

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, APRIL 9, 2013

The Interagency Autism Coordinating Committee (IACC) met in Conference Rooms C/D at 6001 Executive Boulevard, Rockville, Maryland, from 9:00 a.m. until 5:08 p.m., Thomas Insel, M.D., *Chair*, presiding.

PRESENT:

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

SUSAN DANIELS, Ph.D., *Executive Secretary*,
IACC, NIMH

IDIL ABDULL, Somali American Autism
Foundation

JAMES BALL, Ed.D., BCBA-D, JB Autism
Consulting and Autism Society of America

ANSHU BATRA, M.D., Our Special Kids

COLEEN BOYLE, Ph.D., M.S.Hyg.,
U.S. Centers for Disease Control and
Prevention (CDC)

JOSEPHINE BRIGGS, M.D., National Center for
Complementary and Alternative
Medicine (representing Francis
Collins, M.D., Ph.D.)

PRESENT (continued):

NOAH BRITTON, M.A., Bunker Hill Community
College

SALLY BURTON-HOYLE, Ed.D., Eastern Michigan
University

MATTHEW CAREY, Ph.D., Left Brain Right
Brain

DENNIS CHOI, M.D., Ph.D., Stony Brook
University

JOSE CORDERO, M.D., M.P.H., University of
Puerto Rico

JAN CRANDY, Nevada State Autism Treatment
Assistance Program and Nevada Commission
on Autism Spectrum Disorders

GERALDINE DAWSON, Ph.D., Autism Speaks

DENISE DOUGHERTY, Ph.D., Agency for
Healthcare Research and Quality (AHRQ)

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

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

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

DONNA KIMBARK, Ph.D., U.S. Department of
Defense

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

PRESENT (continued):

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

SHARON LEWIS, Administration for Intellectual
and Developmental Disabilities,
Administration for Community Living
(ACL) (attended by phone)

DAVID MANDELL, Sc.D., University of
Pennsylvania

JOHN O'BRIEN, M.A., Centers for Medicare &
Medicaid Services (CMS) (attended by
phone)

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

SCOTT ROBERTSON, M.H.C.I., Autistic Self
Advocacy Network (ASAN)

JOHN ROBISON, Self-Advocate, Parent, and
Author

ALISON SINGER, M.B.A., Autism Science
Foundation

LINDA SMITH, Administration for Children
and Families (ACF)

LARRY WEXLER, U.S. Department of Education
(attended by phone)

ALSO PRESENT:

STEPHEN BLUMBERG, Ph.D., CDC

KATHERINE CARGILL-WILLIS, Administration on
Intellectual and Developmental
Disabilities, Administration for
Community Living

ALSO PRESENT (continued):

AMY GOODMAN, The Arc

MAUREEN GORMLEY, M.P.H., M.A., R.N., National
Institutes of Health (NIH) Clinical
Center

CONNIE KASARI, Ph.D., University of
California, Los Angeles

ALICE KAU, Ph.D., Eunice Kennedy
Shriver National Institute of Child
Health and Human Development (NICHD)

MICHAEL KOGAN, Ph.D., Health Resources and
Services Administration (HRSA)

HELEN TAGER-FLUSBERG, Ph.D., Boston
University

TABLE OF CONTENTS

Welcome, Roll Call and Approval of Minutes	
Thomas Insel, M.D	7
Susan Daniels, Ph.D.	11
 Update from Administration for Children and Families	
Linda Smith	15
 Changes in Prevalence of Parent- Reported Autism Spectrum Disorder in School-aged U.S. Children: 2007 to 2011-2012	
Michael Kogan, Ph.D.	33
Stephen Blumberg, Ph.D.	37
 Project SEARCH at the National Institutes of Health	
Maureen Gormley, M.P.H., M.A., R.N	69
 PANEL ON MINIMALLY VERBAL CHILDREN WITH AUTISM	
 NIH Autism Centers of Excellence Update	
Alice Kau, Ph.D.	103
 NIH Workshop on Nonverbal School-Aged Children with Autism	
Helen Tager-Flusberg, Ph.D.	109
Connie Kasari, Ph.D.	112
 Communication Growth in Minimally Verbal Children with ASD	
Connie Kasari, Ph.D.	115
 Minimally Verbal ASD: From Basic Mechanics to Innovative Interventions	
Helen Tager-Flusberg, Ph.D.	131

TABLE OF CONTENTS (Con't.)

Autism NOW Website	
Katherine Cargill-Willis	174
Amy Goodman	176
Oral Public Comment Session	185
IACC Member Discussion of Public Comments	223
IACC BUSINESS	
BRAIN Initiative	
Thomas Insel, M.D.	266
Comorbidities and Safety Discussion	271
OARC/IACC Update	
Susan Daniels, Ph.D.	297
Discussion of How to Address Public Comments	303
Update from Subcommittee for Basic and Translational Research	
Question 1 Planning Group	319
DSM-5 Planning Group	320
Update from Subcommittee for Services Research and Policy	321
Committee Discussion	323
Wrap-up	413
Adjournment	414

PROCEEDINGS:

Dr. Thomas Insel: Thank you and good morning to everybody who is here in the room with us in Bethesda, as well as many joining us by phone.

The agenda has got a lot of things on it. We have been pretty busy. I know there were four meetings of the IACC or its subgroups in March. So, lots to catch up on in April, which is, of course, Autism Awareness Month.

And I thought I would start just by pointing out a number of events. In fact just today, we have released the *Summary of Advances* and Susan sent that around to everybody this morning. It is out on the IACC website. This is the document you all worked on late in December, January and February to get us the 20 most, what you thought were the 20 most significant research advances of 2012. So I am delighted to have that out and hopefully it will be helpful to the Group as

you do some of the work on the research update.

There is also - and it is in your packages, a Presidential Proclamation from President Obama about autism. There is a statement from Secretary Sebelius as well that we have included in your package. These are also on the IACC website. And a statement as well from the Secretary General of the United Nations on April 2nd, which is World Autism Awareness Day when there was an event at the U.N.

We are doing at least one special event, which will be coming up next week April 17th on the NIH campus. There is a very significant lecture given by John Robison, who isn't here yet but I noticed that - he is in the building, okay. And his poster is sitting outside, the poster announcing the lecture. So any of you who want to come to this, it will be next Wednesday at 2:00 p.m. in Lipsett Auditorium, which is on the NIH campus and is

a great venue for this.

Susan points out we will be webcasting that. So it will be available to anybody who can't make it to Bethesda. But that should be a really wonderful event to hear about John's most recent reflections on growing up with autism and also being a father.

Just a few other administrative details before we get into the meat of the agenda. We have an unusually heavy load of public comments this time, both written and verbal comments that will be at the meeting. We have set aside an hour this afternoon from 1:00 to 2:00 for our public comment session with the idea that the first half of that would be to hear from the public, the second half for our discussion. But my last count was that there is something like nine public comments, which will be very difficult to fit into 30 minutes. As I have looked at the ones that came in, because we have the written comments, I simply don't see how that will happen. Some of them

look like they would be 30 minutes long just individually.

So for those of you who are all here to give public comments, I just want to encourage you to think about what you have sent in as kind of a template and try to condense that down to something much briefer. Think elevator speech to the extent you can. You will have about three, maybe a little bit more than that, minutes to cover really the heart of what you think the IACC needs to hear about. And I'm afraid that if we go much more than that, there won't be time for everybody and there certainly won't be time for discussion. So, I want to encourage you to use a little time this morning to the extent possible, condense down the comments.

And one thing we haven't scheduled in today because of the busy agenda was the kind of round robin that we have done on other meetings, where we have used the first hour just to hear about what is going on in

different agencies or in different organizations that you think your colleagues here need to know about.

What we will do is leave that to the end of the day so that we have some, we have a couple of hours at the end of the day for Committee business. And while there is quite a bit to discuss, if there is time left over, I hope we can use that to hear about some of the advances that are going on in each of your corners of the world of autism.

Okay, Susan, anything else to cover in terms of administrative details or what to expect from today?

Dr. Susan Daniels: Thank you. You have covered it, Tom. Would you like me to go through and do attendance?

Dr. Insel: Yes, let's do that.

Dr. Daniels: Tom Insel is here. Jim Battey? Linda Birnbaum - or Cindy Lawler?

Dr. Cindy Lawler: Present.

Dr. Daniels: Coleen Boyle?

Dr. Coleen Boyle: Here.

Dr. Daniels: Josie Briggs? Denise
Dougherty?

Dr. Denise Dougherty: Present.

Dr. Daniels: Tiffany Farchione?

Dr. Tiffany Farchione: Present.

Dr. Daniels: Alan Guttmacher?

Dr. Alan Guttmacher: Here.

Dr. Daniels: Laura Kavanagh? Donna
Kimbark?

Dr. Donna Kimbark: Here.

Dr. Daniels: Walter Koroshetz? Sharon
Lewis on the phone?

John O'Brien is not going to be able to
attend.

Larry Wexler? Idil Abdull? Jim Ball?
Anshu Batra?

Dr. Insel: She's here, just checking in.

Dr. Daniels: Okay. Noah Britton? Sally
Burton-Hoyle? Matt Carey? Dennis Choi?

Dr. Dennis Choi: Here.

Dr. Daniels: Jose Cordero?

Dr. Jose Cordero: Here.

Dr. Daniels: Jan Crandy?

Ms. Jan Crandy: Here.

Dr. Daniels: Geri Dawson?

Dr. Insel: Geri is going to be late. Her flight has been delayed.

Dr. Daniels: David Mandell?

Dr. David Mandell: I'm here.

Dr. Daniels: Lyn Redwood is on her way.

Scott Robertson?

Mr. Scott Robertson: Here.

Dr. Daniels: John Elder Robison?

Mr. John Robison: I'm here. And Matt Carey texted me that he is on the way, too.

Dr. Daniels: Okay, thank you. And Alison Singer?

There was unusual traffic this morning so some people might have gotten stuck in traffic coming from their hotels.

One other item is all of our materials are up on the website. And so most of the materials that will be mentioned in today's

meeting are accessible to anyone who is listening in from the public or watching the webcast.

Dr. Insel: And for the many of you who just arrived because of the delay out front, you didn't miss much. We just went through some of the documents that had been posted. The *Summary of Advances* is now up on the website, as Susan mentioned. And also documents related to Autism Awareness Month are on the website for any of you who wanted to see them.

With that, let me introduce - we have a new member of our Committee who is sitting to my left - Linda Smith, who comes to us as the Deputy Assistant Secretary and Interdepartmental Liaison for Early Childhood Development in the Administration for Children and Families.

Linda, welcome. And I thought we would give you a few minutes just to talk a little bit about your interest here and make sure the

Committee has a chance to welcome you.

Ms. Linda Smith: Thank you. And thank you, Tom.

Well I want to just say thank you for allowing us at ACF to participate in this. I think it is a very important topic for us. I want to just go over and explain just a little bit about why ACF would be interested in this and what we do.

In my area of ACF, I have responsibility for the Head Start program, Early Head Start, childcare, the Race to the Top-early Learning Challenge and the Tribal Home Visitation Program, among other things. And then children's health obviously is high on our list.

My background, I come out of a childcare background, primarily. And I have seen over the course of my lifetime so many providers who are struggling to understand what to do and how to work with children with any type of special need. And right now, they are

confronted with—they are the first line in a lot of cases for identifying children and yet they are not given very many tools to work with.

So our interest in that really our interest is in representing the workforce that we have out there, although they are very unprepared to do the work are doing the work. And so what is it that we can do at ACF and throughout the Federal Government to support this?

I just want to call quick attention to the numbers of children in these settings. On a daily basis, we have close to 12 million children under the age of 5 in some type of non-parental childcare in this country, another million children in Head Start, and then a variety of other unlicensed, unregulated situations. So we have got a lot of children out there who are in settings with very little support and very few services provided to them.

So that is essentially why I was interested in coming to this because we are trying at every juncture to figure out what we can do to support these people.

We have been doing a lot and I need to give credit to my special assistant, Shantel Meek, who is sitting over here on the side, who has a great interest in autism and to another bright young start at ACF, Katie Beckman, who is also working on health for us. And between the two of them, they are very interested in pushing this topic at ACF and helping support our work.

Katie, as some of you may know is out on maternity leave. We got to see her little baby yesterday but she will be back in June.

So in any event, we do have a lot of work that we are doing. We are doing some work right to recognize Autism Awareness and Acceptance Month. We have been putting together a tool kit in conjunction with the centers for disease control and NICHD. And we

will be sending this out to childcare providers, Head Start providers, and the community in general, the early childhood community. In that toolkit is a variety of things that we would hope will help them.

And I want to call attention to one thing that the autism community at large helped us with at Shantel's urging. She sent out a request to top researchers and asked them for tips. What would they say to childcare providers if they had one tip they could give them on how to work with children? So I think we have 10 now, 10 or 12 tips that people throughout the country sent in to us. And they are things like how do you incorporate certain things with play and help children focus?

So they are really fantastic and it was a really great effort that will be going out with our toolkit. And they are really written in plain language so that childcare providers and I think actually parents, too, will benefit from them. So when we get a little bit

further down the road, we will share some of those things with you. But they are among some of the things that we are working on, just to give people an idea of what to do with young children birth to 5.

A second thing that we are working on and we have been working on this since I came to this position is how do we help early childhood people understand development screening and be able to select instruments to use that will help them and help parents as well?

So we have been working with a committee - a working group, I should say. I need to make sure I get these terms right because in the Federal Government, you can't have some things. But we have a working group and I have to say it is one of the hottest tickets in town. I think we had over 40 agencies actually ask to be a part of this. And in that group, we are looking at developmental screening for children birth to 5.

And so we have basically been approaching this from three different ways, looking at, number one, a campaign that we will hope to launch this fall around development screening in the earliest years and how to help the early childhood community with that issue.

The second thing to support that is going to be materials and a guide on how to do this but what we are hoping to do by next fall is have a list of screening tools that we have used certain criteria to evaluate and say these meet the criteria that we are interested in for birth to 5 for that population. Our Office of Policy and Research is doing that work for us. We set the criteria. They are evaluating the screening instruments, and we will be putting out a guide as to how these were selected and how they should be used, in hopes that some of our early childhood population get more comfortable with the idea of incorporating developmental screening into their programs.

Along with that, we are very interested in and those of you who have worked with ACF and Katie, in particular, were very interested in getting into the public domain some screening instruments. I know that a lot of people sit and think well these instruments that are out there aren't all that expensive. But if you are a family childcare provider or a childcare provider that is operating on a shoestring, it is very hard to - I mean it is really cost prohibitive to use some of these things.

So we have been supporting work to look at development screening instruments that can be in the public domain and supported so that early childhood providers have access to them. And we are working on that and, hopefully, we will have something within the next year that we can say to our population here is what we would suggest that you look at, in terms of what instruments are viable and they should be thinking about.

I think the last thing that we are interested in and I am personally is interested in is because of my own background. I was born and raised on an Indian reservation and I am very keenly interested in tribal issues. And we are, right now, in a small pilot, validating an instrument for tribal communities with our home visitation program to make sure that the instrument is culturally sensitive and meets the needs of the Native American population, which we know has been long left out of the discussion at the national level.

So that is in progress in conjunction with our Tribal Home Visitation Program and we are very hopeful that we will have some results with that sometime next year.

So that is basically what we are working on. I am, again, thankful for being here. And I do hope that along the way I can get to talk with each and every one of you about how we can work more closely, especially with the

early childhood population. I do think they have a lot - they just really are the front lines out there with so many parents and we really do need to get them some help.

