of Autism Services in the Pennsylvania Department of Public Welfare, our state agency for autism, and I am also a PhD student at Penn State researching cyberbullying and face-to-face bullying.

And what I'd like to see in the adult world is to have more research on adults who are bullied actually, so I was going to mention that in the comments.

So Pennsylvania has become one of the few states nationally to create both a state agency for autism and develop autism-specific and community support systems for autistic adults.

With our Adult Autism Medicaid Waiver and autism community assistance program, and I had the opportunity to serve on the advisory work group that defined both the services definitional criteria for the Adult Autism Medicaid Waiver in 2007, and since then I have also provided advisory recommendations for the administration of that program, and another program, the ACAP Program (Adult Community Autism Program) in Pennsylvania, and it's been fortunate because we are doing things that aren't being done in other states.

The challenge is we only have a few hundred autistic adults being served right now because we have limited funding and supports from the government.

We only have several million dollars in Pennsylvania to support for both these programs, to provide in-community supports and services, employment and other areas.

And even if we raise the slots by providing more funding, some autistic adults would not meet the eligibility criteria, which is not defined by intellectual disability, but by functional eligibility, ICF criteria.

And so we have that challenge of the functional eligibility and funding and it reflects a large situation across the United States, where to expand those supports and services, we need to think on government, but we need to think broader than that.

I think it's been a big pitfall for the broader developmental disability and intellectual disability community that we have focused so exclusively on government will fix everything at state and national levels, and I think we have to also be thinking about how non-profits, the public sector et cetera, can be part of the change process.

And part of it also is research. All the research has greatly improved for autism, it's greatly increased over the last several decades. Research on service and supports for autistic adults has ridden fairly -- it has not kept pace with other research areas.

I believe I saw in the last -- one of the research reports from the IACC from 2009 I think, that it was about three percent or about $8 million was funded specifically for services, which is a very, very small portion when you consider that it's a few hundred million dollars being allocated for research funding, and that is a big, large gap that does not exist in the cross-disability community quite as much.

And the problem is if you do not have the funding and grants, researchers will not necessarily study areas. Research is a business like other businesses.

So we need to improve the research in these areas and this will necessitate shifting our priorities to make research on service supports for autistic adults a priority.

We must prioritize research particularly that enables autistic adults to obtain self-sufficient employment, pursue a post-secondary education, live in our own communities, create friendships and romantic partnerships and participate as active voting citizens.

We must also prioritize research that studies adolescent victimization, abuse and bullying of autistic adults, which is practically non-existent.

And we must also prioritize

research that studies how assistive and supportive technologies can empower autistic adults, and support our ability to achieve a high quality of life.

And I of course highly value the technology side of things, coming from a background in technology myself, having a Bachelors in Computer Science, a Masters in Human and Computer Interaction and studying right now in my doctoral studies information sciences and technology, when I'm looking at cyberbullying and how technologies can empower on teaching anti-bullying strategies is what I am looking at with my dissertation research.

I have also seen first hand how augmentative and alternative communication devices and technologies can make a major difference in the lives of autistic adults and other people with disabilities, in my experience in the advocacy community.

So I would strongly urge the IACC to look at how we can shift toward growing the allocation of money both privately and government-wide, that supports research on services and supports, and look at how we can address gaps more creatively and fill in areas where government alone may not be able to do things, but maybe government with some other partnerships or maybe non-profits, and maybe other new ways of doing business that we are not doing right now.

I think we tend to sometimes just keep doing the same old thing, and I think that's also part of the research process for looking at service and supports for autistic adults, is how we can be coming up with new ways of doing business for supports, and also be looking at things in Pennsylvania and other states that are going well, and how we can replicate these support systems across the country.

That's my comments. Thank you very much for inviting me here to speak.

Dr. Insel: Thank you.

(Applause.)

Dr. Insel: I promised you a break at 3:10. It's 3:15. Unless there are comments for this past session -- are there any?

(No response.)

Then let's plan to take a break now. I need to have everybody back at 3:30. We have still got some committee business to do which is really important, and we certainly have to have a discussion about the future of the IACC, which we will do between 3:30 and 4:30.

(Whereupon, the committee took a brief break starting at 3:16 p.m., and reconvening at 3:30 p.m.)

Dr. Insel: All right. We are going to reconvene for committee business, and we have a lot to do in about one hour to get it all done.

So, let's start with the safety subcommittee update. There are many people who have been working on this: Sharon Lewis; Lyn

Redwood; Alison Singer.

Alison is going to take us through the update with some supporting comments as well from other members of the subcommittee.

Ms. Singer: Thank you. Just to remind the committee, last October, in response to a very heartwarming and moving representation by Sheila Medlam, Lori McIlwain and Wendy Fournier, we created the safety subcommittee.

The committee has been working very diligently, really focusing in on two key issues: The issues of wandering; and the issues of restraint and seclusion.

With regard to restraint and seclusion we have been working closely with the services subcommittee and we will hear more about that in a few minutes.

So the safety subcommittee right now wants to report out on our activities with regard to wandering, which have focused primarily on fielding a survey to gather hard data on the scope of the wandering issue, and then using that data to try to effect public policy changes.

And then the second piece that our committee has focused on, is trying to change the ICD-9 coding to create a medical subclassification for wandering.

So, first today we are going to hear from Dr. Paul Law on the wandering survey, and then after that we will hear from Coleen Boyle from the CDC.

So first like I said we are going to hear from Paul, who is the Director of the Interactive Autism Network.

Dr. Daniels: And I'll say that we have copies of the report that is on the web from IAN in your packets, and it's up on the website as well.

Dr. Law: Okay, thanks a lot for inviting me. I have been coming to these meetings for some time. It's a pleasure to get to talk, hopefully not on the last IACC meeting.

So what I am going to be talking to you a little bit about is the elopement and wandering survey that my team at IAN did with a number of partners.

First of all, just a -- you need to know a little bit about IAN first. So IAN is a project that is devoted to accelerating the pace of autism research.

It consists of a research project and a community website that's devoted to research. On the research side, families are invited to join the project online by registering entirely online, consenting online and providing data online.

So we are sort of the experts in online assessment, and we have 38,000 members and of those, 17,000 have ASD and the remainder are family members.

And IANCommunity has lots of articles, 50,000 visitors a month and families really engage in research and so we are excited about that.

So, in October of 2010, again the autism advocacy organizations reported to the IACC that elopement in ASD led to fatalities, injuries, family stress and burden.

A lot of this was anecdotal so there was the sense that we needed much more information.

In November 2010, the IACC created the safety subcommittee, which was to focus primarily first on the issue of elopement or wandering.

This slide was meant to be -- I meant to have this one slide up, but back to IAN for a second, we leverage internet mediated research, that's our area of specialty. There's actually a journal named after this area of expertise that we are interested in.

There's been two diagnosis validation studies for IAN and 98 plus percent of families that report that they have a diagnosis on IAN and then -- and also screen positive using the SDQ, which is a screener for autism, turn out to have autism by the gold standard, so this is pretty good quality data overall that we are dealing with.

And overall, you know, there's always issues of bias and I just thought I'd mention this up front, in any study. IMR as a field of research has been shown to be less biased than anything -- compared to center-based research, which is where most of autism research is based, but certainly not as free from bias as population-based studies of the type that the CDC is involved in.

So despite community knowledge and concern, there was virtually no research that had been done on elopement in ASDs. The research that is out there, you kind of -- it's not in abstracts. You have to go digging for it. Cathy Rice just told me about another study that she stumbled upon that pertains to this.

But in a study by Lowe in 2007, in a checklist of many behaviors associated with autism, wandering or elopement was found to be common, and there was a literature review in 2008 of treatments for wandering, but it was for all developmental disabilities, not for autism.

And IAN was uniquely positioned, because of the many families participating, to give us some initial information about it, and there was really no article devoted to autism in the literature yet.

So, IAN was partnered with, was really approached by several wonderful organizations, who not only contributed financially towards the project, but really were the domain experts on wandering.

I mean, there are no experts I think in wandering in autism, but together, there was a lot of experience and a number of people in particular had a lot of practical experience putting together resources for families.

So, together, over the course of eight weeks, we wanted to work quickly to get some information out there for everybody to react to, and then to learn and move forward quickly.

So we developed a 41 item survey quickly. This was done on the weekends. This was done with a lot of extra effort.

The survey was launched on March the 24th a few days before Autism Awareness Month, to try to leverage, you know, the increased activity of the community in that month.

The partners really helped to disseminate and activate the grassroots network. We have had more than 1,500 responses so far.

The results were shared in the report. You will look at the date on your report. It's less than 30 days from the launch of the survey, which we are proud of.

We also did press releases at the same time, and as the data was coming in, it's automatically being shared with the National Database for Autism Research, because these families have consents on file to have their data join the National Database for Autism Research. And already we have a team of researchers working on the paper.

So a lot of this presentation is just giving you a sense of how quickly we moved, but now we get into the actual results of the survey.

So there were 1,098 preselected children that we wanted to have participate in the survey, and then there was -- and then others were allowed to take it if they wanted it, but we didn't push them to take it or incentivize them to take it.

So we wanted to have a relatively -- well, a representative sample as best we could, but with a very high response rate.

So these -- amongst these

children, who were four to 17.5 years, 655 completed the survey, which is 60 percent, which is very, very good for surveys.

These groups were selected because they were relatively active, which mainly meant that they had joined IAN relatively recently. They were incentivized with the potential of drawing for an iPod.

We stressed the importance of people who didn't have kids who wandered to complete the survey, and because of -- we oversampled within the African American participants in IAN to get a more nationally representative sample.

And then you have the other 900, which I'm not going to talk about for the rest of the slides. So these results come from the best, most representative sample that we could get from IAN.

The key question was -- so we didn't like the term -- we didn't like any of the terms that are used for this behavior.

We didn't like wandering because that has connotations. Wandering is an aimless behavior as defined by Webster's, and when we asked parents what these words meant to them, it just -- there wasn't consistent definitions coming out of it. So we went with a very descriptive approach in constructing our question.

So the question -- the key question that pertains to prevalence was at what age(s) did your child attempt to leave safe spaces and/or caregiver supervision.

So the whole issue was safety and it has to do with supervision and safe spaces. And this was -- there was a lot of examples and lead-in to this question, so we felt like families were able to interpret it very consistently.

Again, we looked at other questions that were out there and we really didn't like any of them, so we made our own.

This is just reiterating the

concept, so you have a safe space, like a home, with locks perhaps, and then when you are out in public, the parent turns on their radar and they are watching their kids and making sure that they are keeping them safe, and this is another sort of picture of appropriate supervision in public.

The age distribution of participants for the survey, you can see that there was more younger kids. But the sample sizes aren't -- you know, they are not terrible within these latter years. There's more than 20 17- and 16- and 15-year-olds.

All right. So here's really the key slide for the whole presentation, and I was presenting this to a friend the other day and they pointed out the key point of this whole slide.

And that is that it looks like a shoe. That's supposed to be funny, but I was thinking about sharing that funny joke, and as I was thinking about it, somebody out in the hallway said, oh I wish I had her shoes, so anyway.

So this kind of looks like a high heel, so if I didn't say that, you wouldn't remember the shape of this at all, so -- so this is age, and this is reported ages at which the child eloped.

And it starts -- so our definition of elopement started at 4. We didn't really -- we had to come up with an age at which we were going to start counting elopement and there wasn't actually a whole lot of guidance. I need to talk to more developmental pediatricians as to when this becomes abnormal.

But we decided just to go ahead and start collecting data, one, to see if there was differences in autistic kids versus you know, their peers at younger ages.

And as you can see, there's certainly more wandering behavior in the siblings at this age ranges. There's much more in the children with ASD.

And the rate stays much higher, many times morefold, even though -- the ratio of these numbers is staying very high even as you move into the latter years.

And you know, we will see whether this holds up as a significant bump, but it is right around the age of puberty, so perhaps that is meaningful.

The overall rate of elopement over the course of these first 17 years -- that's cutting here -- was 50.4 percent, which turns out to be reasonably similar to what the other couple of studies that just reported the rate were -- that are in the literature.

So let's skip down to here in the interests of time. Of all who attempted -- I'm going to start drilling down now -- so all -- so not everybody attempted. So of all who attempted, nearly half succeeded, you know, so there was the tendency or the attempts to elope, and then there was the actual successful elopements, which we looked at differently.

So those who actually succeeded in elopement, well, half of them, of those who attempted, half made it. So now let's try to look at more concrete outcomes that pertain to this.

So, of those children who actually eloped, which is about 25 percent of all children in this study, and I'll try to go slowly because I get confused by the numbers myself, but of those 25 percent that actually eloped in those instances of elopement, 30 percent of the time the police were called, and two-thirds of the time, there was a report of a close call with a traffic injury, and a third of the time there was a close call with drowning.

And then these numbers here give you the numbers for the -- for the -- the rate for the total population, not just those who actually successfully eloped.

So these are pretty significant, I mean, almost 10 percent of the time families have an experience with the police in regards to their children.

And keep in mind that actually these are not -- many of these kids, remember the population distribution at the beginning for the sample, so a lot of these kids haven't actually made it all the way through these years yet.

So these rates are actually going to go up when we go in and adjust for them and I get some statistical help.

So we asked a lot -- we obtained a lot of qualitative descriptive information about elopement to help better understand it. This is just an example.

And the point I wanted to make here is that the state of mind that parents are reporting their child to be in, confused or in a fog, is only nine percent of the time.

So in Alzheimer's research on

wandering, it's all about you know, adults who are confused or in a fog. So wandering in autism is not -- there's no precedent really.

I tried going through the Alzheimer's literature. It wasn't all that helpful because it's not the same thing. All our -- most of our kids, they are trying to get away from something, they are trying to get to something and so forth.

So, we were able to collect data very quickly. We hope to be there for anybody who wants to address additional issues. We can mobilize things very quickly and very cheaply.

And some of the upcoming projects that we are working on -- I didn't know this when -- prior to seeing the agenda for today -- but one of the key, one of the next surveys we are going to do is on bullying and children with ASDs, and one of our -- I'm not an expert in this, but the person who is going to be working with us is Catherine Bradshaw, who I think spoke at the -- at some of the conferences that Ari was talking about. Anyway, she is a world expert on bullying in children with developmental disabilities.

And the data that -- as it came in, immediately provided traction to the advocacy efforts and I'll stop there and let somebody else comment on how the data was actually used in the advocacy arena.

Dr. Insel: Alison.

Ms. Singer: Well first I want to thank Paul and Connie and everyone at the IAN network. I think the IAN database that has been created is just a hugely important and robust resource for the community, and I also want to thank Autism Speaks and the Simons Foundation and the NIMH for funding the IAN network.

I think it's a great example of how we can proceed with a sense of urgency, with the type of urgency that this committee always talks about.

This project went from concept to

data reporting in less than six months, and now we are able to take those data and use them to affect public policy change.

So what's happened since the data were released is that we have created a working group of autism advocacy organizations led by Lori McIlwain and Wendy Fournier and we have been talking about the best way to try to create an emergency response system for children and adults with autism.

And we talked about whether or not to expand the Amber Alert and the Silver Alert systems, but where the group has really come down, based on these data, is that we think that we need a disability-specific, non-age related emergency response system.

So we are now taking the data that came out of the survey and using them to approach Department of Justice and state and federal legislators to try to move that forward.

So again, I want to thank Paul for

his tenacity and just the speed with which he approached it. So many thanks again to you.

Dr. Law: I would like -- I took out the slide that was supposed to remind me to do something very important, which I'm going to do now.

But, so Autism Speaks helped us to get going from the beginning, and we really want to thank them and Geri Dawson and the Simons Foundation is one of our sort of steady, core supporters of the core part of IAN, and the National Institutes of Mental Health, so just really appreciate their support, in addition to the project support we got for this.

Dr. Insel: Thanks Paul. Why don't we hear from Coleen, and then see if there's any comment from the committee?

Dr. Boyle: To give my update on ICD-9? Okay. So I think the last time we met I did give everyone an update on the proposal that was submitted to the coordination and maintenance committee, and this is the committee that oversees new codes, new CM codes to ICD-9, and this committee is actually a joint committee led by the National Center for Health Statistics at CDC as well as CMS.