Dr. Insel: Great. Well, welcome to the Committee. I am sure that the issues you just laid out, whether it is issues around diversity or the need for better screening instruments is something we have talked a lot about already. So it will be great to have your expertise on the Committee.

Any comments or questions for Linda before we go on? Jose.

Dr. Cordero: Thank you for your comments. I am very thrilled to hear about what the Work Group is doing in development screening and the point on diversity.

And so I think your point on the cost for the practicing physician is a real one in my area. One question I have is can you talk a little bit about the screening tool that would be used in other languages, like Spanish? We

have a large population of Asian, et cetera.

Ms. Smith: And that is a really good point. We are not at a point to where we could say that yet because we are in the process of doing that work right now but we are very keenly aware of the need to have that.

And it is interesting that you bring that up because that whole issue in so many, especially of our Head Start programs, are migrant Head Start programs. We really do need to and we will make sure that it is included in this. It is just too soon to give you that answer but thank you.

Dr. Insel: Other comments? Anshu?

Dr. Anshu Batra: I didn't raise my hand but I will comment.

Dr. Insel: I'm sorry.

Dr. Batra: No, I will. I will take this opportunity. Thank for that presentation. I am very excited to find that we are looking at early tools because I think, as you mentioned, that is really where the most gains can be

made.

And as a pediatrician, that is what I am always advocating for because that is where I see my kids six to ten times a year and that is what I would like as a tool.

So I was curious if you could comment on what tools are being looked at.

Ms. Smith: Well in terms of the public domain, the work that we are doing is a lot around the SWIC and that is the one that we are validating in tribal communities. We are doing the validation on that because it is the one that it is just the one that was most there for us. We have done some work; Katie in my office had done some work with Tufts in her previous history. So we are interested in that.

I mean we are open to any number of things but what we are going to make sure is that anything that we put out there has had some rigorous evaluation of it because we don't want to be - we can't make a

recommendation, as all of you know, but we can certainly put out a list of tools that meet certain criteria and then let people choose from that.

And I want to say something. You triggered something that I skipped over and I really think it is important. And in the birth to 5 population, it is so easy to work with children on any number of issues, if they get identified. And it is why I just love the tools that we are working on right now because people, the providers and the workforce may not really understand exactly why they are doing a lot of things but they can still do them. And I think if we can change and get these things into practice out there when a child is two or three, you can really change the trajectory of a child's life with simple things. You know the older they get the harder it is but in these birth to 5 years, it is so easy to change these things that is almost a crime that we haven't focused on them before

now.

Dr. Batra: Have you looked at Ages and Stages?

Ms. Smith: We have, yes.

Dr. Batra: Okay.

Dr. Insel: Idil?

Ms. Idil Abdull: Hi. Thank you also for that wonderful presentation. And I really appreciate a tribal pilot. I think that is long overdue.

I just had a question about, because we always hear Learn the Signs so you can act early. And when I contacted CDC a while back and I wanted to see how they made that available in Head Start and in childcare centers where children are showing up very young so that people can catch, not just the parents but the professionals, they were training, they referred me to your department and I just haven't had a chance to contact you.

Ms. Smith: Oh, okay.

Ms. Abdull: So I was wondering if you can comment that how does your agency make sure that childcare and Head Start professionals are trained to recognize the autism signs.

Ms. Smith: Well and part of what we are doing, and I can also let Coleen talk about this, but we do work a lot with the Centers for Disease Control on this and a part of our toolkit will be Learn the Signs. Act Early. And we will be doing more work around that as we move forward.

So I think we are in total sync with what CDC has been doing around this. Camille Smith comes to all of our meetings. So I think if there are suggestions for other things that we can do there and other materials, we would be really wide open to that but we are using them already and we are working in concert with CDC.

You know it is interesting. I looked at my title up there and I say it is the longest one in history of the government probably. But

you know when you look at the interdepartmental liaison, that is the piece of my job that I really take seriously about how we get out and work with the other agencies. So if there are agencies that we haven't reached out, that is something that we are really interested in doing, in making sure that we are not duplicating, that we are using tools from other agencies, I mean especially CDC but so many, SAMHSA and other groups.

Ms. Abdull: So for example, in Minnesota there is lots and lots of childcare centers, even just for mommies, maybe 50 or 60. And many of them, the majority of them have no idea of autism signs. So for childcare centers and Head Start, how would they - who would train them? Like where would they register? Where would - how can we make sure that they are trained, those professionals are trained so they can figure out what the signs are and help the parents get early intervention? I understand that government takes long and

stuff but like today, what is on the ground?

Ms. Smith: In Head Start, that is fairly easy because that is a direct Federal to local and they actually have this as part of their mission and they should be already doing that work. So on one hand, Head Start is an easier one for us to work with. Childcare is very diverse and the funding is a block grant so we don't have quite that same ability to influence but we do.

And I think one of the things that there are a number of agencies within the early childhood community at the state level, the state childcare administrator, the state advisory councils which are out there and funded by the Federal Government, there are a number of vehicles to get to people to make sure that this happens.

One of the things that I think we are going to be trying to do over the next year, along with the toolkit and some other things are webinars for these folks. Because just in

many cases like you are asking, people don't know where to go to get the answers and we need to give them those. So we are taking a look at that and we will be doing more webinars to connect people to resources as we move forward. We are fairly novice at this right now but we are trying.

Dr. Insel: Anshu.

Dr. Batra: I would just add that I love the idea of webinar. I think that it is very expansive. But maybe tying in some maybe continuing medical education or credits or CEs, I think that is always - that is a good draw for professionals.

Dr. Insel: So we are going to need to move on but I think this is a good taste of what the Committee does at its best, which is the coordination. So finding out what is going on across different agencies, making sure that you also use this as your antenna to find out what is happening in Minnesota or California or various places on the ground and what is

needed more urgently.

So you have got a taste of I think how this Committee can be very helpful and how you can be helpful to them as well. So, delighted to have you here.

We are going to move on with the next part of the agenda, which is related to a report that came out a little over a month ago, I believe around new prevalence estimates for autism spectrum disorder in school-aged U.S. children. And we have asked Stephen Blumberg, who is the Acting Associate Director for Science in the Division OF Health interview Statistics at the National Center for Health Statistics in CDC and Michael Kogan, the Director of the Office of Epidemiology and Research at HRSA to join us just to take us through some of those findings and to give us a sense of how we should interpret them and be available for your questions about these as well.

Welcome to both of you.

Dr. Michael Kogan: Good morning, everyone. I am Michael Kogan. I am going to start off by giving you some general background about the National Survey of Children's Health. Then I am going to turn the program over to Dr. Stephen Blumberg, who was the first author of the report.

Just to give you some background, the Health Resources and Services Administration's Maternal Child Health Bureau embarked on a program to collect data on children's health in collaboration with the Centers for Disease Control's National Center for Health Statistics, beginning with the 2001 National Survey of Children's Special Healthcare Needs and then followed by the 2003 National Survey of Children's Health.

Since then, each of these surveys have been conducted every 4 years since their inception. For our purposes today, the National Survey of Children's Health has been conducted in 2003, 2007, and the most recent

one was 2011-2012, where the data from this report came from.

There were a number of reasons for initiating the surveys. The Maternal and Child Health Bureau provides the majority of funding for the states for Maternal and Child Health Programs. They need to respond to performance measures. In addition, at the beginning of the 21st century, there were no state-specific data on children's health in the United States.

And so the purpose of the National Survey of Children's Health was to produce both national and state-based estimates on the health and well-being, their families, and their communities. We sought not only to look at health conditions but to look at the broader spectrum of a child's life. We asked questions about parental health, family engagement. We asked questions on neighborhood conditions, safety in the neighborhood. And I will talk a little bit more in a minute or two

about some of the specific sections of the questionnaire.

These are telephone surveys. They started off in the beginning as land line-only surveys and have since evolved to both include land line and cell phone, cell phone-only households. They are done by computer-assisted telephone interviewing and we screen for the National Survey of Children's Health. We screen all households for children under 18 years of age. The base for the survey is the National Immunization Survey. We piggyback onto that.

These surveys are quite large. For the National Survey of Children's Health, the sample sizes have ranged from between 91,000 and 102,000 each time or about 1,800 to 2,000 children per state.

As I mentioned, these surveys cover a lot of different topics, including the child's health and functional status, the child's health insurance status, the child's

healthcare access and utilization, medical, home, family function, parental health, and neighborhood conditions.

We also have age-specific sections of the questionnaire. So for children 6 months to 5 years of age, here I draw your attention to questions that we have on developmental screening, the parents' evaluation of developmental status, the PEDS, Child Developmental Screening Test. And for school-aged children, what we are focused on here are questions about how is the child doing in school. How do they work with their families? How they engaged? We look at activities outside of school and time spent reading, computing, and television watching.

And then we have questions on autism. In the latest survey we asked questions: on has a doctor or other healthcare provider ever told you that your child had autism spectrum disorder. And then we asked does the child currently have ASD. We asked about the

parents' perception of the severity of the condition. And then we asked when the age when you were first told that the child had ASD. And finally, we ask about the type of doctor or other healthcare provider who told you this.

And now I am going to turn the program over to Dr. Blumberg, who is going to talk about the results of the study.

Dr. Stephen Blumberg: Thank you, Michael.

So as the title of the study suggests, we looked at changes in autism prevalence from 2007 to 2011 and 2012. This project was a collaborative effort among two centers at the CDC, the National Center for Health Statistics and the National Center on Birth Defects and Developmental Disabilities, as well as a collaboration with the Maternal and Child Health Bureau at HRSA. And the authors here come from all three agencies.

As Michael already alluded, the questions used to assess autism prevalence were the same

in both time periods of the National Survey of Children's Health. Parents were asked whether a doctor or other healthcare professional had ever told them if the child had autism, Asperger Disorder, pervasive developmental delay or other autism spectrum disorder. And if yes, the parent was asked does your child currently have autism or autism spectrum disorder. A yes answer to both of these items is what classified a child as having parent-reported ASD in this report.

Now based on these parent reports, we estimated that in 2011-2012 approximately 1 in 50 school-aged children or 2 percent of children aged 6 to 17 nationally have ASD. The 2 percent estimate is up from 1.16 percent in 2007, the last time that the survey was conducted.

To put this in a little bit of perspective, the census bureau estimates that there are about 50 million school-aged children in the United States. We estimated

that 1 in 50 has ASD and so that means that approximately 1 million school-aged children nationally would be reported by their parents to have ASD.

Now, as you all know, CDC's ADDM Network estimated that 1 in 150 children had autism several years ago, then estimated 1 in 88 more recently. It was, perhaps, inevitable, I suppose, that people would ask us which estimate is correct; is it 1 in 50 or it is 1 in 88? But the new data from the National Survey of Children's Health are not directly comparable to the ADDM Network data for many reasons.

So for example, they are collected using a very different methodology; telephone surveys as opposed to medical and educational record review. And they are from 2011-12, whereas the most recent estimates from ADDM are from 2008, more than 4 years ago.

The samples also differ. The National Survey of Children's Health estimate is for

children 6 to 17 years of age, from all 50 states and D.C.; whereas the ADDM Network data, our estimate is for 8 year old children in 14 sites across the country.

So as you can see, these data systems are quite different. And so it is probably inappropriate to compare estimates from them. But if you must, and plenty of people have, it is worth noting that the NSCH estimate of 1.16 percent from 2007 was nearly identical to the ADDM Network estimate of 1.13 percent from 2008.

Now we prefer, instead, to focus on the increase in prevalence within the same data systems. In this case, the NSCH, where we saw this increase from 1.16 percent to 2 percent.

Now for many surveys and data sources we have known that boys are more likely than girls to have ASD. The survey results presented in this report certainly demonstrate that this remains true but moreover the increase in prevalence that we observed was

seen almost exclusively among boys. The 2011-2012 data revealed that 3.2 percent of boys 6 to 17 have parent-reported ASD; that is, 1 in 31 boys. And boys are more than four times as likely as girls to have parent-reported ASD in 2011-2012.

When we look at age groups within the larger 6 to 17 year age range we did see differences in 2007. So focused here on 2007, adolescents were half as likely as younger children to have parent-reported ASD. Those age-related differences, however, were much smaller and statistically and not statistically significant in 2011-12. Compared with estimates from 2007, statistically significant cross-sectional prevalence increases were seen in every age group shown in this slide.

Now, at NCHS, before we accepted that the increased prevalence of parent-reported ASD was reliable, we felt that it was important to demonstrate that differential survey

measurement error over time increased survey non-response over time or the inclusion of cell phones in the 2011-2012 survey were not major contributors to this observed prevalence increase. Those analyses make up much of the technical results and technical notes within the report. And I am not going to get into them in great detail here but those analyses are also the reason that we focus the report on school-aged children 6 to 17 years of age. The idea was to evaluate the potential impact of measurement change by comparing estimates from 2007 to 2011-12 for the same population of children for diagnoses that could have been reported at both time periods.

Let me show you what I mean by that. In 2011-12, we asked parents how old the child was when they were first diagnosed with ASD and our data revealed that of the parents with or of the children with parent-reported ASD, about one-third had received that diagnosis in or after 2008; 1.37 percent had ASD that was

diagnosed in or before 2007 and, therefore, had ASD that could have been reported back in 2007, the last time that the NSCH was conducted.

These children who were 6 to 17 years of age in 2011-12 are from a birth cohort that would have been 2 to 13 years of age back in 2007. When we compared the estimates for 2007 with estimates from 2011-12 for this birth cohort, 6 to 17 in 2011, 2 to 13 in 2007, and when we looked only at the prevalence of ASD diagnosed in or before 2007, now that is diagnoses that could have been reported in both survey years, we found the estimates to be statistically insignificant from each other. That is the 1.16 to 1.37 comparison.

Now this greatly increased our confidence that any change in measurement error over time was not a major contributor to the observed prevalence increases. Similarly, had there been increased survey non-response bias in 2011-12 or had there been substantial coverage

bias in 2007 because cell phone-only households were not included in 2007, we should have seen big differences between the 2007 and 2011-12 estimates in that birth cohort analysis. We did not see those differences.

As a result, we were left with two other possible conclusions. One, that there was a sudden rise in ASD symptoms among school-aged children, symptoms that were not present before or that the recent diagnoses of children were of children with previously unrecognized ASD.

We discounted the first one, that there was a sudden rise in ASD symptoms because, as most of you know, the research generally suggests that whatever autism's causes may be, they are genetic or they occur early in life, and the symptoms are often recognizable or identifiable earlier in life. As such, we thought that it was unlikely that these were new symptoms that were just appearing among

teenagers and among school-aged children. So instead, we believe that most of the prevalence increase from 2007 to 2011-12 was the result of recent diagnoses of children with previously unrecognized ASD.

Now that conclusion is bolstered, in our opinion, by our finding that more than half of the children with recent diagnoses were classified by their parents as having mild ASD and very few were classified as having severe ASD. That is the column that you see over here on the right. And again, looking at the two columns on the left, you can see strong consistency in estimates from 2007 to 2011-12 for the same birth cohort when we are looking at diagnoses that could have been reported in both time periods.

So from these findings we concluded in the report that the increase in prevalence of parent-reported ASD was largely due to improved ascertainment of ASD by doctors and other healthcare professionals in recent

years, especially when the symptoms were mild.

And I will close there. This is the website where you can get to this report. I also brought some copies with me. If anyone would like them, feel free to come up to me at the break.

Dr. Insel: Thanks very much. We have some time for questions and discussion. John?

Mr. Robison: One of the things I didn't hear from anyone in the discussion of this yet, wouldn't it be fair to say that your survey ascertained a prevalence for what we might call educational autism, where the parents are reporting autism based on getting services for autism in school, where the other survey with the lower prevalence was based on a review of medical records and was, therefore, determining medical autism? And we already recognized that those two have very different rates in the different states, depending on how they treat autism in schools.

Dr. Blumberg: I don't think it is

entirely fair to make that conclusion only because the ADDM Network does do expert review of both medical and educational records. So they should be picking up both of those types of diagnoses, if you will.

Mr. Robison: Maybe I actually phrased that wrong. I didn't mean to sound as if I was dismissing or questioning the validity of what you found based on that difference. Rather what I meant to say is do we actually know what the difference is between what we would call educational and medical autism rates around the United States? And could we, therefore, make an intelligent comparison to draw a conclusion based on that?

Dr. Blumberg: We certainly don't, from the data that we have available in this survey. We don't know the source of the diagnosis. We don't know where parents have heard that their child has ASD. So we are unable to do that here.

But one of the things that we recognize

is that when you are talking about a parent survey and you are talking about a survey such as the National Survey of Children's Health, that it has such broad coverage of a lot of topics, ultimately we are left with the ability to only go a few inches deep into our understanding of a particular topic such as the prevalence of autism.

One of the advantages of the ADDM Network is though their sample may be more focused, 8 year olds, 14 sites rather than national, they do have the opportunity to drill down and perhaps look at those questions that you have raised. I don't know if they have. Perhaps Coleen can answer that.

Mr. Robison: Well thank you for that answer. I guess it is really an open question whether we are seeing what is now an explosion of awareness of the idea that autism diagnosis qualifies you for necessary educational supports and, indeed, that is a different thing than the medical questions we have

traditionally addressed here but thank you.

Dr. Insel: Coleen, do you want to respond?

Dr. Boyle: I think that was a great explanation, Stephen.

I guess one thing I was going to just say in response, the survey information, from my perspective, is what families are experiencing and then the ADDM Network, the Autism and Developmental Disabilities Monitoring, essentially what is happening in the community from what we would call an administrative perspective. So they are not exactly comparable.

Dr. Insel: We will start with Scott and then Alison, and then move around the table.

Mr. Robertson: So I think this is really interesting with your findings. And I would like to look at your study a little bit more later on, being a person in research myself.

I wondered if there is any - and maybe this is a complex question to answer but I

will throw it out there anyway. Is there any feasibility potentially in the long-term to be able to add on because this was added to an existing survey, if I understood right - these questions on autism were added and were not on the survey previous to years ago, right, a long time ago.

Dr. Blumberg: No, questions on autism have been on this survey since 2003. It has only been conducted three times.

Mr. Robertson: Oh, okay.

Dr. Blumberg: In 2003, 2007, and 2011-12.

Mr. Robertson: Because what I just wondered is if there is any feasibility through some other - it is a broader survey, though. It covers other questions. Because I wondered if there was any route with that manner to survey, to find out possible rates of autism among adults for some kind of community survey or some other means in the health sphere. I don't whether that is feasible right now but maybe in the future if

there is any possibility to do that, so that we could find out what it looks like throughout a broader age range past where you hit. You kind of hit the endpoint here at 17 and I wondered for individuals who are just somewhat a little bit older than that, is there any route to do that through another community survey?

Dr. Blumberg: The National Center for Health Statistics certainly conducts a number of surveys of the health of adults. None of them, to my knowledge, look at the prevalence of autism among adults but I will take that suggestion back to them.

Mr. Robertson: But they could potentially?

Dr. Blumberg: They could potentially, yes.

Mr. Robertson: Okay, thank you.

Ms. Alison Singer: So there are always issues inherent in studies that are done by surveying parents. And I think those are - you

add to them when the survey is conducted by telephone. So I am wondering how in the survey you accounted for issues that we know are part of telephone interviews, like selection bias and ghosting, and trying to please the interviewer. How do you account for those issues?

Dr. Blumberg: You are right that there are challenges when it comes to conducting surveys on the telephone and those challenges have been growing over time. Our response rates decline, particularly as we have had to add cell phones.

Dr. Insel: What are the response rates? Could you tell us that?

Dr. Blumberg: Well it is a little difficult to put it into perspective. The overall response rate, if I was going to give you one number is 23 percent. But that number is a very conservative number. And the reason that I say it is conservative is that it takes into account all of the telephone numbers that

ring with absolutely no answer, that we have no idea what is at the other end of that line. But we do believe that more and more of those telephone numbers are assigned to things that aren't households. They are assigned to the OnStar system in your car. They are assigned to, in some cases, your refrigerator. There is more and more various appliances that now have ways of connecting to the phone system.

Now the reason that I say that is that we see, for instance, that about half of the telephone numbers, half of the cell phone numbers that we call ring with no answer. We never get an answering service. We don't know what is at that end of that line. And so but we have to take a hit to the response rate as the result of that. But if we only look at the interview completion rates, that is, once we have reached a parent, will they complete the survey? We have an interview completion rate that is 54 percent for land line and about 42 percent, if I remember, for cell phone. Don't

quote me exactly on those.

Dr. Kogan: And 66 percent for 2007.

Dr. Blumberg: Right and 66 percent for 2007. Thank you, Michael.

So getting back to your question about telephone surveys. Yes, we certainly expect that to some extent there are parents who are going to answer questions in ways that may be different on the telephone than if you do it by mail or if you do it in person.

Generally, however, we found that telephone surveys get less socially-desirable responding than a face-to-face type of survey because you have got a certain degree of anonymity over the telephone. And so, therefore, we don't suspect that there is going to be a lot of error in terms of reporting ASD diagnoses.

Dr. Insel: Just to clarify, though, I mean what would it take to validate this so that you would actually, out of the 100,000 take 1,000 people and actually identify, as

other surveys have done, what the validity of the diagnosis is? And then you could make the correction that would actually give you a better sense of prevalence.

Dr. Blumberg: So if I understand what you are suggesting, you are suggesting that clinical follow-up or evaluation of a selected sample from the telephone survey could be useful.

Dr. Insel: Has that been done?

Dr. Blumberg: It has not been done, to my knowledge.

Dr. Insel: Matt?

Dr. Matthew Carey: I believe from your report it says, and there is a lot of material not covered, you have a follow-up report coming.

Dr. Blumberg: That is correct.

Dr. Carey: I was going to say one question would be how long before we see that. I think there is a couple things in here that are very interesting. There is a lot of

interest in the previous study you did with the response rate of previously told but not now considered. And I know that is not in this report.

Dr. Blumberg: But will be in the following.

Dr. Carey: Yes and the other one, I think is it a new question of which type of provider made this diagnosis because I don't recall that from the 2007 report.

Dr. Blumberg: You are correct. That is a new question in 2011-12.

Dr. Carey: Well then I am going to circle back to roughly can you tell us when the follow-up will come?

Dr. Blumberg: It is hard to make those sorts of predictions simply because reports of this nature need to go through our various agencies' clearances. And then once they are sent to Journal editors, it is out of our hands as to how fast things can happen at the Journal, even assuming that the peer reviewers

love it and don't want a million changes.

Dr. Carey: Is it possible to say where it is in that process? I mean is it still internal or is it -

Dr. Blumberg: It is still internal, right.

Dr. Carey: Okay, so we have got a ways. Thank you.

Dr. Insel: We have a few other hands up and I know that we need to get on pretty quickly. But let's quickly get some of these issues in. And I want to make sure Coleen has a chance to talk about this as well. So Jan and then David.

Ms. Crandy: My question is on when you asked parents to rate the severity, was it a rating scale? Because I have done intake for years and I can tell you most parents say their child is mild or moderate and then when we see the kid, they are not. So how did you tease that out?

Dr. Blumberg: It was a very

straightforward question that asked parents to classify their child's ASD as mild, moderate, or severe and it is up to the parent how they do that. And I think you are right, that you are going to see some positivity bias there.

Ms. Crandy: So if you did a clinical follow-up, could you actually go out and see those kids and see how this looked and that piece to it?

Dr. Blumberg: In theory if we were able to do that kind of a study, yes.

Dr. Insel: David?

Dr. Mandell: Thanks for a really concise description of what I know is a really difficult and complicated survey process. And thank you also for explaining why my ice maker keeps ringing.

(Laughter.)

Dr. Mandell: So in 2011-12, the 8-year-olds in the ADDM Network study were about 12, which is the median age of the survey that you fielded - of the kids in the survey you

fielded. So I don't think we might expect like so much age difference between them. Also the ADDM Network includes in their prevalence estimate kids who aren't carrying a diagnosis of autism who no parent was ever told that child has a diagnosis of autism but it is ascertained by about 20 percent of that sample actually wouldn't have responded positively as far as we know to your question about whether anyone had ever told them their child had autism.

And so which makes the differences in the estimates I am not sure one of cohort effects and perhaps even more drastically different than we might observe by just comparing those two numbers.

And so I know these are two difficult surveys or two difficult estimates to compare but what do we - so the question is then, what do we learn about the limitations of each of these methods that might inform?

So here are two different efforts fielded

by the same organization to hopefully get an estimate of the same condition in the population. And not so much how do we reconcile the estimates but how do we reconcile the methods and think about they should be informing each other?

And sort of to add to that, does the follow-back that you have done on the older data of the kids with autism and ID tell you anything about either the validity of these numbers or give you some more sense of what we could be doing to inform each set of methods?

Dr. Blumberg: You have packed a lot of questions in there and, obviously, I don't have time here to get into results of other studies.

You know I think you have highlighted certainly many of the methodological differences here. I think it is worthwhile understanding them to the extent that we can. Ultimately, I think that these are two very different systems and that the prevalence

number that comes out of each of them is perhaps less relevant than the changes over time and what that tells us about autism and about the needs out in the community of children and families with autism.

Dr. Insel: Lyn, you have had your hand up all along. Go ahead.

Ms. Lyn Redwood: Thank you so much for the information it is very informative.

As Dr. Carey said, I am very fascinated with the 2007 survey where 1 percent of the families responded that their child had autism and then 0.6 percent said they no longer had it. And I am wanting to know how much you're going to drill into that question to be able to ascertain were they wrongly diagnosed or did those children recover. And if it was recovery, what did the parents report as what they felt was most successful? Because that is the recipe we are after. So I think that information is really important.

So I want to know how much information,

what detail of information you are getting on that question. And then the second has to do with these milder forms of autism. We had a very robust discussion last night during dinner about children presenting now with what we call autism lite. And I think that also beared out a little bit in the CDC data with lower intellectual disability in the last data set.

So I am very fascinated by that because we are always looking at metrics to measure progress. So if we are now seeing milder cases, more recovery, lower intellectual disability, that is hugely important. So those are the questions that I have about this data.

Dr. Blumberg: Unfortunately, we didn't ask parents what services they think were most effective in treating their child with autism or that were so successful that they reduced the child's autism symptoms to the point that the parent doesn't think that the child has autism anymore.

We did ask parents that set of questions; ever diagnosed, current diagnosed. And indeed, you do see a difference. Our preliminary numbers suggest that it is between about 15 and 20 percent of those ever diagnosed are said to no longer have the condition within the survey.

Dr. Larry Wexler: This is Larry Wexler. Any chance I could get a question in?

Dr. Insel: Now is your chance.

Dr. Wexler: Thank you, Tom. I am with the Department of Education and I was just curious. We, of course, do prevalence rates also based on child count numbers within the state. So I was just interested if you wanted to comment on from 2005 to 2011 as a percentage of the population, the rate has doubled, pretty much exactly doubled. And I am wondering if that would be consistent with some of your findings.

Dr. Blumberg: Yes, generally. We are only looking at 2007 to 2011. But that certainly is

an increase. Going from one to two percent is almost doubled.

Dr. Wexler: Okay.

Dr. Blumberg: And our increase is consistent with the ADDM increase as well. So we are all seeing increases over time.

Dr. Insel: I appreciate your fielding all these questions. We will have one more and then I am going to ask Coleen to sum up. So Idil?

Ms. Abdull: Thank you. And thank you very much for the information. I was just wondering on the ADDM network it said Utah was the highest and Alabama was the lowest. And so the one in 88 is the medium. Did you get by, any chance, a sense of which state has the highest or the lowest? Was it Utah and Alabama or no?

Dr. Blumberg: We certainly are working on that. The survey itself is designed to produce state level estimates for various measures that are on the survey. Now unfortunately because autism is - well, fortunately autism

is still rare enough relative to other conditions but from a survey statistician standpoint, unfortunately, the data are sparse enough that when we try to look at state-level prevalence estimates, those estimates themselves lose precision. That is, the confidence interval around those estimates gets very wide on us.

And so while we can produce an estimate, I don't have a lot of faith in it but we are continuing to explore ways that we might be able to improve our estimations at the state level.

Dr. Insel: On that point and then we will go to Coleen, is there a plan to make all this public so that those kinds of questions and other questions can be explored by any of us who had an interest in this?

Dr. Blumberg: The data set is public. You can go out onto the NCHS website, go to SLAITS, that is the State and Local Area Integrated Telephone Survey, which is the

mechanism, the overarching umbrella that these surveys have been conducted through. There, you can download this data set and if you have got the right software, you can analyze any of the questions that we have been presenting here today.

Dr. Insel: Terrific. Coleen, last comments.

Dr. Boyle: Well thank you, Stephen. It was wonderful.

I just wanted to mention one thing. The first was in response to Lyn's questions about these children who had ever and don't currently, based on their parent report. There is a study that is being conducted by NIMH, the follow-back study, I believe, and I know that is somewhere in the works. So hopefully, we will have a better sense of those children sometime soon and I think that will give us some clarity.

In response to the individual from the Department of Education, again, these are all

really tricky data sources. So in our ADDM Network the percentage of children who met the case definition based on expert review, I mean the percent actually had an autism classification and their education records varied dramatically from 10 percent and I don't remember this date, about 75 percent, I have it in front of me, from Arkansas to Alabama. So very dramatic differences in terms of percentage of children, who actually have a school designation of autism.

So I guess that was just a way of wrapping up and going back to David's point. These are very different ways of trying to get at the same question. To me, each of them presents a different piece of that puzzle and it is really trying to see what you are getting from an epidemiologic perspective, what you are getting from each one of those.

And I think no one way is perfect, particularly when you are trying to encompass such a large geographic area, such as the

United States and all of the forces at work, in terms of the community, in terms of identifying and diagnosing children with autism. But it is continually trying to put that information and those sources together and trying to get below the surface of the question. So I appreciate that.

Dr. Insel: And if Geri Dawson were here, she would add that Autism Speaks is hosting a population-based study to actually, in South Carolina, nail down the question of what is the prevalence, which we still don't have the most precise estimate of. So, important questions.

Thanks very much to both of you for joining us and for taking us through what was a very clear, succinct description of complicated data sets. So very, very helpful.

We are going to move on to hear from Maureen Gormley, who is the Chief Operating Officer at the NIH Clinical Center.

And I think most of the people around the

table will have no idea what the NIH Clinical Center is. So just as a very quick introduction, this is our hospital, which is in Bethesda. You have been on the Bethesda campus the last time we met. What you didn't see was there is a very large building in the center of the campus, which is a hospital of about 240 some beds and huge outpatient facilities. And it is a national center where people come to participate in research protocols. Everybody is a volunteer who comes in there. It is the place where many of the most dramatic breakthroughs of the last half century have taken place. And it is an extraordinary opportunity for training as well.

And Maureen is going to tell us about a particular project of relevance to transition-aged youth. So with that, welcome and thanks so much for joining us today.

Ms. Maureen Gormley: Thank you and thanks for inviting me. It is really a pleasure to be

able to share what we have done at the Clinical Center and, even more broadly, at NIH with hiring transition-aged youth with intellectual disabilities through a program called Project SEARCH.