There was a window of opportunity for this code and this, actually the idea of the code was proposed by the National Autism Association when they presented to the committee, the full committee last September.

So we did end up going forward with the proposal. There was a deadline for January and there really was this very brief window of opportunity.

And this was part of the normal process for the committee, so this was the last time they were going to consider proposals for new codes, and there wouldn't really be another opportunity until 2014.

At the time the committee actually received over 160 proposals for codes and the wandering code was one of those 165.

There was an open meeting to discuss the autism proposal -- the wandering code proposal I should say, not autism proposal, wandering code proposal -- as well as the other 165 codes, and then there was a public comment period that occurred in March of this year.

The committee actually received over 6,000 comments about the proposed code with the bulk of the comments coming in favor of the code.

And after considering the significant number and content of the codes received, a code was added. This code is V40.31 and it's wandering in diseases classified elsewhere.

It was posted, as well as all of the revised ICD-9-CM codes were posted on the website of the committee on June 10th and I have the website which I can share with the full committee.

And the codes will actually go

into effect in October. The committee -- this is the coordinating and maintenance committee for ICD-9-CM -- will post guidance on how to use the code, and this guidance is actually part of the coding clinics for ICD-9-CM, a lot I learned through this process.

And both NCHS and CMS must approve the content of what is put in the coding clinics, and there's other organizations that are part of that, the American Hospital Association and the American Medical Association, the AAP, American Academy of Pediatrics, all have a member on this committee in terms of approval of codes.

And essentially the instructions will indicate that wandering should be coded if documented in the medical record by the provider.

And the code itself is not specific to autism, but it will be -- could be used in -- as a secondary code in relationship to any disorder in which this behavior is indicated.

Again, the proposed code is really intended to promote better data collection for and understanding of this behavior, as well as to prompt important safety discussions among healthcare providers, caregivers and the person with the disability, the full extent possible.

So there's the -- I will share though the website information with Susan, since she can distribute it to you, and by October the actual guidance for the use of that code will be available.

Dr. Insel: Great, thank you. Comments for the safety subcommittee? Anything?

Dr. Lawler: I just have a quick comment. The IAN survey, did it collect information about the intensity of the behavior, was it just you know, one or more instances of wandering, because I was wondering that -- what the distribution is and if there were, you know, a group, that it was particularly at risk, you know, and that could help potentially guide how this code is documented?

Dr. Insel: Paul did you hear the question?

Dr. Lawler: Rather than just the percentage of families that reported wandering, did you ask about, you know, how often it occurred or would it be useful to do that in the future?

Dr. Law: Well, I think the answer to your question about the level of intensity, the answer is yes. I'm trying to remember the exact wording of all the questions in the survey, and without going back to my chair and pulling it up on my computer I can't give you that exactly.

Dr. Insel: If memory serves I think there was one piece of this where, if I've got this right Paul, 31 percent of respondents said that this was their number one concern, as a parent?

Dr. Law: Yes, that's another good way of looking at it. That was -- yes. That should be in the report that you have. But yes, we did ask parents to give -- to rate it against other problem behaviors, and it was pretty high up on a lot of families' concerns.

Dr. Insel: Ellen.

Ms. Blackwell: Paul, your paper indicates that in the future you plan to survey, quote, dependent adults unquote. Could you explain to me who that population is and what your plans are so that I can better understand what a dependent adult is?

Dr. Law: Okay, so actually we have already surveyed them. We didn't give the report -- we didn't include them in the report because it's a very different, very different and it's also a smaller sample size that we are letting accumulate for longer.

But anyway, so -- but the different -- the distinction is that -- so you kind of have three types of individuals with ASD in IAN.

You have the kids, who are under guardianship of their parents; then you have adults who independently on their own, choose to participate and consent for themselves and provide data about themselves; and then the other category are those who are under legal guardianship, or have a legally authorized representative, and that's the way they came into IAN.

And so we -- we didn't see any reason to survey independent adults on this topic, because a lot of the issues just wouldn't apply. They are under their own supervision, not their parents'. So --

Dr. Insel: Denise.

Ms. Resnik: I want to thank the subcommittee for all their hard work, and the impressive result. I think this represents an excellent example of the problem, the intelligence gathering, how swiftly we moved as an organization, all the different agencies involved, and then impact.

So I again, thank everybody involved in addressing it so quickly.

Dr. Insel: Yes, Ari. Sorry.

Mr. Ne'eman: So two questions. First, I was wondering, did you collect any information on the characteristics of the children included in the survey?

Dr. Law: The children included in the survey had to have completed our baseline forms before being eligible, so we actually have a fair amount of information about them you know, in terms of SEQ and SRS data, and our just basic intake form. So we have a lot of data on them actually.

Mr. Ne'eman: I'd be very interested in seeing that. The other question I had is -- so you mentioned that this is very clearly a different phenomenon than what's occurring with elderly adults, and it seems fairly clear, both with respect to the data you had around state of mind, the majority of individuals wandering seem to be playful or happy, and the data you have on motivations -- enjoys exploring, heads for a favorite place -- seems to be similar motivations that might be present in the general population.

What conclusions did you draw based upon the information you have regarding motivation and state of mind, and how might they suggest a different response than is present with regards to the elderly or the Alzheimer's population?

Dr. Law: Ari, I -- what I have come to conclude is that the topic is relatively complicated and it's going to take us a while to make our maximal contribution from the data we have already collected.

But I think that there's things that I strongly suspect, for instance that the motor abilities of our children sometimes you know, their abilities and their knowledge on how to keep themselves safe is not keeping up with their motor abilities, so that's what makes them more vulnerable to getting themselves into unsafe places, as an example.

Mr. Ne'eman: Did you draw any conclusions about different responses between the elderly and the developmental disability population based on the differences between the phenomena?

Dr. Law: I'm sorry, responses by whom?

Mr. Ne'eman: Just in terms of either parental or societal or public policy, or anything of that nature?

Dr. Law: I'm afraid I still don't quite understand the question.

Mr. Ne'eman: So I mean in the sense that you know, presumably there's a set of potential actions one can undertake to address the issue of wandering in an individual with an Alzheimer's diagnosis --

Dr. Law: Okay I --

Mr. Ne'eman: -- and you know, how

are those sets of actions different or similar in your opinion, based on the data you have collected with regards to the instances of wandering and elopement with autistic children and adults?

Dr. Law: Great. Now that I understand, I think that's a great question. So I think if Alzheimer's wandering is predominantly a result of individuals just being confused and in a -- that the way that one would treat or prevent wandering is very different.

If you -- we have clear indications in our data that suggest that children are trying to escape sensory overload environments and therefore people need to be aware that the fact that they are running out of the classroom every five minutes possibly is due to sensory issues that have not been addressed for the child, as an example.

So I think, you know, bottom line, you have to -- as a clinician you would have to dissect you know, what's -- what are the antecedents of the behavior, and get down to that. Are they running away or running to, and sort it out.

Whereas wandering is -- depending on your definition of behavior, is not really a behavior per se, it's just somebody who is being -- is confused, whereas behavior is motivated, at least that's the way I define behavior, but I get myself in trouble in this crowd.

Dr. Insel: We are in danger of wandering into the time that was allotted for other subcommittees so I would like to bring this to a close and thank those who have been involved.

Just to echo Denise's comments, within a year we have seen a lot happen in this area, and I think it's a good example of what the IACC can do.

Let's move on -- thanks Alison, for putting together that report. So the services subcommittee update, very quickly, from Ellen Blackwell and Lee Grossman.

Mr. Grossman: This will be very quick. Let's go to the next slide. Maybe it won't be as quick as I thought it would be. The activities of the services subcommittee have been primarily -- recently have been primarily working with the safety subcommittee on pulling together this letter which will be discussed here very shortly, on seclusion and restraint, and there was a workshop that was held also on that that I think was excellent.

We are now moving into the phase of planning the fall services workshop and town hall meeting which is scheduled for September 15th and 16th.

Is it here or the North Bethesda? Okay, it's at this fine location here. And let's see, how do I, there we go.

So this workshop will be here at Pooks Hill. We can all stay until then if we wish. I think one of the highlights of this will be that it will include a town hall meeting. We are trying to figure out when, ideally, to do that.

It's going to be a day and a half conference covering services issues, and in the midst of that we are trying to figure out what is the best time to have a town hall meeting.

It's been suggested that we do that after hours so that families can attend. It would be more convenient for them to be there in the evening versus during the day, so they don't have to take time off from work, the disadvantage to that, that the poor IACC committee members will be subjected to a day-long conference and then having to spend their evening as well with a town hall meeting, but I think we can all deal with that.

We have to make some decisions as a services subcommittee on what the take-home message will be from this next, not only town hall meeting, but the workshop.

You know, are we to issue a report, or should there be some other actions that will come out of that?

Ellen and I have been discussing this and we certainly want to get the feedback and input from the entire services subcommittee on how we wish to handle that.

We are going to have a very limited time frame from the 16th to the potential sunset date to get something done, so we have to make decisions prior to that conference in terms of what it is that the outcome will be, and do as much work as we can actually before the conference to make that happen.

We want to focus on maximizing opportunities and the potential for individuals across the lifespan.

The next two slides represent the topics that will be covered, that have been suggested to be covered, and we had a discussion on this last week, during the safety subcommittee and services subcommittee joint conference call.

And Ellen and I have started to put together a list of names that -- around some of these potential topics, one of which that we definitely are going to want to do is to bring people in from the Department of Justice to go over the Olmstead and the ADA enforcement, and we certainly want to have home and community based services.

There are some very good people that we have identified to talk about employment and vocational opportunities. And some of these can be lumped together, like recreational support, family support, infrastructure etcetera.

And so we will be working on that very diligently and pulling that together pretty quickly to make sure that this conference is a success.

Dr. Insel: Great. Thanks. Anything else about this? Denise?

Ms. Resnik: Based on the case study that we just alluded to with the safety subcommittee, what I'd like to understand is, based on this workshop, what are the deliverables, what are the action items, what are we wanting to share beyond information?

Mr. Grossman: That's a good question and that's one that the services subcommittee needs to factor. I think that what we had alluded to do in the November workshop was to do a report, and then that was delayed and people suggested well, there's so many other things that we have to bring to bear before we do provide a report.

One of the things that we may decide to do is a letter on whatever is the most pressing matter that comes out of this conference in the dissemination of the information, and pull that together.

I -- if it was up to me we would do a full report on services across the lifespan. I'm not sure if we are going to really have the time to do that.

In 2005, as many of you will recall, we did have a services roadmap report that came out, that some of the people here had worked on, and I thought that was an excellent -- that was an excellent paper that we pulled together.

At that time the IACC really didn't have the advisory authority or the ability to advise the Secretary as we do now, but that would be quite an undertaking for us to do in a limited amount of time.

Ellen and I are very open to suggestions on what we would like to accomplish. What the safety subcommittee did was a phenomenal job in pulling that together, getting data out and issuing a report that has resulted in public policy change.

And if we -- if somebody has suggestions on how we could do that on the services, I'd be wide open to do that as well.

Dr. Insel: Alison.

Ms. Singer: I think that at the November services workshop we had an opportunity to hear from many representatives from the public sector, and I think it's critical that at this particular workshop, we have an opportunity to hear from more projects taking place in the private sector.

I think as our kids were younger, it was parent-based groups and the private sector that started to create schools and launch schools, and now we are seeing a lot of those same organizations starting to move in to support employment and housing projects.

I think there was a great presentation given by Denise Resnik at the UJA symposium about what SARRC is doing in this area and as a result of that presentation, there are already many groups that are coming together to talk about how that project can be replicated outside of Arizona in other states.

So I would strongly suggest that we might want to hear from Denise at this conference.

Dr. Insel: Ari.

Mr. Ne'eman: Yes I think one of the more interesting opportunities at the last services subcommittee, or the last services workshop, was hearing as to what the mental health field had done around restraint and seclusion.

And it causes me to ask what other best practices are out there from other disability communities that we are not aware of in the autism community.

So I would encourage us to cast a wide net and not limit ourselves to presentations with the word autism attached to it, because frankly I think that may be where some of the most innovative things may be occurring, in the broader cross-disability community, or in particular, other disability communities from which we can draw lessons for our own.

Dr. Insel: Geri.

Dr. Dawson: So Lee, since you said suggestions, I'll go ahead. It would be great out of these two workshops to first of all have a list of priorities in terms of what are the most urgent needs for services right now.

And then the second is what are our knowledge gaps, you know I think that we have heard today that there is a lack of information about a lot of issues, and I think that when -- just listening for example to Paul talk, and it just opens your eyes to understanding where some of the resources need to be put and what new directions you could go to to really try to address some of the problems.

So I would love to see, even if it were pretty concise, a set of priority areas in terms of service needs as well as you know, knowledge gaps and areas where we really need to have a better understanding of adult development and services and supports right, that will optimize adults with autism as they, you know, go through their adult life.

Ms. Blackwell: One of the things that Alison mentioned when we had our last call, Geri, was maybe having a services 101 presentation, and I think that's really a good idea, to help everyone understand how the services system in the United States is constructed and how people with autism fit into it.

Dr. Dawson: So just to -- I guess the only thing I would say is you know, it would be helpful to be forward-looking, right? So rather than just describing what's there, which of course I think is extremely useful, but really to say okay, now that we know this, this is what exists, you know, if you had to list the five top priorities, what are they, you know, where do the resources need to go and if you had to list the five areas where we absolutely need to have more research and knowledge, then you know, what would those areas be. I would love to see something like that.

Dr. Insel: I'd like to second that. I think one of the things that sometimes happens in the committee when we get into this topic is this sense that it's so overwhelming and there are so many problems. It would be really useful, and Paul's presentation helps to tee this up because there's such clear gaps of things that are doable but we don't quite have the information we need, and in some places, like that information about the role of income and social determinants of outcomes, it's already clear enough to be able to see where the differences might be.

So I think having some priorities and having sort of a top five kind of an approach would be great for the rest of us to have a sense of where the major issues are.

Mr. Grossman: There is a -- actually when it comes to the knowledge gaps, we had reviewed that pretty extensively as we went through the numerous strategic plans so we probably should go into that, dig a little bit deeper and see what we can pull out of that as guidance here, because what you are asking for, which is very, very good, may already exist.

Ms. Singer: I think that's the issue I was trying to get to with what I called on the call sort of Medicaid waiver 101. I think there are a lot of families who don't understand the services that already exist, and how to access them, and I think that's where we might want to start the day, which is sort of a base level of this is what's currently available, and then talk about where the gaps are and where we need to be moving.

But I think it's -- just like we have dissemination issues with regard to research, it's clear from the calls that we get, that there are certainly dissemination issues with regard to services and supports that are already available.

And I think since this is going to be a town hall meeting, it's the right environment to do that.

Dr. Dawson: So then coming out of it, it would be wonderful to see -- if that's a key area, right, that there are services out there people are not accessing because they don't have the information about them, you know, that could be a recommendation, that dissemination of information and you know, widely -- helping people to widely understand what's available and how to access it, may be one of the top priority areas.

Dr. Insel: We are going to have to move on. Is there anything else in the way of feedback for Ellen and Lee in preparing for September? Other comments? Denise, did you --

Ms. Resnik: To pick up on what Geri was saying and where this conversation was going, looking for things that are actionable when we talk about this agenda, what the priorities are, what's actionable, so that we can come back to what we heard today, of taking specific steps to make things for our families.

Dr. Insel: Okay. Message clear? Anything else Lee, that you need from us? All right. There's a joint group between services and safety that's been meeting and there are a whole series of names: Ellen, Lee, Sharon, Lyn, Alison. Who is going to get us up to date on this? And Sharon's on the phone. Great. Ellen?

Ms. Blackwell: Yes, I'll get us started and then I may actually pass the hat to Sharon. Oh, I'm sorry. Thanks. So I'm going to give an update on our -- actually it says joint activities. We have had a couple of joint calls but we had one really, really great meeting. It was on May 19th, and this was a meeting where we heard wonderful presentations. I mean, I can't even believe I'm using the word wonderful in the same context as seclusion and restraint, but this was a terrific meeting, and I can't urge people strongly enough to -- not just to review the slides that are in your packets, I asked Susan last night, and she did include a set of slides in everyone's packets. They are up on the IACC website and the other day when I was reviewing the minutes, I told Susan this, I think the minutes are actually even perhaps more representative of what a great day we had, and really informative.