We started this program in 2010 and it is really an innovative school to work transition program where we provide workplace training and hopefully hiring opportunities to transition-aged youth with intellectual disabilities.

Of importance for this Group is over half, just over half, of the student interns that have taken in and subsequently hired are on the autism spectrum.

So this is really what happens to the 8- and 10-year-olds 10 years later when they are going out and completing secondary education and transitioning from the very structured supports they received while they are in school.

So how did we get into this? This is a

lay initiative and I have to say I am humbled by the knowledge around this room, the science behind this topic. And this is really an administrative perspective of how I think organizations can help make a difference to this tremendous population of people.

When I was approached about starting Project SEARCH, I was really aware that it aligned with the NIH mission. Part of our mission, in addition to enhancing health and really trying to lengthen life through the science is to reduce the burdens of illness and disability for all people. And so I was pleased that Project SEARCH really supported the NIH mission.

At the same time, there was an Executive Order by President Obama to increase the hiring of individuals with disabilities. This was in July of 2010. And his commitment was to make much more of a concerted effort to hire individuals with disabilities. There are a lot of initiatives that come across our plates as

administrators at NIH with which we have to comply but I can say that this is one where our compliance was really just the sort of as the lowest bar to get over. We have approached this initiative with a tremendous commitment because we have really grown to understand the important agenda and to really get behind going the hiring for people with disabilities.

I also was struck by the Project SEARCH representing a very well organized collaboration. And I will explain a little bit more about that in a minute. And at the same time, the Clinical Center, we have a spectrum like all hospitals of entry-level hiring opportunities. So Tom gave the introduction to the Clinical Center. We are the research hospital of the NIH. I would add that our patient population is very diverse. They come from all walks of life, all parts of the U.S. and abroad and represent a variety of needs as they combat their diseases. We are aware that having a diverse employee population puts our

patients at ease.

So the Project SEARCH model represents a really active collaboration. And I want to just take a moment to introduce two colleagues I brought with me. And Lou Merrick, who is the Director of the Post-high School Programs at our local Ivymount School and Denise Ford, who runs our Patient and Guest Relations Program at the Clinical Center and she has taken on the lead as Project Manager for Project SEARCH. So these two individuals have really made this happen.

The collaboration on how the Project SEARCH model works is that you have a local school meeting special needs for exceptional students, you have the vocational rehabilitation system and their role is to come in and provide job coaches. And we work with SEEC, and they are a local group out of Silver Spring. They provide job coaches who come in to reengineer the jobs and tailor the jobs in a way that they can be done to meet

the needs of the individuals filling the jobs. And the Clinical Center is the employer. We provide the job site. So we really going around the organization, and it is not a typical hiring model where we go to our managers and we say what are your vacancies. We go to our managers and we say what is the work that you are doing that you think could be done better by somebody else? You don't need a professional pharmacist, for example, looking at all of the expired medications and taking time out of what they are trying to do at the bedside with the patients. And so we really re-engineer the jobs in a way that they can be filled by our Project SEARCH interns.

So how does the program work? We have 30-week unpaid internships for up to 12 individuals annually. Each intern completes three 10-week rotations, so that they get a real sense of what it is like to integrate into the workplace and do a variety of different jobs. And Project SEARCH is

different in that it really represents the demand-side model. And what do I mean by that? That is: what is the work in the organization that we really need done? We are not trying to do anybody any favors here. We are really trying to respect that these individuals that we hire are doing work that we need to have done. And so the interns are matched to the work sites, based on their skills and their abilities. And that is where the Ivymount partner comes in. They have active weekly meetings among the job coaches, among the school representative and our on-site project manager to look at what are the skills that are available and what is the work that needs to be done in the organization.

So these interns are with us Monday through Friday. We have taken a small conference room in the Clinical Center and set it up as a classroom. And so they are there for one hour in the morning and they receive instruction on any number of items: how to use

the computer, how to get their ID badges, how to interact socially appropriately in the elevators and public areas. And then they are 5 hours fully immersed into the worksites. So they are not segregated in any way. They are working side by side with coworkers around the hospital and in other parts of NIH. And the goal is really to hire them when we are finished.

We have the special hiring authority in the government called Schedule A, which is very helpful because it is an accepted hiring authority and we don't have to go through the more laborious process, shall I say, of the HR system.

Project SEARCH, nationally, was established in 1996 at the Cincinnati Children's Hospital Medical Center when a woman named Erin Riehle, who is the Director of their Emergency Department was really struggling with high turnover for their stocking of supplies in the emergency room. A

really busy area and she couldn't afford to stop and have nurses and others be restocking supplies within a busy emergency room setting. So she contacted a local rehabilitation agency and partnered with them and that is how the Project SEARCH model began. She said don't you have people that you could train to do our jobs, because we would love to have them? And it worked.

And so currently there are 200 Project SEARCH sites across 20 states and four countries and there is a really active network. We have participated in the Project SEARCH national conference for a couple of years and we go there and we share our experiences and we certainly learn a lot from other organizations.

Hospitals are great sites for Project SEARCH because it is like a mini-city. You have so many different types of roles that need to be filled. But we have also had a lot of success across the country with banks,

other Federal agencies that I think you have heard about, businesses and universities also engaged in the Project SEARCH model.

So in the Clinical Center, some examples of our assignments have been when every patient comes in the door a couple of years ago we implemented a new patient safety initiative, an IT initiative for bar coding. So everybody gets a bar code and a wrist band so that the computer system links up when medication is being dispensed or when patients are about to have a procedure, everything is checked by a bar code.

So we have one of our Project SEARCH employees now interacting with all the patients as they come in the door to provide the bar coding. We get a lot of positive feedback, too, about those interactions because this individual is really terrific.

We had a problem in the hospital, as many hospitals do, with hand hygiene, especially during flu seasons. And you see those

dispensers of the alcohol solution around elevators. And one of the things that would drive me crazy is I would walk by and it would be empty. And who is going to do that job? We got a really great Project SEARCH intern who was engaged with our materials management department to step up and her job was to go around and fill the dozens of those dispensers every day. And we credited her with helping us foil the flu this year. She did a great job.

We have interns in hospitality, in pharmacy I mentioned, in the OR. We have one young intern who is so good at the computer that he figured out a way to reduce our lost linen by automating our inventory by computer. And we subsequently hired him in our housekeeping department and it was really nice. One of our housekeeping supervisors took him on as a mentee. And we had to interview him for his job and the people in the housekeeping department who worked in and around him bought him a suit for his interview

because they wanted to make sure that he actually put his best foot forward.

And I have a lot of stories like that about the positive esprit de corps that these remarkable individuals have added to our organization where you walk around and you see and you feel this sense of tremendous coworker support because they are happy to have the help and because there is a certain magic that has happened that is hard to describe, other than that word.

I have met many colleagues through this work, one of whom is Paul Raymond at Virginia Commonwealth University and he is doing a lot of work on outcomes for hiring of transition-age youth with intellectual disabilities. And the first time I spoke with him over the phone, it turned into about an hour conversation. And I was telling him about our experience at NIH and he shared with me that in the hospital that he is working with down there, which is the Bon Secours Hospital, that

what I kind of called the magic in the Clinical Center, they called the Bon Secours effect, where these individuals who they had hired had had just a tremendous positive impact on the morale of the organizations in which they were placed.

So I am really pleased that we have many NIH partners in this effort. NIMH has, I believe, recently made an offer to one of our wonderful interns who is here today, Charles Needner. And he came down because he is working in this building. Charles, are you here? Here is Charles. And he is terrific, one of our big success stories.

We have also had the opportunity to work with Charles' mom who is a special assistant to one of the directors of the Smithsonian Institution. And recently our team went down and kicked off a Project SEARCH effort to the undersecretaries of the Smithsonian and they are embarking this season on their first year of Project SEARCH. And our commitment is to

really help them with our lessons learned and our experiences.

We have been able to get a lot of support around the NIH, now that we kind of know what we are doing with 3 years' experience.

Here are our results. In our first 2 years, we graduated 22 interns after the 30-week internship program. And we hired 13 at NIH and three were hired in the community, meaning mostly by NIH contractors. Hires that are still employed are 14. So overall, we hired 73 percent of our interns. And of those that were hired, 88 percent have had sustainable employment.

We project in year 3, which we are just finishing, that we are going to hire nine of the ten interns. So we are really pleased with our results and I have some sort of lessons that we have learned along the way that I would like to share briefly.

First of all, these statistics, just like the ASD prevalence statistics are difficult to

pin down but I find that the literature that I have looked at seems to point to a 30 percent lower national employment rate for individuals with disabilities. And notably, employment gaps are most problematic for transition-aged youth. And when these youth are finishing high school and the structured support that they receive from their parents and their teachers and the community resources begin to come in question.

There is a lot of confusion at that time, as these individuals, just like individuals without intellectual disability, are expected to complete their secondary education, obtain meaningful employment, gain financial independence and make autonomous decisions. I think what we find is that the tasks that these individuals have to accomplish developmentally are the same but they are longer in scope and duration and they meet many more challenges than youth without intellectual disability. And that is why the

support programs that you find with Project SEARCH and the real collaboration among the community, among the employers, and among the local schools. That is a real need at that time.

What we have learned about the societal challenges is that it is really important to shift the paradigm for these individuals from segregated to integrated employment. There are studies that show that individuals with intellectual disability have just as much desire to have social interactions at work, to have meaningful work, to contribute and to make a difference.

And so they are integrated right alongside of all our other coworkers at the Clinical Center and that is the beauty, I think, of the Project SEARCH model, is the total immersion. And it really increases the expectations for these individuals to function, despite their limitations.

One of the other challenges is the notion

of presumptive employability. You can read a lot about the stigma that employers have against people with intellectual disability. The first one to overcome is that they are not even aware that these people can hold mainstream jobs and do a terrific job at them. And we have learned that that is absolutely true through our experience. And then when you get beyond the fact that they are not even considered in a viable pool of job candidates, you have to overcome the issue that people are afraid. They are afraid that it is too burdensome and too costly. And what we know is that that is not the case.

So we think that it is really important as a big employer to look at people with intellectual disability, including the large percentage with autism spectrum disorder as in a viable pool of job candidates. And that takes effort on our part to move from employer awareness to employer engagement.

And in the case of how it is having an

intellectually disabled coworker side by side with all our other coworkers, we must deal with perceptions of fairness and the expense of accommodations and the judgments that people make about disabled employees. Because if we don't understand and tackle those stigma, we can't overcome them. And we have really begun to learn how to do that as we talk about this initiative throughout our organization.

One way we can do that is by understanding and educating our managers and our hiring officials about reasonable accommodation. Now, reasonable accommodation, if you ask most supervisors around our organization what it means, it conjures an image of making sure that you comply with the physical disability requirements of ADA like having ramps and having heavy doors that open with automatic openers. It is really important for us to promote the concept that reasonable accommodation for people with intellectual

disability has to do with understanding their skill level and independence in both intellectual functioning and social adaptation. And that is done in Project SEARCH by really understanding who our interns are and what unique capabilities they bring to the table. And it is not a one size fits all, just like any other employee doesn't have the same exact skills and abilities as their coworkers.

So, personally, I have learned a lot in this initiative. And I will just share a little anecdote. A couple of months ago I dropped my kids off at school early one morning and I was in the office around 7:30 and my phone rang. It was one of my Institute colleagues calling because there was a ruckus outside the medical boardroom and it was one of our Project SEARCH interns. So I said okay, I'll be right down.

So I found Jeremy, who I knew. And he was sort of flailing outside the elevator and kind of slamming his backpack against the ground.

And I said, "Jeremy, what's wrong? You know you can't act like this. We are in the hospital and you are going to scare people."

And I said, come sit down on this bench, it was right near the elevator, and tell me what is going on.

And so he was all upset because he couldn't get logged on to his computer and I think people remember a couple weeks ago when we had to implement the new PIV Card logon. So Jeremy was not the only one having these kind of difficulties because I met a lot of people that week who were really, really frustrated that they couldn't get on to their computer. He was just manifesting it a little bit differently.

So I said, "Jeremy, look, you know you can't do this. Somebody will be here really soon to help you log on to your computer. Can you please go in the classroom and get a hold of yourself?" And he said, "Okay, Ms. Maureen, I can do that." And he was fine.

And I wouldn't have known to do that, unless I had worked so closely with my colleagues Lou and Denise, who tell me that you really have to just understand that it is a little bit of a different way of being and a different way of knowing that our interns exhibit. And it is nothing that we should shy away from. We should embrace them and understand their differences because their differences make them capable in a whole new way that teaches our organization.

So Project SEARCH has really, I think, brought to the forefront of hiring transition-aged youth with disability, a program that attempts to battle the high unemployment levels for people with intellectual disabilities. There is a lot of stigma to overcome among employers and employees, a lot of fear that we all come by quite naturally, unless we work in this and closely with individuals with ID.

As I explained, I think explaining the

differences and how to deal with this special population can be framed in the context of reasonable accommodation. And if we are good supervisors and managers, that is not very hard. We should be doing that for every employee. I think of all the employees I supervise and everybody needs a little bit something differently. Some people have children and they need more flexibility to pick them up or drive the car pools. Some people have adult parents that they are taking care of. Some people need flexibility because they have other disabilities and this is just something else for us to understand.

It allows us to embrace organizational diversity in a new way and to meet our patient population with diversity. And it allows these individuals to find meaningful work, which they deserve. It has allowed our team to find meaningful work in this initiative.

This is also a very business-driven program. This isn't all about feel good or how

do we help other people. This is a business-driven program. We need the work to be done. We need to figure out how to partner, which we have done with our local voc rehab agencies. And in our organization, figure out how to communicate with our supervisors in a way that they understand. It is not the typical paradigm of having a position that is fluid and inflexible. It is about identifying the work, creating the jobs, and re-framing it in a way that is more flexible and fluid.

We have learned in our organization that it works when we find willing internal partners. Not everybody is willing and that is fine. There are 16,000 employees at NIH and we certainly haven't hit anywhere near that saturation point of the people who are willing to help. It is about understanding that the contributions that these individuals make really add to our organization and also about somebody like me figuring out how to manage organizational change in a way that is going

to be able to sustain the effort and not die on the vine after the first few months.

I think our ingredients for success have been our pretty permeable organizational boundaries of organization. A lot of our institute colleagues are really willing. We have a really strong internal project manager. Denise really makes this happen on a week-to-week basis. We had leadership support, which is essential. My institute director, John Gallin, thinks this is a terrific initiative and is always wanting and willing to support our effort in this.

We have employee accountability, which is essential. You know, I will say a word about this. One of the things that -

Dr. Insel: We are a little tight on time. So we will just have to -

Ms. Gormley: All right, I will move along, Tom.

Dr. Insel: Yes, I'm sorry.

Ms. Gormley: So let me just say we, as I

mentioned, rejected the negative stereotypes. We have really accepted this group of people into our organization. Our next steps are to figure out how to make this sustainable, increase further participation with NIH and identify additional job sites.

Thank you.

(Applause.)

Dr. Insel: That was just terrific, Maureen. Don't go away. In spite of being way, way past where we need to be on the schedule, I just want to make sure other people have a chance to comment. So we will start with Scott and then move to Noah.

Mr. Robertson: So I did have a contact question but just one quick clarifying question. My understanding is that Project SEARCH refers to - people who participate are people with intellectual and developmental disabilities, including some autistic people who don't necessarily have co-occurring intellectual disability. Is that the case also

for this Project SEARCH site that, where you are referring to intellectual disability, you mean intellectual and developmental disabilities?

Ms. Gormley: Yes, that is true.

Mr. Robertson: Okay. I just wanted to make sure in terms of clarifying on the terms. But the broader thing that I was just wondering on is: do you have an intention to maybe use some methods like interview surveys, et cetera, to dive more deeply into some of the successful outcomes to find out what occurred, to document it a little bit more or get some qualitative and quantitative data that could be published on this? Because my understanding is that a lot of the other Project SEARCH sites really extensively collaborate. And it looks like you have collaborations with the universities, so maybe that is part of that. I have spoken with Dr. William before about the great work with this and the immense success. You guys are, for

instance, seeing the same thing they have seen kind of more broadly of how beneficial this model is in terms of the internship as a gateway to competitive integrated employment. So it would be nice to see when the data comes out for your sites.

Ms. Gormley: Right. There is more literature on outcome data than there is qualitative data. I am doing a little study as part of a Ph.D. program on coworker perceptions, working alongside with people with intellectual disabilities, a minor contribution but really interested in the topic. Not a lot of literature on the qualitative side.

Dr. Insel: Noah?

Mr. Noah Britton: Yes, I am wondering do you give aptitude tests or is it more achievement-based for your interns at the beginning?

Ms. Gormley: I am going to defer that to my school colleague.

Ms. Lou Merrick: Our interns come from either their last year in school so that we have all the support of the school assessments and information or from our partner, SEEC, who is one of the community rehab partners locally, and they have assessments from DORS and VR for the individual. And they are all individuals with intellectual disabilities, some with intellectual disabilities and developmental disabilities.

Mr. Britton: Right. Well I guess the reason I asked was that I am thinking, of course, of somewhere like a Spiratec, where they take autistic people's superior processing in certain areas and let them utilize this. And I am hoping that SEARCH doesn't end up being yet another day-hab program, where people are doing something really, really beneath them and just hoping that you are making sure that you take the aptitude for superior processing and apply it. Even though someone's general functioning

might be very low, their ability to sort through data very quickly might be incredible. And I just am hoping that this is something that you are thinking about in this hiring, because I am sure that the schools are giving those aptitude tests when they refer you.

Dr. Insel: John.

Mr. Robison: First, I would preface this by saying that I want to see all of us at IACC take a much more activist role.

I take two things away from what you presented. First, I think that you have shown us a very optimistic and encouraging validation study for the idea that people with these disabilities are much more employable in successful employment - in employment than was previously thought.

Then I combine that with your showing the statistic of the employment rate for people with disabilities is 30 percent lower and we must recognize that that must mean that burden of financial support is heavier on the

government for those people because they are not working.

So could we use this finding as the basis for another letter, this one to the Department of Labor, to suggest that we actually deliver some real meaningful incentives for employers to employ people with disabilities because, frankly, the kinds of things they talk about now, the tax credits that we give people with disabilities are so complex and so long-term that they are absolutely worthless to small business, which employs the vast majority of Americans. So could we use this as a basis to first advocate that your work be replicated at other sites around the United States? And we support that with tax dollars because it is a good tradeoff versus disability. And could we then argue that that be expanded to the employer group as a whole in this country? How does the Group feel about that?

Dr. Insel: So that sounds like a discussion for time when we can really dig in

and bring in some of the expertise from the Department of Labor. We have talked about doing this in the past and maybe this is just the right moment to bring the question back to the table. We will circle back to this later in the day.

Mr. Robison: I agree, yes.

Dr. Insel: But it is a great question.

Sally?

Dr. Sally Burton-Hoyle: That was a wonderful study. And I think that what it says is that when person-centered approaches are used to employ people, there is success. And I think we all know that.

The problem that I have experienced in advocacy with people getting employed is a little bit less on community understanding and awareness of autism but more of what voc rehab policy is, which is to close cases. And when people with or without intellectual disabilities with autism go into the voc rehab system, if they have high functioning or

Asperger's, they are seen as having an attitude and, thus, unemployable. If they are nonverbal or have any other kind of cognitive/intellectual issues they are seen as unemployable and, hands are washed.

So what is it, I concur with John - and I have heard much higher numbers of unemployment for persons with disabilities. It would meet the needs of additional services and supports if people had jobs. And when they have jobs and they have productive and meaningful lives, then we will take care of so many problems. But thank you very much for your study.

Ms. Gormley: Thank you.

Dr. Insel: Last comment from Jan.

Ms. Crandy: The National Project SEARCH program in all the other states, do we know what the sustainability employment rate is? Is it as high as yours?

Ms. Gormley: The statistics we hear are about the same as ours. Some better, some less. And we hear it at the national

conference.

I think project search, itself, struggles with inadequate funding infrastructure to have a central database of information. So it really is run as a grassroots effort, where people are reaching out and networking and learning from how people are doing it in different areas.

Ms. Crandy: It would be nice, Tom, to have Project SEARCH come here and tell us that.

Dr. Insel: Yes, it may be one of the things we want to do with this as an introduction.

I think for those of us who work at NIH, besides being enormously grateful to you for describing this project and to your colleagues for meeting it, we are just amazed that you are able to hire anybody because it is so difficult during the sequester to get through any kind of a hiring process at all. So it is quite amazing that you have been able to bring

so many of these interns actually into the workforce. Spectacular.

You guys have definitely earned a break. We are about 20 minutes past where we should be and we are still early in the agenda. So I want to shorten the break to be, let's say, half of what it was going to be. It was 15 minutes before. So, we are going to have you back in 7 minutes, which I know means 8. We will get started in about 8 minutes. Thanks.

(Whereupon, the Committee members took a brief
break starting at 10:40 a.m. and
reconvening at 10:51 a.m.)

Dr. Insel: So I want to welcome Alice Kau, who I think is well known to everyone on the Committee. Alice is from the National Institute of Child Health and Human Development and is the head of the autism program within that institute, has been very involved with the ACE Centers and with other projects. But she is coming to us today to talk about a meeting that was held on children

with minimal verbal abilities and opportunities that were being developed for them.

So Alice, I am going to turn this over to you and you can do the introduction of the various members who will be reporting out from the earlier meeting.

Dr. Alice Kau: Well, thank you for inviting me here today to give you an overview of the NIH-funded Autism Centers of Excellence Program or the ACE Program. And I will give you an overview and lay the foundation for our next two speakers.

First of all, a little bit of history. Before ACE program, NIH had funded two autism programs. The first is the Collaborative Program of Excellence in Autism, funded by NICHD and NIDCD for 10 years. And then the Studies To Advance Autism Research and Treatment from the five NIH Institutes, NICHD, NIDCD, NIEHS, NIMH, and NINDS. And the STAART Network activities was coordinated by the NIH

Autism Coordinating Committee.

In 2007, NIH consolidated the CPEA and the STAART Program into the ACE Program. And the funding of the ACE Program came from the same five NIH Institutes, NICHD, NIDCD, NIEHS, NIMH, and NINDS. The funding started in 2007 and were renewed last year, 2012.

There were two types of ACEs. One is ACE Centers and the other is ACE Networks. ACE Centers are the traditional NIH Center grants. The projects are synergistically related, usually it is an in-depth probing of one subject matter. Each ACE Center needs to have a minimum of three projects, but no more than six projects. ACE Networks are usually multi-site projects. For ACE Network, it has to be multi-site projects commonly used for recruitment purposes.

There are some requirements for the 2012 re-competition. All ACEs need to create a research training environment for all levels of scholars who are interested in being

trained into conducting autism research. And also nationally, in non-Centers of Excellence, all ACEs are expected to actively involve in educating the community, actively disseminating research findings into the community. And all the ACE projects are in supportive of the IACC Strategic Plan and all data from the ACE Program will be submitted to the national database for autism research. And this is a list of all common measures for all the ACEs.

So last year we re-competed the ACE Program and last year NIH released nine awards. And last week NIMH also released the two additional ACE awards. So in total, we have 11 ACEs; 3 centers and 8 networks. And this is the map of our distribution of the PIs and their institutions.

Three centers are the UCLA, Emory University, and Boston University. And Dr. Helen Tager-Flusberg is here today, representing one of the ACE Centers. And her

center focuses on minimally verbal ASDs, which is definitely fitting of the IACC strategic program needs.

So ACE Networks, I am going to present you each ACE network on a map. So I think it is the most visually informative way for you to appreciate the networks. The first is Autism Genetics Network with PI Dr. Geschwind. I would like to note, mention to you that this network plans to recruit 600 African-American families with a child with autism.

The next network is Adaptive Interventions for Minimally Verbal children with ASD in the community. And Dr. Kasari is also here today. So we have a theme of minimally verbal in autism as this session. And I am sure she will talk to you about the two very innovative intervention methods and the very creative design that will be used in her ACE Network.

The next ACE Network will study multi-modal development of neurogenetics of females

with ASD. And we all know that the nature of ASD in females is really poorly understood. So this network will have the capacity to recruit the largest number of females with ASD.

The next network is a longitudinal MRI study of infants at risk for autism. And this is the network which reported the abnormal brain development at 6 months in infants who were later diagnosed with ASD.

The next ACE Network is Dr. Reichenberg's Multigenerational Families and Environmental Risk for Autism Network. And this network will leverage existing resources that links data, population-based epidemiological data from seven countries.

And I would like to mention that the resources actually were funded before. It was funded by Autism Speaks. So that was one example of how Autism Speaks funded a pilot program and enabled a group of investigators to be able to pursue NIH funding.

The next network will focus on the

intervention effects of intensity and delivery style for toddlers with autism. And the next one will focus on early biomarkers of ASDs in infants with tuberous sclerosis complex. About half of individuals with TSC will develop autism. So this has a potential of really informing understanding of the courses and developing treatment for children with autism, just like the Fragile X has done for autism.

The last ACE Network will focus on the study of oxytocin nasal spray in autism to assess whether it will improve social behavior and communications in individuals with autism.

The final map I want to show you represents all the centers, center sites and network sites that were part of this cohort of ACE Program. And these are the program officials who have worked on the ACE Initiative. And that is all for me. And I think that Dr. Helen Tager-Flusberg and Dr. Kasari will present to you a workshop that was held at NIH to explore the minimally verbal

children.

Dr. Insel: Helen and Connie, given that we are a little bit behind on time, I just want to make sure we have time with questions as well. So if there is a way that we can squeeze some of this into a shorter time frame, you will have a chance, I am sure, in the question period, to get back to a lot of the main points.

Dr. Helen Tager-Flusberg: Right. I think we really just want to run through this. I do want to want to remind the Committee that in fact I did present a summary of the workshop right after it was held at an IACC meeting.

So I am just going to zip through this to say it was co-chaired by us and Dr. Cooper from NICDC. There were several members of the committee from NIH and our goals were: to find out what we know about minimally verbal school-aged children, what are the gaps in our knowledge, and what are critical opportunities. And I think this led to a great

deal of work that we have done and many other colleagues are beginning to do.

We had participants from around the country and we focused on three specific topics. Who are these individuals? How can we assess them? And what are the interventions that are potentially effective? And the paper summarizing the workshop itself, sort of a review of the literature on these topics is now in press in Autism Research, which is the flagship journal for the International Society for Autism Research. A plug there.

So, who are they? They are very heterogeneous. They are very challenging to work with. And we did focus on the issue that some children do learn to speak after the age of 5 and the idea that you can't beyond that point is a myth, but after puberty, there is truly only one case that is out there. And we really spent 2 or 3 days talking about how there really is almost no research on this group of people.

In terms of assessment, in the workshop itself, we focused primarily on novel methods of how we might tap into the cognitive abilities and brain functioning of individuals who are minimally verbal and we talked about several novel methodologies for doing so. And in terms of effective interventions, we focused both on non-augmentative behavioral approaches, as well as on augmentative, which can be effective and we will hear more about that from Connie. It can be quite effective for increasing communication, but the reality is that they are not very widely used either in the classroom or the home, although we are optimistic that things are changing as the technology is improving.

And in terms of future direction for interventions research, we focused on the fact that there is - we really know little about people who have been in published studies. The study designs have been very limited. We know nothing much about predictors of response to

specific intervention. We worried a lot about measurement issues, what is meaningful change, and we concluded that there is an urgent need for novel interventions for this population.

And I think what you will see is that both of our ACE programs really grew out of our opportunity to lead this workshop.

Dr. Connie Kasari: Okay, so we also wrote a paper on assessment. In the assessment paper, we defined what minimally verbal was. We spent a lot of time thinking about this and it is not an easy definition. So it is children who have a small repertoire of spoken words or fixed phrases that are used communicatively. The exact number of words may vary across children from no spoken words or phrases to perhaps 20 or 30, depending on a lot of different factors like age and intervention history, access to AAC systems. And I think Helen and I really saw this when we were just in Vietnam, where all of the children that we saw were minimally verbal but

that was because there is no infrastructure for early intervention services. So, most of those children had no access. So having access to intervention is really important, having access to AAC systems.

Spoken words or phrases may be restricted to limited context and one or two functions, oftentimes requesting. The rate may be very low. It may include scripted phrases that have been highly trained like "I want." And children may use echolalic or stereotyped language that does not appear to be functionally communicative, as well as some words and phrases that are used communicatively. So that is the definition and we would recommend that researchers really define how many words of a child using words functionally that they are using in their research projects.

So in the assessment paper we felt like that was the first area to address - that would be the easiest area to address in this

sort of large area. Interventions depend on good assessments and good assessments can lead to meaningful outcomes.

We had a year-long Work Group with our NIH colleagues listed here and then four folks from the workshop, Nancy Brady, Catherine Lord, Helen, and myself.

In the assessment paper we focused on core areas of development. So language, social, and repetitive behaviors. And then we also looked at associate concerns, oral, motor, medical history, nonverbal cognition, and then pre-linguistic skills that might be related to the use of spoken language; imitation, intentional communication such as joint attention and play.

And we came up with measures tables with some recommendations as to how well-suited those might be for minimally verbal children, some to use with caution and some that are unlikely to yield meaningful results. And we were not completely exhaustive. There are a

lot of experimental measures out there. So it was hard to get a handle on a lot of these measures.

Our recommendations are, of course, to have measures that have some validity data for these children, which is often absent. And probably researchers will want to use a combination of both standardized and experimental assessments.

And then of course, future goals are to figure out some novel assessments that can yield some meaningful results for this population of children. And of course measures that can be implemented easily and applied widely.

Okay, so that is a summary of our workshop and I thought I would just go right in to talking about the ACE, if that is okay.

Okay, so our ACE, as Alice had said, has another title but I didn't realize that was what I was supposed to have as my title. So, my ACE really grew out of this workshop and

some other work that I had been doing. It is clear that we have very few interventions that are specifically for minimally verbal children. But language teaching is the focus of almost all early interventions.

And most early intervention studies really focus on preverbal children. In other words, the children are going to talk. We expect that they are going to talk. They are just not talking now. And so what is critical to think about is who is going to go on to be minimally verbal or nonverbal. And right now, we can't predict with any great confidence who those children are. There are some studies that have looked at the sort of longitudinal of the natural history of children who are speaking or not speaking by the time they enter school. So we have some hints of what some measures should be that we should look at. But it is clear that speaking with spoken language by age 5 is really critical to optimal social outcomes. So it is an important

area to target.

The paradox in the community is that children who aren't speaking by school age often received decreased language services, not more. And so instead of throwing a lot of services at these children, we assume that it is something about the child and not that we actually have failed them because we haven't figured out the right treatments to use with them.

Okay, so who are these children? Well, there is a lot of heterogeneity, as stated before. As many as 25 to 30 percent of the children are minimally verbal by school age. But it is up to 50 percent, depending on your definition. So we really have kind of a wide-ranging percentage.