I don't know of any other meeting other than the hearings on seclusion and restraint that dug as deep as we did into this issue.

And so I really thought it was a great meeting. So we talked about what the output would be, and we talked about writing a letter to the Secretary, which we can get to in a moment, but I just wanted to briefly talk about what happened at our meeting.

Commissioner Lewis kicked off the

day. She is one of the country's experts or perhaps the country's leading expert on seclusion and restraint issues.

She gave us a lot of historical background on seclusion and restraint that was extremely helpful. Alexa Posny, of course all of you know Alexa from the Department of Education, gave us an update on issues taking place in the Department of Education to address these very serious issues.

She also suggested that there would be a couple of items of follow up with us. The first is that the Office for Civil Rights has started to collect information about restraint and seclusion from about 7,000 school districts.

That information will be released this fall and second, OSERS is working with SAMHSA, our partners here in the IACC, on a guidance document that Alexa suggested that DOE would share with us, also this fall, provided that we meet again this fall.

So there's information about you know, the nine principles that Secretary Duncan outlined in the minutes and in Alexa's presentation, that I think is very valuable to review.

There was a GAO report a couple of years ago on seclusion and restraint in schools that most of you are familiar with.

So this is perhaps the -- there's also some legislation on the table now regarding seclusion and restraint in schools, so this is a particular setting where there's a lot of focus and a lot of development to come.

I talked a little bit at this meeting about seclusion and restraint rules and the status of what we deal with in Medicaid and also to some extent Medicare programs.

Larke Huang, again our partner member at the IACC, gave an absolutely terrific presentation on seclusion and restraint. It was just wonderful. So again, you can even watch this online if you take the time.

Chas Moseley, Chas is with the National Association of State Directors of Developmental Disabilities, talked a lot about state practices and policies, of course, laws vary from state to state and jurisdiction to jurisdiction.

Chas has decades of experience in this area. It was a very moving presentation, as was that of Curt Decker. Curt again, decades of experience with seclusion and restraint.

And Curt talked mostly about violence or seclusion and restraint in schools, but he did a wonderful job and then we wrapped up the day with Bob Putnam, who talked about positive behavior support and what it can -- what can happen as a result of implementing positive behavior strategies in school settings, for all students, not just students with disabilities.

So again, I thought this was a fantastic day. At the end of the day, we agreed that Commissioner Lewis would lead us in drafting a letter that the committee could send to Secretary Sebelius on the topic of seclusion and restraint, and just as recently as last week or the week before, Commissioner Lewis gave us a wonderful draft that I have to say, there are several people in this room that all contributed very quickly to help edit and make contributions to the draft, so that is what you have in your packet today for us to discuss.

So with that, I will pass the mic to Sharon Lewis, who I hope is with us on the phone to talk a little bit about the letter, which I think is -- really fully represents all of our agreement between the safety subcommittee and the services subcommittee on what the contents of this letter should be.

Dr. Daniels: Sharon are you on

the line?

Ms. Lewis: I am here. Can you guys hear me this time?

Dr. Daniels: Yes. We can hear you.

Ms. Lewis: Oh good. I have been trying to talk multiple times and I wasn't sure. I think Ellen has done a fantastic job of outlining the day that we spent together and our deliberations, and so I guess all I really would like to add is that the two committees came together and had a, I think very thoughtful phone call and further email conversation about the content of the letter, and we put forward the letter to all of you for consideration.

I do want to add that there has been some concern expressed by the Department of Education about the letter and I know that we don't have anyone from the Department of Education here with us today at the meeting.

But I did want to acknowledge

those concerns, and you know, that they feel that the work that they are doing in the establishment of the principles is important work that should be acknowledged by the IACC, and that those activities need to move forward and that the role of the IACC should be focused on the Department of Health and Human Services in terms of this particular area.

So I you know, I said that I would mention those concerns, having spoken to the Department of Education, and unfortunately again, I -- we are in a little bit of an awkward spot because they are not with us here today but I wanted to raise those issues as we move into a discussion of the letter.

Dr. Insel: Sharon this is Tom. It is awkward, because there is no one here to represent the Department of Education. Is there anyone? I don't think there was earlier. Is anyone from Department of Ed on the line?

(No response.)

Dr. Insel: Okay. The question in

front of us I think is to what extent do we want to move forward with this if they have such serious reservations, without at least hearing them out and understanding what the issues are.

For those of us who aren't in this area, it's a little bit confusing to know what to do, given that they feel so strongly about this, and if it is going to come to a vote and they haven't had a chance to explain their reservations, I guess I'm just -- I'm concerned about understanding the full spectrum of issues. Alison?

Ms. Singer: So my response to that would be that the Department of Education is a member of this committee and if they felt so strongly, they should have made it a point to have someone attend and express their reservations.

Dr. Insel: My understanding is that there was a meeting today that they were required to be at, and which is -- so there's a real scheduling issue, as I understand.

Ms. Singer: Everyone from the Department of Education was required to be at that meeting?

Dr. Insel: From the --

Ms. Singer: They couldn't send someone to even read a statement or -- I mean, to me, it -- to not move forward with it because they chose not to attend, seems rewarding bad behavior.

Mr. Ne'eman: I'm inclined to agree with Alison actually, and I think you know, looking over this letter, if there was something in here that was incredibly controversial, or you know, implicated the Department of Education in some accusatory way, I might feel differently, although I think the question still does beg to be asked, you know, if it's that big a priority, then they should -- you know, why didn't they send somebody to be here.

But this seems to me to be a list

of fairly basic steps that could be taken, so my inclination here is that we move forward, and you know, if anybody has a clearer idea of what the Department's objections are, I hope that they raise it, because I'm not sure I entirely understand what they could be, given the fact that this letter seems really to just lay out some minimum possible measures.

Dr. Insel: So Susan I think can do that in a moment. I just want to point out that among the points here, you know, is to have a conference or summit with the Department of Education, so we are committing them to a number of activities in a letter which they say they want to have nothing to do with this, so Susan can help to explain why that might be, but I don't think it's as simple as just making sure that even though they are not here, we will go ahead and do this, because it does make commitments on their behalf which they appear to be unwilling to support. Susan?

Mr. Ne'eman: I guess -- oh sure.

Dr. Insel: Let's hear what their concerns are.

Dr. Daniels: So I'll do my best to try to summarize what I have heard from the Department of Education. I hope that I will be accurate in portraying what I have heard.

My understanding is that, as Alexa shared with us on the May 19th meeting, that they are working on a document, a guidance document that will go out to the public in the fall, and some additional activities surrounding that. They are working in collaboration with SAMHSA and the White House and that these are very sensitive issues.

They would prefer not to see us, see the IACC request additional things that are not a part of whatever activity they are currently doing that is not completely known yet.

And they also mentioned that they felt that because this committee reports to the Secretary of Health and Human Services, they didn't feel it was appropriate for us to include education-related activities in the letter.

However we aren't technically limited in that capacity. This committee can make recommendations on any area it wishes. So -- but they recommended that the IACC consider removing references to education and stick to HHS issues that are within the purview of our own Secretary.

Mr. Ne'eman: I mean I guess what I would say there is first on the second point, our -- the CAA does very explicitly task the IACC with monitoring federal activities related to ASD, which is not limited to the Department of Health and Human Services.

You know, I know about the ongoing efforts regarding those principles. I think that's a very positive measure, but I don't know that there's anything in here that would preempt that or preclude that from occurring.

And you know I also don't think that we would be committing the Department of Education to do anything, by virtue of the fact that -- by virtue of recommending that they do so.

Those are simply my thoughts. I look forward to hearing the other committee members.

Dr. Huang: This is Larke Huang from SAMHSA. I have been on listen only so I haven't been able to weigh in, but I did -- can you hear me?

Dr. Insel: Yes.