It is clear that most children are not nonverbal, meaning that most children can say words or even have some phrases. There is only a very small percentage probably, that cannot make any sounds or words at all. And the issue

for us is that most early intervention studies are actually excluding children who may end up being in this population or this group of children. So we exclude children who have less than a 35 IQ. We exclude children who are under 12 months developmentally. So we, again, really don't have a good handle on the percentage of the numbers of children.

We were also really sort of motivated by the dismal result of this review paper in 2009, which just looked at studies that had children, school-aged children with ASD and whether or not they could actually learn to speak. And the sort of window for when kids could learn to speak best would be between 5 and 7 years. Most of the kids had IQs above 50, but it is clear that there wasn't enough description of these children. The interventions that gave rise to this later speech development were mostly ABA-based as one would expect, and 70 percent of the individuals who could learn to talk just

increased in words and only 30 percent in phrases. So again, when we talk about "talking," what does that mean?

So my induction into this area was that I had focused a lot on pre-verbal children, so really early intervention studies. And given that we have much more intensive and varied early intervention services, we are finding that today there are probably fewer children who are going to end up being minimally verbal if they have access to these kinds of interventions. And that, of course, is the big question.

But in 2008, I was funded through Autism Speaks and I'm sorry Portia Iversen isn't here because she really cheerleaded and championed this effort of characterizing cognition in nonverbal individuals with autism. It was a high-risk, high-impact project, where we tried a novel intervention and a novel design. And that is really what provided the pilot data for getting the ACE project, which, the title

is Adaptive Interventions for Minimally Verbal Children with ASD in the Community.

So just a little note about that CCINIA study. It was a multi-site study with Ann Kaiser of Vanderbilt and Becky Landa at KKI funded by Autism Speaks. We saw 63 minimally verbal 5- to 8-year-olds. Again, thinking about that window when we could perhaps get children talking. The kids had fewer than 20 functional words but they had to have a 24-month nonverbal cognition receptive language. I felt like we needed to start somewhere. And one of the arms of the treatment was to give them a speech-generating device. So there was a lot of belief that we needed to have a minimum level of receptive language.

And we also wanted the children to have 2 years of early intervention. In other words, we wanted to know that children had had access to early intervention before we tried something different with them. It was a 6-month treatment. We only saw the children two

times per week and we had a 3-month follow-up. It was a therapist/child intervention but it was augmented with parent training at month 3.

And we had a lot of design considerations. So it was important to me to not give children a no-treatment community control, since we already - people already thought they had so-called failed to make good language progress. So we wanted to give them something that was efficacious. So we gave both groups of children the same intervention and we just randomized the augmentative speech-generating system with one group. And we used a SMART design, which is a Sequential Multiple Assignment Randomized Trial, which is mostly used in medicine, a lot of trials in cancer. It hasn't been used in autism. This was, I think, probably the first time it had been used in an autism trial.

And the goal here is really to test a sequence of interventions and to determine the best sequence. So the belief is not that one

treatment is what a child needs but is likely a sequence of treatments and really looking at the child's response to that initial treatment and then making changes in a systematic way.

So the CCINIA project, we had presentations at SRCO and IMFAR - late breaking news. So I don't want to talk too much about the findings here but just to say that nonverbal IQ ranged from 38 to 140 in our sample of kids. That is hugely wide. It didn't seem to be that associated with the child's outcomes.

And the best sequence we found was when we started with the augmentative system, the treatment itself was the same. It was a play-based treatment that incorporated both developmental and behavioral principles. We had evidence that that could work for improving language in preschool children and we now just applied and adapted it for older children.

We took a language sample at four time

points. The non-AAC group actually does catch up by the follow-up to some extent but starting with that augmentative device, we got a huge boost within the first 3 months of children actually spontaneously using words.

And then the session data with the therapist, we got a significant increase of four-plus matched conversational terms over time. It is like seven different assessment periods of time, again with the AAC group somewhat outperforming the other group. But meaning that children are actually staying in a conversation, and I think that that is really important. It is not just words produced on a vocabulary test.

Dr. Insel: Can you just define for us so the AAC study and the JASP-EMT? What are those?

Dr. Kasari: So I am going to talk about the JASP-EMT in just a second. But the AAC is an augmentative device. In this case, it was a speech-generating device. So we used a

DynaBox. Sometimes we used an iPad. Sometimes we used a GoTalk. It really depended on the child. So it has pictures on it that are chosen for that child's interests and child's vocabulary level. And the child presses the button and the device says the word or says the phrase. And we incorporate that within the actual intervention approach. So it is not just teaching the child to press the button. It really is within an interaction. So we provided those for the children.

So to summarize that CCINIA projects, it just suggests that access to communication is really critical. An AAC device can be instrumental but only in the context of an intervention where children learn to communicate with others in using the device. It is not just giving them a device. And these pilot data led to our ACE proposal.

I think it is important to note that we saw, we screened over 100 kids. Less than one percent of those kids had ever been exposed to

an augmentative device that was speech-generating. So it is not very common out there. It is probably changing now that iPads are everywhere. Let's hope that that is changing.

But it did prompt us in our ACE study to use an augmentative device in both arms.

So this minimally verbal grant is with these sites. So it is myself at UCLA, Ann Kaiser at Vanderbilt, Tris Smith, at University of Rochester, Catherine Lord at Weill Cornell, and then our statisticians are the SMART design folks, Danny Almirall and Susan Murphy at University of Michigan. And they have been really instrumental in sort of helping us think through this design, which is complicated and I will get to it in a sec.

So our study aims are: to construct an adaptive intervention, meaning an individualized treatment protocol adjusted based on the child's response to initial treatment. Our primary aim is to first compare

these two treatments - I will talk about those in a second - to see which one produces the greatest increases in socially communicative utterances. That is our primary outcome. We want children using words that are socially connected.

Our secondary aim is to determine whether adding in parent training actually gives us more benefit for children who respond early to this treatment. The second one is to compare in contrast four different pre-specified adapted interventions - I won't go into detail about those - in terms of both our primary and our secondary outcomes. And the third one is to try to figure out moderators of who is benefitting from these treatments.

And I want to say straight - well, let me talk about the study design first. So the details are, each site will see 48 children, hopefully, 492, ages 5 to 8, again that window, minimally verbal with fewer than 20 words used functionally, and 18 months

nonverbal cognitive age. We went down a little bit because what we learned from assessments is that we can't get a good handle on what children know or don't know. So I think we are safe with 18 months.

Intervention details. So we are going to compare CORE-DTT we call it, which is your basic discrete trial training program, ABA. It is widely used in the community. It is often what a lot of our kids coming into this trial have had, but we want to make sure that they had a good trial of it, a really good attempt at this particular intervention versus our play-based intervention, so focus on joint attention and symbolic play, engagement, regulation, as well blended with a language intervention, enhanced milieu training out of Vanderbilt which is very language-based.

The treatment is 4 months with a 4-month follow-up. And we are actually having daily contact with children in the community and we are in the public schools because we want a

very diverse sample. And where children are that are diverse are in public schools. It is much harder to work in the school setting but it, I think, places much less burden on parents to have them drive to us to a clinic which is too high of a burden, honestly. So we are partnering with schools.

So the DTT is an adult-directed approach. It works well for a lot of children. Our children have often had it and maybe haven't done so well but we want to make sure that they have had a good dose of it at a high quality. The JASP-EMT is play-based with a lot of behavioral aspects thrown in the design.

So, SMART design is a really complicated design. I am going to walk you through it. So we screen the children. They have entry assessment and they first get randomized to either the DTT or the JASP-EMT. Again, we are seeing kids every day for about a half an hour, 45 minutes and we are not going to stay there very long. After 6 weeks, so 24 sessions

based on our pilot data from CCINIA, we are going to measure their response to the treatment and we have that defined as who is making really fast progress and who is making slower progress.

For those children who are making fast progress, so they are early responders, we are already seeing some changes in both the socially communicative utterances and maybe the use of an augmentative system. Those children get re-randomized and - let's see - those get re-randomized to either parent training - so we are going to add in parent training in the home - or they stay the course.

So some children might be doing - they are responding and we are just going to stay the course and see if we get the same response or if we can boost their communication by training parents.

Now for those children who are slow responders, some of those children may need to

also stay the course. In other words, they need some more time. They are just slowly responding or they may need a rescue protocol. And a rescue protocol is combining both treatments - we have a flow chart for determining how much of one treatment versus another for this particular child, and we are going to see if we can actually move them, increase their communication. And then we have a series of exit assessments.

So you can see it is fairly responsive to child response.

All right, our expected outcomes are that - you know we have hypotheses about which sequence of treatment we think is going to be superior and we will see. Again, we are not comparing DTT against JASP-EMT. We are comparing this sequence of treatments.

And we think that some children are going to benefit more than others to a particular sequence and that characteristics of children who are slow responders is going to become

much more clear to us by doing this particular design. And the ultimate goal is to predict an effective sequence of interventions that personalizes that intervention, based on child response or child characteristics.

And I want to acknowledge all of the funding that has gone into all of the pilot work that led to the network. So NIH, of course, for funding of minimally verbal children, Autism Speaks and HRSA, who have both funded us also on various parts of this. The families and children who participate and of course, all of the staff and students, thank you.

(Applause.)

Dr. Kau: So next we will hear from Dr. Helen Tager-Flusberg to talk about her ACE Center. But we need to first find her slides.

Dr. Tager-Flusberg: I really want to thank you all for the opportunity to come and talk about the Center, which is just getting underway. And like with Connie, I think the

impetus at the NIH workshop pilot, was some basic funding that we received earlier in my lab from Autism Speaks, and also supplemental funding from NIH really has led to our being able to implement this particular center. And most importantly, I think the wisdom of the IACC to have identified minimally verbal children as such a critically important gap in the literature.

All right. So at BU, our ACE focuses on a single question. Why do these children fail to acquire spoken language? We know almost nothing about them either as children or as adolescents. There are literally no theories out there to explain why they don't acquire spoken language. And as we have already heard, there is a dearth of novel treatments.

So the goals of our ACE are to advance knowledge about the heterogeneous phenotypes associated with this population through very extensive phenotypic core assessments; to develop and disseminate some novel methods for

assessing cognition language and behavior; to propose and evaluate several mechanisms related to neurocircuitry, to explain why spoken language is not acquired. And I want to say here, in case I forget, we don't think there is a single explanation. There is potential for success across all the projects and there are many additional interpretations or possible explanations but we are not going to be able to address within the 5 years.

We are going to complete randomized control trials of the novel intervention that is specifically designed for this population and we want to develop neuromarkers that predict response to intervention and serve as a measure of outcome success.

So our overarching conceptual framework, which brings together a group of individuals, whose expertise lies outside of the autism world. That is really what the idea it was to identify at Boston University and some other collaborators in my community people who work

on topics that are related that, in my view, were conceptually relevant and were making very significant advances, all of whom, incidentally, are NIDCD-funded senior investigators in the world of communication disorders, but to bring their science to bear to the question of autism. So I think that is what makes our ACE quite distinct.

So we look at the deficits in speech and language related to impairments in neural connectivity. And of course that is not a particularly novel idea but you will see how we play that out by testing highly specific hypotheses about the neurocognitive mechanisms that underlie the speech language deficits in this population.

And interestingly and importantly and probably our greatest challenge are to investigate whether these potential mechanisms can be tested in the context of an intervention study. So we are interested in exploring these mechanisms within the

intervention study itself that allows us to investigate developmental plasticity in older children.

So this is the just the organization's structure. I'm afraid I don't have - maybe this is -

All right. Anyway, we have three cores: standard administration and data management, the research training and education, and the clinical core. And frankly, this is where all the expertise and the data management and statistics lie in autism itself.

And then we have three funded projects. The first is an intervention project; the second investigates speech mechanisms; and the third auditory - perceptual or auditory processing mechanisms. And I will discuss each of these in turn.

So the first project is the intervention study that is led by Gottfried Schlaug from Beth Israel Deaconess Medical Center. And he has developed a training called AMMT or

Auditory-Motor Mapping Training. And he derived this - he is a neurologist, an adult neurologist, and one of the most successful behavioral interventions for nonfluent aphasic patients, people who have suffered a stroke in their left hemisphere and were left with very disfluent speech. It is called melodic intonation therapy. It is a kind of singing therapy, singing rhythmic therapy.

And so what Dr. Schlaug has done is to adapt this to a more developmental perspective. It trains the association between sounds and articulatory actions, by which we mean the movements of the mouth itself, to facilitate speech output. And the key elements are that it combines intonation or song. It is a kind of a sing-song rhythmic presentation of the verbal stimuli and a pair of tuned drums, which the child is banging along with the therapist to facilitate auditory motor mapping.

It is an engaging therapy because it

draws on the relative strengths and interests of children with autism spectrum disorder. They like the music. They like the drums. They like the singing. And so they are learning to speak in the context of those activities. Of course, those activities are really there because we believe they serve the underlying neurocognitive mechanisms that are at the heart of what may be impaired in this group. It is delivered in the context of a structured ABA style but socially engaging context.

So what are the critical components? We don't actually know. Maybe it is the intonation of singing itself, instead of just engaging primarily the left hemisphere like spoken language engages a more bilateral, both parts of the frontal-temporal cortical speech network. The presentation rate is significantly slowed, which is maybe facilitative. The phonemes, as you present them in the context of words and phrases are more isolated and perhaps easier to process

from an auditory perspective.

There is a strong imitation and there is a lot of repetitive training. And I am going to come back to this construct of repetition in the context of Project 2. And there is also hand-motor activities. They have to tap the drums while they are singing the words. And this may engage a sensory motor network that controls both hands and articulatory activities. And I just want to say we have known for a long time that when we speak, we engage our hands, all of us. We gesture, whether we like it or not. It is hard for us to tie our hands behind our back and not do so. And there is some very interesting and exciting work on the gesture or hand movement speech connection.

And so all of these are elements are integrated into AMMT. And the goal of AMMT is simply to promote spoken language production. It does not have, as its goal, more extensive social communicative use of the language. We

see this perhaps as a kind of a jumpstart treatment. In future ACEs, this will be the pre-treatment in a SMART design in a collaboration with Dr. Kasari.

And this is sort of what it looks like on a tabletop with a child and the therapist engaged with the hands on hands and then drumming together. And last year in *PLOS ONE*, Dr. Schlaug and his colleagues published. This was a series of case studies, children whose both trained and untrained items increasing at different degrees to be sure in the six children in the study.

So as part of the ACE, there will be two RCTs. The first will enroll 40 children 5 to 10 years old; 20 will be assigned to the treatment itself and 20 to the control therapy. There is baseline assessment, 25 sessions 5 days a week for 45 minutes each, and then the outcome assessments over time. And Study B basically looks at dosage effects, where we compare the same number of sessions

delivered either in high frequency 5 days a week or low frequency 3 days a week.

And basically the training trials, this is a manualized treatment now, during the training 50 picture symbols relevant to the child, social phrases, important every day words that a child doesn't use at all are introduced using picture symbols. First the therapist intones the target word or phrase so the child is listening. Then the child is engaged in unison production, let's sing together and all the while they are banging on the drums with them, with the speech itself.

And then the therapist fades out of the second part of the production. Then there is a lot of repetition. The therapist says it, now the child says it. There is turn taking around it but of course of a more repetitive nature and then the child produces the word or phrase themselves.

The control therapy introduces all the same words or phrases and it is done similarly

in an ABA style with the trained therapist but there is no singing and there is no drums. So those are the key elements that we are trying to isolate here.

And the outcome measure, the lab-based measure, the primary one is the ability to produce both the 15 trained and then a set of matched untrained items that are matched on a variety of speech features. And then we are also planning to collect some more home-based, more sort of naturalistic data. We send this device called LENA home with the families for 24 hours. And it just picks up and we just wanted to get how much now is the child speaking in the home. And of course, there is a pre and post assessment of that how much, even if it is just vocalization.

We are looking at a range of predictors of response to treatment. And then within the context of study one, Dr. Schlaug and his colleagues are interested in a particular set of structural and functional neural

connectivity measures that focus on the arcuate fasciculus, which is the major fiber tract that connects the frontal and the posterior language region, which we know shows atypical asymmetry, particularly in these nonverbal children but also in verbal children with autism, as well as functional resting state MRI between the frontal and temporal cortical language regions. And we are predicting that we will see changes, particularly in the functional resting state MRI. And these are just some preliminary data. And Dr. Schlaug and his colleagues were able to collect DTI and MRI scans from five of eight minimally verbal children who they had enrolled in their study. So that gives us a good deal of optimism that with the right training and preparation we'll be successful with this.

Now the data to be analyzed, the imaging data are all collected. The brain imaging MRI data are all collected as part of Project 2,

which focuses on speech mechanisms. And the principal investigators are Frank Guenther from BU and Dara Manoach at MGH. And Dr. Guenther is the architect of the single most comprehensive and most widely influential neurocomputational model of speech production and it is called the DIVA or the GODIVA model. The GODIVA is the kind of newer instantiation. And the argument is speech production - I mean we sit here and sometimes when I think about it and I watch people speak, it is truly a miracle what comes out of our mouths because it requires the integration of so much information and so many different brain areas, auditory, somatosensory, motor information in the brain, in addition to the language areas.

Speech sounds are learned and there is a developmental model for DIVA. What you have to do is you have to store - and if you have ever gone to a foreign country you know about how hard this can be for us - you have to store the target. You use auditory feedback control

systems to control the production and it is your own repetition, repeated sounds, not just hearing it from the outside but also your own repetition and the auditory and the somatosensory feedback and motor feedback that you are getting, all of that together is what promotes speech sound production, according to this model. And it is this repeated productions that lead to tuning and changes in the system, such that it becomes automatized over time.

And this is just to overwhelm you with all the different parts of the brain that are both a subcortical and cortical areas involved in just plain speech production.

This is a schematic model of the essential elements. And this is the connection here that we are testing, that it is this connection between the left SMA, the motor program triggering to the left ventral premotor cortex. This is a supplementary motor area. It is this connection that is the

central hypothesis that we will be testing in this particular project. So there are deficits related to abnormalities in both white matter integrity and coordination of activity in the speech network, particularly in this pathway. And this is a pathway that is critical to initiating speech output.

And there are two studies that will be testing this hypothesis. The first is the study that is embedded around the intervention. So it is the children from the intervention study, both pre- and post-AMMT and control therapy where we can. We collection anatomical scan, functional, resting state MRI and DTI and we are trying, as much as possible, to optimize the sequences so that they will be as quick as possible because we know that we have limited time with these children in the scanner.

Study 2, it takes an older population where we are looking at the full range of language ability in autism from minimally

verbal to intact language but all with ASD. And there will be 75 adolescents and young adults matched to 25 age and sex matched controls going through the same protocols.

And this is some pilot data where we do see differences, particularly in FA values, lower values in the ventral premotor context and lower resting state connectivity here. So there is some promise from the pilot data.

The final project focuses on auditory processing. And again, let me say these are not mutually exclusive ideas and they may be overlapping. They may be synergistic. We simply don't know because no one has ever looked at this. And the principal investigator is my colleague Barbara Shinn-Cunningham, who is an auditory computational neuroscientist at BU and she focuses her work on how we organize the auditory environment. We know so much about the visual system and we know relatively, much less - I mean I am working on this for the past several years getting to

know her. And I said, really we don't know this? We don't know how we segregate the auditory input? And it turns out with the science, which just sounds so basic to me and fundamental is this is the advanced knowledge of the field. So, what we do have to do is to segregate the input into meaningful units. And we all know this because we know there is sometimes in contexts where we can't separate out when someone is talking to us from the sounds around us. But the argument is that deficits in auditory scene analysis that result from abnormalities in structural and functional connectivity lead to speech and language impairments in this population.

And this is just a nice illustration where it is very hard when we look at this to segregate out what the words are and this is what happens when there is good segregation. Of course there is a visual analog here for us so that you can see it.

The grouping is what is enabled to

distinguish out different terms from this, allows for better segregation and more rapid efficient and accurate auditory analysis.

And the argument is that particularly for minimally verbal children with autism or at least some of them, this is what the sound world may be like. And we know that this sort of is consistent with all the anecdotes about their atypical responses to sound and so forth.

So again, the studies are the same. The same children will be enrolled in Projects 1, 2, and 3. This time, we are using event-related potentials and EEG signals to tap into auditory scene analysis. And this is just to sort of maximize our opportunities and use a range of different neuroimaging tools. And we are basically depending on a mismatched negativity paradigm we are using to detect perceptual organization with terms and speech, changes how we detect using this to detect changes in frequency and intensity, and then

looking also at the neural oscillations. And Study 2 will use these same paradigms with the adolescents and young adults who are in the MRI study.

The important point to note here is we have designed all these paradigms are completely passive. Okay? They require no instruction. The individual doesn't have to understand or say anything.

I see my red light is blinking. We have got our three core units and Bob Joseph is the co-PI with me on Cores B and C. And Core C we are doing this comprehensive assessment and diagnosis, including some novel assessment approaches. And the Clinical Core will be involved in the evaluation of the children enrolled in the treatment study.

And we are, I should say, coordinating as much as we can with Dr. Kasari and her ACE to ensure that we are using as much as possible the same kinds of measures and learning from each other so that ultimately we can compare,

at some level, even at a meta-analysis level what we are doing and what we are finding.

This is just to show you the very complex flow of participants. Nothing like the SMART design, though. I thought this was bad and the reviewers would hate this but I realize that they read Connie's proposal and realized this was perhaps a little bit simpler.

(Laughter.)

Dr. Tager-Flusberg: And how do we achieve all of this? Well we think the only way we are going to have any potential for success is for us to partner all of us on the scientific side with the families themselves. And we are creating an online community to maximize our success. We are developing this research collaboration platform that links all the components of the ACE both internally, links all the projects to the families, provides access to videos, scheduling, participant tracking systems and so forth, tons of training materials, training materials for the

kids and the families that gives them advance understanding about what all the different components are. And there is also training for the staff and the students on this and all of this incorporates multi-media instruction and feedback and evaluation. We have a lot of communications. We are only going to success. I have studied language my whole career and I definitely believe the route to success is through communication, both through our internal teams and the project family coordination, and file sharing across the projects, which you can see is so well integrated.

And finally, I really just want to thank all my colleagues. This is truly an ACE that would not have been possible without the outstanding scientific background knowledge and contributions of my colleagues, all of whom up here are new to the field of autism and to my ongoing group in my lab at Boston University and the families who are already

beginning to invest, I don't mean financially, this is a time and commitment investment in our dreams.

Thank you all for listening.

(Applause.)

Dr. Insel: And thank you for getting us back on schedule. So we do have some time for discussion. Let's start at the end with Donna.

Dr. Kimbark: Thank you very much. I really enjoyed your discussion. And I did have some questions about your one arm where you were changing the time - well the dosage three times a week versus five times a week. And I am wondering if you are worried about dropout rate because five times a week is a huge commitment for families to do. And how long is the session? I mean do you worry about whether it is in the morning or evening or whatnot? How do you deal with that?

Dr. Tager-Flusberg: Yes, you know we are in the midst of running some focus groups with families to discuss all these elements and we

are not - while we expect to be running this in the lab, I think we are very open to the idea of running this in alternative places. I am not sure about schools but we will see. We have also partnered a lot with schools. It is a little bit tricky for us to go into schools, which are mostly private schools, serving this population in Massachusetts. We are a little bit concerned about whether we can do it in the schools but potentially in the homes. So we are running some focus groups to try and understand this.

But I can tell you I have been contacted by four families already who have heard about this, who live in other parts of the country, and are saying to me because this is really only an 8-week commitment and then you have got to add on the pre and the post, they will say I will move to Massachusetts for 3 months to be able to be part of your study. So I think there is a bit of a tradeoff here. And I think some families will make that as a

commitment.

The sessions are only 45 minutes but we certainly accommodate time of day and weekend opportunities. We always do in our work.

Dr. Insel: So we will go around the table here this way this time, in the other direction. So Idil, I think you are next.

Ms. Abdull: Thank you so much. Hearing this was sort of like putting a painter in a Picasso museum. You totally speak my language. I have so many questions but I won't ask you all of them. I am so grateful that you are talking about nonverbal - minimally verbal and that you guys have invited them.

I just have maybe two questions. I am not sure who said it but it was one of the previous speakers before you said you recruited 600 African American families. So I wonder why that it is, number one.

Dr. Tager-Flusberg: That is going to be part of a genetic network. It is a different ACE program, nothing to do with us here.

Ms. Abdull: Right. Yes, I know you sort of had - I have questions for maybe all of you.

And then also the person before you mentioned Portia Iversen whose career I really did follow. And I was wondering if you had a comment what you thought of the RPM method or the Soma method which has helped my son a lot. And I think Donna asked about moving families and I would move to Texas, if I could be near RPM therapy.

And then finally just the last point about music. A lot of people - when my son was getting early intervention - ABA, they would say well if we did music or if we did the AAC machines, why would he talk. Because if a kid can point, he is not going to communicate. And it turns out, the total opposite. This child loves Starbucks cookies. And he would point to the cookies from Starbucks, the picture of Starbucks, the shoes, the car, and he would tell me in sentences but he never got that

from ABA. So I am just so grateful, so grateful to all of you.

Dr. Tager-Flusberg: Thank you. I am going to let Dr. Kasari respond to the question about RPM.

Dr. Kasari: Well, I was going to respond to what you just said about the fact that the augmentative - the speech generating device actually increases spoken language from our data. They also used the device but they parrot with the word. And some kids will repair, they are very unclear in what they are saying, their articulation is poor and so they can repair what their meaning is by pressing on the device. We have also had children who, within five sessions, are programming the device. That is a child who knew he wanted to communicate, was a reader - so about a third of our kids could read. So they had a language system, they just weren't able to use spoken language. So again, I think it is all about access.

So the RPM and all these other approaches, music, that are in the community will work for individual children. But what we don't know is we haven't subjected them to scientific methods. And so you don't know. It doesn't work for all children, for only certain kinds of children. Does it really work better than something else? So again, I think that there is a lot of different interventions that are out there. But until you really test them, it is hard to recommend certain things with any kind of confidence. So we need more research.

Dr. Insel: So I should say that Portia was supposed to be here today. We had some hiccups with her travel. So at the last moment, we had to cancel the trip. She will, I think, come to the next meeting. And the reason we wanted her to be here so much for this presentation, not only has she pushed this whole field, but she has a video which she wants to share, which I think you really

would enjoy, that was made by her and her husband, John Shestack, of their own son who was minimally verbal and how he acquired language over 15 years. It is a series of images put together over that period. Since John is the Hollywood film maker, it is pretty well done. And it is a really impressive narrative about how this happened and their son. And unless you see the video, which I could actually show you but we are going to wait and let her do it, you don't get a sense of how this worked. It is really quite amazing.

Dennis, you had your hand up.

Dr. Choi: I think these are great projects and it occurs to me not only for their intrinsic importance of the affected kids but also as potentially a valuable model system to get at autism mechanisms. Leveraging the fact that speech circuitry and localization is better understood than most other higher cortical functions, based on

decades of work with aphasiology, stroke, epilepsy, and the like. So one could imagine that even a small number of very well-characterized individuals might serve as useful test beds for therapies, designed to repair long distance connectivity. And you would have the advantage of an unusually sensitive and informative and well-understood readout for improvement. So you would know directionally if you were moving in the right direction. So not only for the kids themselves, but potentially for the field. This could be very important work.

Dr. Tager-Flusberg: Thank you for that comment.

Dr. Insel: Again, just to add to this, since you are in Boston, the Human Connectome project at MGH has really focused on the language circuitry at a very, very high resolution using this new approach of diffusion spectral imaging or the Connectome, as they call it. And that is not published but

we have the images. They are looking at the arcuate fasciculus specifically at a level that we have never, ever seen before. Now whether that could be done in children or not is a question but Van Wedeen and Bruce Rosen, so since you are right there, it would be such a fantastic opportunity to bring that technique to autism.

Dr. Tager-Flusberg: So Dara Manoach, who is the imaging PI for the MRI studies and the DTI studies is at MGH. And she works very closely with Bruce because whatever we wrote in the proposal we are expecting that we are going to be three generations ahead and doing the best we can to draw on the next generation of work. Of course, it is going to depend on our being able to get good quality images and so it is a real partnership between what they are doing with the analysis and ours with the data collection. But yes, we are -

Dr. Insel: Fantastic. What a great opportunity.

Let's just keep going. John.

Mr. Robison: So earlier in your presentation you talked about plasticity. And I wonder up there in Boston at Beth Israel and Harvard, Alvaro Pascual-Leone's group has suggested that excessive plasticity is shown to be present in people with autism in his research.

I wonder if you have a theory as to whether excessive plasticity is implicated in failure to develop proper ability to speak or understand language. And if so, how that might be occurring?

Dr. Tager-Flusberg: I don't have a hypothesis about that in relation to these older children. I certainly think we know that very early plasticity is what makes language such a miracle of development in typically developing children in such a brief period of time. We are more interested in the idea that actually none of the - all the connections that we are interested in in terms of language

circuitry continue to show developmental change. Whether there is an excess in autism or not, I really don't know. It may be that as we make some progress in this work we will be able to address that question to some extent but I don't think our project is really designed to look at that. We are interested in the idea that in these children we are not only changing their speech output but in some real meaningful way, changing the functional and potentially structural connectivity in critical nodes of the language circuitry that we think are relevant and what is being promoted during this particular treatment.

Mr. Robison: Thank you for that answer. Would it be possible, since you are in the same city, for you two to collaborate and endeavor to learn an answer between their studies and yours?

Dr. Tager-Flusberg: We should definitely - oh. I mean, Dr. Schlaug is at Beth Israel.

Mr. Robison: Right.

Dr. Tager-Flusberg: And I think his lab is right next door. I have collaborated with Dr. Pascual-Leone for many years.

Mr. Robison: I think that would be a very, very interesting thing to hear about.

Dr. Tager-Flusberg: Okay, that would be great. Yes, we should get some seminar together on that.

Dr. Insel: See whenever you come here, Helen, we give you more opportunities than you ever thought you would have.

Dr. Tager-Flusberg: I was looking for something to do.

(Laughter.)

Dr. Insel: Matt.

Dr. Carey: First off, I think everybody has been saying this but thank you so much for this. This is so hugely important. And if I could take a second to say thank you to Autism Speaks and to the previous IACC for supporting this. I mean this is exactly the kind of work much of us in the community want to see

happen. And this is - I am just very much taken aback to see this work going on.

But now I am going to - you already kind of alluded to this. I am going to ask you to start thinking about the thing people always hate to hear right when this happens is start thinking about the future already. I mean how are we going to support this population after this? If we jumpstart them, it is not a light switch for a lot of people. We don't go from - the phrase - my wife was actually so pleased to see just the phrase minimally verbal come up because it just validates so much what we see. I mean it is not nonverbal/verbal. It is not a light switch. There is transition.