Dr. Huang: Oh, okay. I did want to mention that we are in discussions with Department of Education under Alexa to move forward on some of the principles and she sent a set of principles, we sent a response back and we are sort of waiting to hear from them yet.

Dr. Insel: So Larke, does it make

sense to do this without them, or would it make sense to see what they have got and incorporate that in the letter? What's your feeling about how we should -- the most effective way for us to go forward?

Dr. Huang: Well, you know -- and I don't know, is Alexa aware of this letter that is being put together?

Dr. Daniels: Yes, Alexa has seen the letter and wrote just really concerned that somehow that this letter and what is mentioned in it with regard to education would somehow jeopardize their current efforts or be in conflict with their current efforts and wished for us not to do anything that would interfere with what they are currently doing.

But you may have a lot more insight into what that is, and maybe how the language in this letter could be modified if it needs to be modified so it wouldn't interfere with what they are currently doing, because we do want to support any efforts they are already making in this area.

Dr. Huang: I'm wondering if there would be a possibility of a discussion with her to see how the letter could be -- could not get in the way of interfering with what they are doing.

There's been quite a bit of a break between -- since we sent our responses and since we have heard back from them. I think the letter actually has multiple intents, not just that particular piece. I think the piece about promulgating regulations which have been stalled for just under a decade, that the Part H and Part I piece that got stalled with us and with CMS, that bringing this to her attention might help to get that process back on track again.

So to me there are multiple intents in this letter and we might want to think about the piece that directly relates to the Department of Education and see if we can have a discussion with Alexa on what would be best in terms of moving forward on that, without you know, alienating their Department or getting in the way of what they are trying to do.

Dr. Insel: Yes Larke, that's my question, and because she feels so strongly about this and because so much of this letter is about what happens in schools and involves the Department of Education, I'm just wondering if it makes sense to go ahead with this until we understand either where she has concerns, or we can work through those concerns, so that this ends up with something that both the Department of Education and HHS are able to get behind, rather than having this only as an HHS document and in some way, even though it talks about the issue in schools being fairly removed from the Department of Education. I worry about becoming a kind of third rail on this issue.

But those of you who are closest to this may have a better sense of what the issues -- the specific issues are.

Ms. Lewis: Hi, this is Sharon, and I think that one of the inherent difficulties, and can you hear me okay?

Dr. Insel: Yes.

Ms. Lewis: One of the inherent difficulties and tensions here is -- and my perception of some of the discourse with Alexa on this particular issue -- is the dual role that many of us who are representing federal agencies play in serving on the committee, and I think that the role of the committee in providing advice to the agencies on these issues is difficult at the same time as folks are pursuing particular activities to support and address these issues.

And I think that when I certainly tried to work with Assistant Secretary Posny on how we might address her concerns in the letter, it seemed that anything short of essentially removing recommendations that would affect the Department of Education were not going to allow for them to support this letter, that there was just a difficulty in federal representatives of the Department of Ed taking a position related to recommendations that go to the Department of Education.

And as a member who has grappled with some of these same concerns in a variety of recommendations that have been provided to the Secretary, I certainly understand that perspective.

But I think that the committee as a whole needs to determine whether this is information that is important enough to continue to push forward in terms of the -- one of the priorities that came up again and again again the conversation was the lack of consistency across environments, which includes schools, and so I have a hard time seeing how the committee's perspective can be fully represented and completely avoid the implications for education.

Dr. Insel: Walter.

Dr. Guttmacher: This is Alan Guttmacher. I wonder, is there any way -- I am concerned I guess having had -- been on the other side of this or whatever occasionally when other advisory groups that don't actually report to the Secretary of HHS sort of instruct those of us within HHS what to do, I know that the tendency of federal agencies can sometimes be to raise their barbs at that kind of thing.

And I wonder whether the language could not be softened a bit. Clearly there are things in this letter that are just about HHS and which has strong statements about that, which we do. But I wonder whether in terms of working with other departments -- DOJ, Ed etcetera -- whether we should think about just sort of rephrasing it, that the Secretary should consult with those departments.

I know we say discuss etcetera but we urge for instance a meeting, that they cosponsor it, and I don't think we are in a position to advise the Secretary of Health and Human Services that she should have the Department of Education cosponsor something.

I think we can advise her that she should talk with them about you know, the possibility of having such a conference etcetera.

Dr. Insel: Ellen.

Ms. Blackwell: Yes Alan this is Ellen. That was going to be my suggestion as well, that it might be possible to perhaps broaden the language in some of these recommendations to not specify particular agencies.

I have to say that I -- as Sharon indicated, I still think that the Department of Education is the elephant in the room, but we wouldn't be calling out the elephant in the room, so it would be easy to delete the references for example to Education and the Department of Justice and just talk about relevant federal agencies and be a little bit more bland in our language.

Now that doesn't address the last bullet, which is specifically talking about schools, but again, that doesn't call for any action on the part of the Department of Education. So if people would be okay with that, I mean, that might be a compromise to get the letter out.

Dr. Huang: But Ellen, I don't know that we want to delete any of the references to schools, because many of the populations that we are targeted with providing services to or supports or safety measures are going to be in different settings.

Ms. Blackwell: Oh Larke, I totally agree with you. I was only suggesting for example on page three, where the bullet says improve data collection across settings, it could say federal agencies including SAMHSA, CMS and ACF should work together, and the next bullet say relevant federal agencies need to work together.

In the bullet that says bring attention to the issue, we could say just HHS should convene a national interagency conference or summit on seclusion and restraint to highlight alternatives.

In other words, just swipe the language mentioning the agencies, other than HHS.

Dr. Huang: I think it's okay to name agencies.

Ms. Blackwell: Okay.

Dr. Huang: I think this administration seems to really have a lot of Secretary-to-Secretary interactions.

I think you know in terms of two things that I know when we had talked earlier, and Sharon please weigh in on this, when we had talked earlier about a summit with Education, that there was real concerns about a summit, and what were the implications of that for -- at Department of Education in what they roll out to their schools.

I think in the bullet on reduce or eliminate the use of seclusion and restraint in schools, we were able to work with them to get to use the word prevent, because we are trying to look at the prevention of the need for and the prevention of the use of seclusion and restraint.

So I think they interpreted the term eliminate as prohibit, and so I think if we do a little bit of language change there, which actually meant a lot to them when we said no we are really trying to prevent the use of these measures and reduce, with the ultimate goal of elimination, but in certain cases, you know, with the potential for harm to the child or others there may be a need to use these.

But I think if we change some of the language around, you know, since Alexa was involved in that day meeting, I think that she knows we are talking about a number of different kinds of settings including schools and that I don't think we want to back off of it completely. I think we are talking about other settings besides schools as well, like justice settings.

So I think we can probably modify some of the language and still get our intent of recognizing that you know, children and youth can get severely injured and there can be severe outcomes in the use of these practices in schools, and we don't really totally want to back off of that either.

Dr. Insel: We are going to need to bring this to closure. Walter and then Lyn.

Dr. Koroshetz: Yes, so I -- two points. One is that I think that you know, reading this now, with that objection, I can see that some of the wording is very -- could be seen as very prescriptive, you know, telling an agency what to do and that might actually get in the way of our goal which is really to put the issues on the table, not hide about who should be involved. So I wouldn't take Department of Education out of it. I would take out Department of Education do x or y, but I would say -- I would take that out but I would say to solve these problems, we need, you know, Department of Education, Department of Justice at the table.

So I think we could reword it. The other thing I think is I'm thinking is that if we know that there are discussions going on between Department of Education on this issue, you would not want to send the letter to the Secretary not stating that.

So, I think that would be the other thing. In terms of timing, I think if it weren't up to this deadline, what I propose is that we you know wait, see what the Department of Education is doing, and see if they want to add language at some point in time which indicates, when this letter goes out, that they are not behind the eight ball but they are really out in front, trying to do something, especially if they are trying to do something good. We really don't want to get in the way.

Dr. Insel: Lyn, you had your hand up.

Ms. Redwood: Yes Tom. I was just going to propose, and I agree with what Alison said, it's important enough that I think they should have had someone here, but the fact that they didn't, and it sounds as though the committee doesn't really feel completely comfortable moving forward, but we are also facing this deadline of the committee sunsetting, I am wanting to know whether or not we could get together with the Department of Education, the chairmans in the safety subcommittee and the services subcommittee, to have a call to hash this out, and then bring a letter back with edits that's acceptable to all of the committee members, to IACC, to vote on via email. Is that allowed, with discussion, because I don't want this to falter, I think it's too important and I think it's waited far too long.

Dr. Daniels: For an action of this magnitude we would need to have a phone meeting and probably do a vote over the phone. Email votes we have been able to do for things like selecting specific science advances for the Summary of Advances, but for something of this nature, we want to hold any of those votes in public where possible, and so we would probably want to do them on the phone, but we could even have two phone calls, one to discuss and one to have a vote.

Dr. Insel: So let me make a suggestion because we are going to be out of time here in a moment, and I'm hearing kind of the same issues that you are.

I think the gist of this, it sounds like everybody on the committee, and I suspect even the Department of Ed, would support. The problem as I understand it, from their perspective, is that they don't want to be told what to do when they are just in the middle of doing something, and they want to put out what they are doing without this complicating things.

If we could shape the language accordingly -- we have asked for them to help in that, and I am not sure if it was that they ran out of time or that they couldn't do it for some reason -- but getting their input about what would make this helpful to them rather than complicating what they are doing already, which is in the same direction, I think if we could get a sense from the committee that that's what you want, and then the rest of this we could do certainly through a phone call with this going out by email ahead of time so everybody could come to the phone with a pretty clear idea of what the issues are.

I'm getting the sense though that unlike the previous discussion we had, when we did a letter like this on wandering, where there was really a difference of opinion about what that issue was, on this one I think everybody is aligned, this is really a process problem, where they don't want something to come out telling them what they are really doing, or telling them a little bit different from what they are already doing, and if that's the case, I think it is a language issue. I think we can shape it. Is that the sense of the group? And we'll just take care of this in a subsequent phone call with some emails going out, then we can get Alexa's input to make sure that whatever we come up with isn't going to complicate their issues.

Sharon and Larke, would that work?

Ms. Lewis: I think that that makes a lot of sense, you know, I think that I also want to respect my co-chair's perspective and some of the members of the committee who -- in not wanting this issue to get lost.

So the, I guess the other question

is going to be if there is an inability to get to an agreement with the Department of Ed, does the committee want to pursue an alternative path of a letter that doesn't reference the schools or what, you know, in general, what direction would people want to see this go?

Dr. Insel: Well, some heads are shaking no and some heads are shaking yes. So I think that -- that it becomes much more complicated. That's part of the reason for wanting to get their buy-in to this, which we have not done so far.

Dr. Koroshetz: I don't think we can leave out the schools, I mean, I don't -- does anybody think we can leave out the schools? I don't. It's got to be in. The question is whether you say tell the Department of Education what to do or not, that's a different story, but the schools have to be in.

Mr. Ne'eman: I think these are

some of the issues we could address in the follow up call.

Ms. Blackwell: Well, I would just make the point to the committee that the letter is also suggesting that CMS take certain actions. So I guess my perspective is that, as a committee member, I would be voting as my committee self, not my CMS self.

So it's a similar situation for the Department of Education. I mean I think you just have to separate -- the person who is representing the Department of Education has to separate those roles.

Dr. Insel: But from the -- I've watched the emails go back and forth. I think there's some middle ground here. I mean I don't think this is an impasse. But I think we ran out of time to get this letter in a place where they weren't feeling that this was going to create a problem for them, and I don't think any of us want to do that. We don't want to complicate what they are trying to do, because they are trying to do something that's consistent with the spirit of this letter.

So if we can simply get to that point, I am hoping the committee will find some consensus. Any other issues here before we move on, because we are going to run out of time? Lee, last comment.

Mr. Grossman: I guess I just want to express a deep sense of frustration for us to hear about this at such a late period. We have worked on this. We have had a workshop on this. We have done -- we have spent hours of time on this, and then to have this wrench thrown into the machinery, is quite frustrating for me. This letter has -- I thought was very, very adequate. Certainly, we should get their input. I wish they would have been here to express their feelings. I wish they would have done that a week ago so we could have worked on it and had a draft that was ready to go out, because I think the community is waiting for this. It's something very proactive. I don't want to say it's something reactive that we are doing but it's long overdue, and I think it could have -- it can -- this letter can make an impact on the future lives of the people that we are representing.

I am just frustrated by a further delay in this.

Ms. Redwood: Can we set a date certain, it could be one month?

Dr. Insel: Thank you for bringing up a time line. What does the committee -- what are you comfortable with? Two weeks?

Dr. Daniels: Under FACA it will probably take about a month to set up a phone call, so --

(Off mic comments.)

Dr. Insel: No let's do it before then. I think you want -- let's get this resolved before September 1. So why don't we say -- can we say 30 days from this point?

Dr. Daniels: Something along

those lines so we will have to work out the calendar. So we will try to set a date as soon as possible. So realize that your options will be we can work with Department of Ed and see if there is a way for us to edit the language to make it workable for them. From the interactions we have had it didn't sound like they thought that there was a way to make it workable without just removing education, but we may be able to negotiate that.

However, if there is disagreement and they will not be able to agree to a letter that mentions education, the committee can still vote, and the majority vote will carry.

Ms. Redwood: Susan when you set this up and publish it in the Federal Register, can you publish the phone call and then two weeks later, publish the phone call with IACC so we already have that on the record, and it will give us a firm deadline and then circulate this letter around the Department of Education like tomorrow saying we need your feedback now.

Dr. Daniels: We can set up a couple of phone calls at the same time.

Ms. Redwood: Okay thank you.

Dr. Insel: Okay, but I'm totally on board with that, I think we really want to lock in the dates now so we don't lose a month just from scheduling. That's great.

Any other points about this for this joint committee? Okay. Susan, very quickly, you have got some OARC business and then I want to talk about legislation.

Dr. Daniels: All right. So just very quickly I wanted to talk to you about the 2011 Summary of Advances. All of you on the committee have received the request from me for your nominations for the next Summary of Advances, the midyear installment.

So by this coming Friday, your nominations are due and you can nominate up to five articles that you think were groundbreaking advances in autism services and biomedical research, and I know that several of you have already sent those in to me so please send them in by Friday.

Once we receive all of those, we will do like we did last year, make a list for you of all the articles that have been nominated and allow you to vote, and then we will have a final installment of 10 articles, and we will do the second installment or the final installment in about January if we are reauthorized.

And I wanted to give you a quick update on the portfolio analysis. So you will see in your packets that we have a hard copy of the final report from the 2009 portfolio analysis. We also are going to be releasing data tables on the website within the next few weeks, and so be watching your emails for that, and that will contain comprehensive data that we have collected and be presented in really nice formats that should be very usable for the community.

We also are just ready to send out the data call for 2010, and so be expecting an email from me in the next few days. All of the agencies that are -- and organizations that are involved with the portfolio analysis.

And once we send out the data call, everyone will have a few weeks to get us the data back and we will begin data analysis.

And we are planning for a companion analysis of ASD publications and we have worked out a strategy for that and are moving forward very quickly with that at the request of the committee.

I just wanted to quickly show you that these are the funders that we solicited in 2009 but in our background research, to move forward for 2010, we identified a number of other agencies and organizations that we will be approaching in our next data call, including AHRQ, EPA, NSF -- EPA and NSF both have some significant autism funding that we discovered in our background work and so we want to include them this time -- SAMHSA, ACF, and the Nancy Lurie Marks Foundation.

And so hopefully we will have a nice array of additional funding sources to include this time.

Ms. Redwood: Can you also add the Coalition for SafeMinds?

Dr. Daniels: Yes we can.

Ms. Redwood: Thanks.

Mr. Ne'eman: I thought we were going to add, according to the minutes, the Hussman Foundation as well.

Dr. Daniels: I -- that's in the minutes. I don't know if they had an adequate number of projects to be included. We do have to keep to nine -- one, two, three, four, five, six, seven -- and if we add Nancy Lurie Marks and Coalition for -- we still have a couple of slots so we could potentially do that, but we will check.

Dr. Insel: Okay. In the last seven minutes, let me tell you a little bit --

and we haven't done public comment discussion yet, so hopefully this won't take all seven minutes -- about where we are at.

I mean this is, speaking of elephants in the room, Ellen, this is sort of a major discussion we need to have. Whether this will be our last meeting or not remains uncertain.

There is a lot going on, in terms of legislation and autism, actually a total of seven bills that are floating around in one form or another, three in the House and four in the Senate.

Some of them deal with reauthorization of the Combating Autism Act. Some do not. But the top two -- H.R. 2005 and S. 1094 -- are specifically about that.

They are essentially what we would call dates and dollars. They take the same CAA, don't really make many changes and they simply say change the dates.

So rather than sunsetting

September 30th, 2011, it will be 2015. That -- the 2005, that's H.R. 2005, has been under discussion. There was a hearing last week about that, and we have sent you some information on that.

There's markup scheduled for the Senate reauthorization on August 3rd but that keeps getting delayed. Whether it will happen or not I don't know.

Obviously we are getting pretty close to the deadline, since September 30th is a hard sunset. It's not, you know, can't really stretch it beyond that, and Congress tends to be putting things off longer than many people might be comfortable with.

So it's not clear exactly, a) if this will happen and b) if it does, when it will happen.

What this means is that we cannot meet as an IACC after September 30th unless the committee is reauthorized. So unless one of those -- both of those bills are passed and they come together and are signed into law, we will not have another meeting.

My sense, from the hearing that we had, was quite positive. There was a lot of support for the work that all of you have done. There was a sense in fact that it was so successful -- that it was so successful that there was at least one person asked why aren't we doing this for all kinds of different disorders, and indeed there is a hearing next week to do precisely that, to maybe create a whole series of coordinating committees based on the IACC, so some members of Congress actually see this as a prototype that they want to reproduce for other illnesses as well.

What happens if it's not reauthorized? We don't meet. Our -- the work will go on in terms of many parts of the Combating Autism Act -- we will continue to have Autism Centers of Excellence, as far as I know, HRSA's LEND efforts and its projects with the autism treatment network would continue, certainly the $218 million that NIH is investing in research on autism in 2010 will continue in 2011, and I don't know that it will be the same amount of money, but the research effort will continue.

We don't need to be reauthorized to do research in autism. But the IACC would not be able to continue to meet.

If it is reauthorized, what will the membership be? Well that is up to the Secretary. It could be that she will want to retain the same members and continue for the next period of time. She could say well, we are going to have a new IACC with an entirely new membership, and she will have to make that call once there's a reauthorization that's signed into law.

Almost certainly the reauthorization will assign authority for all things autism to the Secretary of HHS. That seems to be in all of those different bills, whether we are talking about research or services.

I would say that if this is not -- if it is reauthorized, and the membership is changed, our intent would be to bring all of you to whatever initial meeting happens, and I'm saying this not knowing if I would be on the new committee if it's formed.

But if I were, the hope would be that either I or whoever chairs this, will reconvene this group so we can meet with the new IACC to have a healthy handoff, and a chance to discuss the process that we went through and to help whoever is on that committee to learn from what we have done.

Having said that there is also the likelihood that if this is reauthorized, the new committee will be precisely the committee we have here. I simply can't tell you at this point what the plan would be.

So, lots of uncertainty. At this point we do not know whether this will happen or not, whether it will be reauthorized, and if it isn't, we need to work very hard between now and September 30th, as Lyn was suggesting, to get these things finished, because we will not be able to have legislative authority after that date.

Questions? Is that clear? I mean I'm sorry to be uncertain about this but we just don't know until there's a vote on both the House and Senate sides, what will happen, and there is some sentiment in Congress that is running against the idea of doing disease-specific legislation. That's been true for some time. It's true again now, and as you know, Congress has a few other things that they are really focused on between now and August 2nd.

So whether this will actually make it through, depends a lot on what happens in the next I would say three to four weeks.

Okay. That said, comments related to what we heard from the public today, either in the oral or written testimony? Lyn. Oh I'm sorry, Walter.

Dr. Koroshetz: I had just one comment. If the group is going to end, I was wondering whether or not there were some things that we should plan to do to wrap things up, particularly I thought that the work done on the restraints and the wandering needs to get publicized somehow.

So I was thinking that if things end, that we should plan to actually write up pieces that could be published, because I think if it goes down, then access to this kind of material is -- I don't think it's very good to be -- I don't think it's that good to begin with unless you get it published, so that was just a thing that I think those two items, the work that's done, could form a reasonable editorial piece in an autism journal.

Dr. Insel: That's a great suggestion, something we could do if -- I'm not sure -- even if we were to continue it, it might be good to do that, to feature what the work of the committee has produced.

I think one of the -- Denise brought this up -- to the extent that we have deliverables, we need to make sure that those are featured some place and that they have some legs.

So we should give some thought to how to do this, whether the committee continues or not. Other comments. Lyn?

Ms. Redwood: Yes, I just had a comment with regard to the oral presentations. Back at our last meeting when members of the administration were here I voiced concerns about feeling as though we needed more support, and at our last meeting when we had the presentation from Abt Associates and they did like the nine-state survey, they specifically said that the states surveyed called for national standards and best practice guidelines.

And after that presentation I

asked, well who is going to develop these, and nobody answered my question. And there were several things that are sort of left hanging, as Walter mentioned.

We have this diagnostic code now, but we don't really have any guidelines for educating parents, and that was something that Officer Reyes had suggested, that we develop some type of educational materials on wandering for parents and we haven't tagged anybody to do that.

So I just wanted to put in another request that we consider asking the administration for more support, either a task force as recommended by NAA, or an office under the White House similar to what they have for HIV that would deal specifically with it, so we had full-time staff that we could turn to, to fill in some of these gaps that we as a committee can't address.

So I don't know how we can do that and I think we are doing a great job, but there's still so much more that needs to be done.

Dr. Insel: That may be beyond our authority but I can tell you that there are people in the room who work for the Secretary directly and I think it's useful for them to hear that from you.

Other comments? Well let's hope this isn't our final farewell. I think that even if this is the final meeting under the current authority, my hope would be that there is still a way that all of us can continue to work together.

As Lyn says, there is still a huge amount to be done, but I have to say, having sat through the last few meetings after we have had sort of a rocky start with this committee, what strikes me is how actually, how much has gotten done, and how much a committee that has no money, really, the only thing we have is kind of a moral authority here, has been able to really have an impact on the field, and has gotten to be significant enough that it seems to me that virtually everybody who has anything to do with autism wants to be on this committee, which must be for a good reason.

So if it doesn't continue, I think there will be a lot of people who will be greatly disappointed, and I think we need to recognize how much all of you have done and how hard everybody has worked to make this happen.

We heard some great examples today of progress that has been made and there's a lot more to do, but I wanted to thank all of you for what you have done for the committee, for being willing to advise HHS, and for the autism community.

That's been, for me, a real inspiration to be part of this and I think this is one of the hardest-working groups, and one of the most committed groups that we could hope to have, so that I think the autism community has a lot to be thankful for in a group like this, that has been willing to pitch in and make a difference.

So I hope that we will be back together, not just for the September meeting on services, but thereafter for a full committee meeting, but let's see how things go over the next few weeks and we will have to see that Congress is willing to continue to support this effort.

Thanks everybody.

Dr. Boyle: Can I just say one last thing. I guess I want to -- I've only been on the committee for less than a year, but I want to thank you for your leadership and guidance. You have been very masterful in terms of moving us through processes, and being very objective in terms of dealing with issues, so I really appreciate that guidance.

(Applause.)

Dr. Insel: Well, thank you.

Ms. Blackwell: And also, I would

second, of course what Coleen said, but also acknowledge the hard work of the OARC team as usual our executive officer Susan Daniels and her staff.

Dr. Insel: So OARC will continue with or without the Combating Autism Act. Our intention is to continue a group that coordinates, because this is an area, like AIDS and like many others, that involves many, many different parts of NIH and parts of HHS and as we have heard, also parts of the Department of Education.

So Susan has a -- and the people who work for Susan, have a lot to do whether we have the authorization or not.

Okay, thanks everybody.

(Whereupon, at 5:05 p.m., the committee adjourned.)