And once you get somebody to be minimally verbal and then moving on, you have got a 5-year-old an 8-year-old and everything else. These people are going to need support all through school and later on.

I mean if you can give me feedback or anybody in here feedback where are we going to

go next with this, I would greatly appreciate it.

Dr. Tager-Flusberg: I am going to let you answer it.

Dr. Carey: I mean, it may be a future thing.

Dr. Kasari: Oh, I think it is. Hopefully not a far future, not far in the distance. I mean I think that we are looking at a fairly small age range and it is clear. And I think Portia really pushed for us to think about adolescents and older individuals. And older individuals can also learn to communicate via typing or other means. And I do think we just, in general, need more research or more attention to this area. It is kind of a wave of the future. They can have friendships. They can have productive work. So I do think that we need to stop excluding this population from all of our studies.

Dr. Carey: Yes, and I also not to get in here really strongly but I was very much

pleased by what you were saying but a lot of the focus that you have of doing this work in a social context, right. Not just we are one-on-one, please tap these buttons, and doing that and how important that was. I mean I think that, for a lot of these guys, is very important. I was very pleased to see that.

Dr. Tager-Flusberg: I think our goal, certainly my goal would be that with this push to develop some novel interventions, which I think the pilot worked both from Connie's lab and from Dr. Schlaug's lab has shown some promise that making this available we are going to continue to see the completely nonverbal group shrink even further.

As Connie mentioned, we were both in Vietnam. And there I would say the statistics are probably more like 70 percent or minimally verbal and we see that changing here. But I think also the idea that in schools they could be implementing novel, highly specific interventions, not just take the child that

has come in at five or six, isn't speaking, and essentially relegate them to whatever educational programs they think will be appropriate but actually seeing this as an opportunity for change for these older children and then, over time, I think we would want to develop to help what we can do to make a difference beyond the early school age.

So I see this as a moment of optimism because none of this has been tried. And you know, the treatment, this AMMT, it is easy. Okay?

(Laughter.)

Dr. Tager-Flusberg: It looks easy. No, it is easy in the sense that I can see how you might be able to train therapists. They don't have to have a masters or a doctorate degree to implement this. I think teachers can learn how to do this. It requires a one-on-one. That is absolutely true. All our treatments do.

But I am really tired of hearing how expensive one-on-one behavioral treatments

are. They are so cheap in comparison to any medication treatments that are out there for making just this much difference in the lives of adults with a whole range of illnesses. They are not expensive and I think we have got to dispel that myth.

Dr. Insel: So we have got Scott and then we we'll finish with Walter and Anshu.

Look, if you want to have lunch, we are going to have to find the time.

Mr. Robertson: Sorry if I was demonstrating over-enthusiasm but it is just exciting to see this focus on individuals who experienced really significant communication challenges. My colleague Ari actually already testified before the House hearings on autism and one of the things he emphasized very strongly in his testimony was how adults and children on the autism spectrum who experience really significant communication challenges tend to be often very significantly marginalized and don't always have access to

both augmented communication. And I love how that is a real part of the elements of this work and don't always have access also to good development of language and speech therapy kind of development of different services to help them develop their communication supports, whether it is use of AAC, whether it is spoken language, in conjunction with AAC, whatever works so the individual can eventually, as they get older, can be able to communicate with other people in a way that gets things met and improves their quality of life.

So this is really exciting to see this work and I really appreciate what you all are doing. And I am really excited to see when this progresses over the next - this is multi-year, I think these ACE projects -

Dr. Tager-Flusberg: 5 years.

Mr. Robertson: 5 years. Okay, so it will be exciting to see what happens at the end of this in 5 years and how this informs the other

work of, I guess, the rest of the ACE and what happens maybe for projects that start 5 years from now. Thank you.

Dr. Insel: Walter?

Dr. Walter Koroshetz: Thank you.

Dr. Insel: Can you use your microphone?

Dr. Koroshetz: How do you guys decide on the timing? I mean it seems like you have a big neurocircuit problem and these seem like fairly short periods of time to me offhand. But is there data that these kind of time frames you can expect to see changes?

Dr. Kasari: Are you talking about the time frame for treatment being 8 weeks? Well, at least in our data set, in 24 sessions we got a huge jump in children's use of socially communicative language. And so we are using data to drive that first decision point for us.

Dr. Tager-Flusberg: And with the AMMT in the pilot work, they actually had 40 sessions and they saw all the gains being made in the

first 15 sessions.

It just turns out if you have got a really good treatment that is well delivered and that is sort of grounded in relevant theory, you can see these changes very rapidly. We are doing 25 sessions.

But let me just say, no. After 15 or 25 sessions, these kids aren't now walking around and talking and communicating. It is a jumpstart. It is really still at this stage, because it is in the context of this RCT, it is jumpstart the very first stage. You would want to see much more follow-on from this from a clinical perspective but this is very much a research study.

Dr. Insel: Anshu, last comment. Then we are going to have to go on.

Dr. Batra: So on behalf of all my kids, this is super cool. And two questions.

Connie, hello, after being 2,000 miles away. On your very slow responder, and I know you said that you would combine both the core

DTT and the JASP protocol, have you looked at possibly motor planning issues for those individuals and perhaps that might be one of the reasons why they are super slow responders?

Dr. Kasari: Yes. So we have identified a few moderators. Motor planning isn't necessarily one but repetitive behaviors. You know, we have to have a very limited set of moderators and so we chose I think three across two different randomizations. So I think that that does affect children. I also think how many words they can use functionally affects how fast they can progress. So I mean some children absolutely cannot make any sounds at all. No words, no sounds. And I think it is just harder. It is just they can make progress but it is a little slower. And I don't think there is anything wrong with being slow, as long as you kind of get to that same point. And that is what we don't know. Some kids just need more time than others.

Dr. Batra: I think it also speaks to your heterogeneity and your spectrum -

Dr. Kasari: Oh, yes.

Dr. Batra: - with the cognitive disparity.

And then Helen, again, so super cool. This is so needed in the community to think outside the box for these children who actually have a language processing and communication disorder, as opposed to looking at it through the autism lens. And I applaud you and thank you, thank you, thank you.

Dr. Tager-Flusberg: Well thank you all very much.

Dr. Insel: There are more questions. I can tell from hands that are sort of - but maybe we can catch you afterwards if you can stay around a little bit. But I think you can get a sense from the Committee how much we appreciate what you are doing and your coming to tell us about it.

And Helen, your focus on the basic

questions as well, I think is so fundamental here. We don't know enough about auditory processing. And getting that information we tend to want to push you guys to do interventions and get to a cure or get to a change but the reality is there is still a lot of basic information that we need to pull together. And this is a great way to do it so it is really exciting to hear this.

We are going to move on and have one more presentation before we break on this. We wanted you to see a little bit about the Autism NOW website. Katherine Cargill-Willis from the Administration on Intellectual and Developmental Disabilities and the Administration for Community Living was going to take us through that. And I don't know if Katherine is - okay.

And I should mention that we also have Amy Goodman, Kevin Wenzel, and Karen Wolf-Branigin here as well from The Arc.

Ms. Katherine Cargill-Willis: Okay, good

afternoon. Thank you for the opportunity to speak to you today.

I am going to give you a little bit and then Amy is going to take you through the website.

AIDD, which used to be ADD awarded The Arc a grant in 2010 for \$1.87 million for the fiscal year.

The purpose of the grant was to create a web-based resource center for people with autism and other development disabilities.

In the beginning, the grant really wanted no more people than they needed. So they had some family members and other people involved and people with ASD, to listen to their questions. It is what they need to hear, people with ASD talking to parents about what their little kids could grow into. Through this process, they discovered what was needed for the website.

The conclusion of these sentiments is a report called "The Light at the end of the

Tunnel." It can be found on the website. The unique part of the report is the resources created by people with autism among other people. Again, that collaboration between children on the spectrum and people with ASD.

AIDD really wanted collaboration with self-advocacy organizations like SABE, ASAN, NYLN, and SLN. You can see the input on the website. It is really different. You get parent input and ideas with AAHD.

We are 508 compliant. There are no charge for resources. And a lot of resources are recordings and webinars and that plenty of people get or watch and listen to. They are also in Spanish. I can't say that word properly - that C word - but a lot of resources in Spanish and Mandarin.

Amy is going to take you through the website.

Ms. Amy Goodman: Okay, well, thank you, Kathy. That was a very nice introduction.

My name is Amy Goodman and I am the co-

director of Autism NOW. And as Kathy says, I will take you through this website.

This just shows you how it is set up but I am going to go through and show you screen shots of the different areas so you can see how it looks like when you look on the website.

Okay, this website is set up in five different areas. We have done At Home, On the Job, In the Classroom, In the Community, and Funding and Public Policy.

If you look at At Home, you will find different kinds of resources that are more about family and relationships and things you can use when you are at home. Then we have an area for On the Job, where you will find more resources and stuff for employment and supported employment and different kind of employment that people could use to get a job.

We also have stuff for college students and In the Classroom we have stuff under IEP - Individual Education Programs - we have stuff

on the Individuals with Disabilities Education Act, and items on stuff under post-secondary education.

And In the Community we have lots of stuff under recreation and safety and inclusion and topics like driving. And our newest one is nutrition. That one was just put up this year.

And under Funding and Public Policy, we have family support grants and we have stuff under Social Security, SSI, SSDI, and that kind of type of stuff on there.

And if you do Browse by Topic, these are all tagged so that if you click on one of those topics, you will get the webinars, the resources, and the videos and anything that is related to education, or civil rights, or community living.

And this part, under In the News, we list our videos and we list our newest resources that have been added. And this is a video called "Presuming Competence," which was made

by one of our partners, SABE, Self Advocates Becoming Empowered, in Vermont. This is a really interesting video.

And then we have Upcoming Events, where we have a calendar and it will tell you when the webinars are or where we might be presenting or exhibiting our Autism NOW.

And then there is Latest Resources. We have approximately 356 resources up there now, but we are still putting up now as the weeks go by. And there is anything from handbooks to guides to articles to websites.

This is our map. We have a section where you click on the map and you click on your state, you will find local resources for each state. You will find non-profits and other agencies that are in that state.

And then we have the Blog section where you can write blogs. And we have a form where if you fill out the form you can send in your blogs. But all the blogs are written by self-advocates and these are just a smattering of

what is up there right now.

And then we have Forums, where you could communicate with other people and leave messages. We have at least 75 up there - topics of different things to talk about.

And that is just a real quick overview of what is on our website. There is much more to it and I hope you all take a look at it. The website is www.autismnow.org. Thank you.

(Applause.)

Dr. Insel: Before we break, any questions or comments for either Katherine or Amy? Noah, go ahead.

Mr. Britton: I just want to say thanks for doing this. This is wonderful. This is something we have needed for years and it has been too localized. You know, the AANE has a site similar to this but it is only for New England. And I am really psyched that this exists.

Do you have any specific plans to disseminate this more broadly?

Ms. Goodman: Yes, we are trying to get it out there. We have been, as she said, we started in 2010 and we would like to go more broadly. I take it out to West Virginia when I go to conferences and stuff. In fact, I will be exhibiting this week. We exhibit at all The Arc conferences and the more places we go the more people will know about it but it is mostly word of mouth.

Ms. Cargill-Willis: There is a link on the AIDD website.

Dr. Insel: Well, it is great to have you here, because this is one of the ways of disseminating the information. It is really useful.

Donna and then Scott.

Dr. Kimbark: I just wanted to ask, I saw on one of your slides that you had a word cloud and one of them said Apps and iPad. Do you have an App for the iPad for this?

Ms. Goodman: No. I believe that was an article about Apps and iPads for autism, is

what it was.

Dr. Kimbark: Oh, okay. But do you have plans to make something that would be applicable to a tablet form?

Ms. Goodman: I wish we could, but unfortunately, if you don't have the money, you can't really do that. No, I don't think we have any plans to do that. But it would be fun if we could.

Dr. Insel: Scott?

Mr. Robertson: So I think it is really great what has become with the Autism NOW initiative is awesome in terms of the resources it provides and it is so helpful to autistic people and our families and allies and supporters. It is a wonderful resource.

And I wondered if the potential exists now that you see a lot of growth at the state level also with similar kinds of initiatives. Like in Pennsylvania, we have these ASSERT collaboratives that are funded at the state level that, for instance, they have now a

brand new website that is going to be coming out this month that has resources. And I wondered if that is a potential future thing of any potential collaboration between The Arc/the Autism NOW Center and state initiatives to see if maybe you can collaborate with innovative things that are happening at the states and get them up maybe nationally. Maybe broach some things that are excellent practices that are happening and resources and clinical services by some of these regional centers in Pennsylvania, Ohio, and some other places that have things like the Autism NOW except for have them at the state level.

Does that potential maybe exist for the future for a state-national collaboration?

Ms. Goodman: Yes, that would be a great idea, to collaborate with different states and see what is out there.

Dr. Insel: I think there was one other hand up over here. I wanted to just make sure.

Yes, Sally.

Dr. Burton-Hoyle: I wanted to thank you for your work in this and that you feature self advocates. Their importance is usually kind of just an ancillary thing and you have made that the focus. So thank you, very much.

Ms. Goodman: You're welcome.

Dr. Insel: Yes, I think you can take that as a comment from the entire Committee. We really appreciate you coming and sharing this with us. We hope this is a good venue to actually disseminate more broadly, at least, more information about this.

We are at the time to take a lunch break. We are going to make that a 30-minute rather than a 45-minute break so we can get back right at 1:00.

(Whereupon, the Committee recessed for lunch at 12:29 p.m. and resumed at 1:04 p.m.)

Dr. Insel: As I mentioned, we have moved

the discussion of the public comments from the end of the day to doing them right after the comments, so we will have a chance to keep these things more connected.

As I mentioned at the beginning of the day, we had an unusually heavy demand for public comment this time. So we are struggling a little bit with the schedule. I think we have nine people who had signed up to make public comments. We usually tell people that they can have 5 minutes. That would take most of the next hour.

So I want to encourage people to try and even cut down from the 5 minutes to something closer to three and really think of this as an elevator speech. And the reason I say that is because every member of the Committee has received in their packages both full oral comments and other written comments as well. So we all have the full extent of what you had submitted. There is no need to read all of it. But if we could just use this to highlight

what you think are the most important points for the Committee to hear about.

In looking through the list, I was also reminded of something that I thought would be useful for us to just put out there before we start this next session and that is that when the IACC began to meet in this iteration in 2007-8, we took on a fairly intensive discussion about what we called our core values and how we wanted the meetings to operate. And just to quote from one of the core values, which was the spirit of collaboration that says we will treat others with respect, listen to diverse views with open minds, discuss public comments, and foster discussions where participants can comfortably offer opposing opinions.

And so while we are always looking forward to comments from members of the public, we also would hope that those who comment would abide by that same set of core values that say that this is not the place for

personal attacks, for self-serving kinds of protests, or a chance to discuss items that really are not entirely relevant to the IACC.

So, that said, let's go ahead and start with this long list so I don't use any more of the time that is very limited.

The first person on my list is Jen Repella. And I would just ask, you can either come to the table or go to the podium, whichever is easier for you, and just say quickly who you are and who you represent. And then to the extent possible, I would like you to hold your comments to about 3 minutes, if you can. Thank you.

Ms. Repella: Hi. I will start by apologizing for my voice. I am a little under the weather so I will be a challenge to hear. But thank you for the opportunity to speak.

My name is Jennifer Repella. I am the Vice President of Programs with the Autism Society of America, and Scott's written comments are actually included in your binder.

But what we just really wanted to stress is the importance for the Autism Society to really look at measurable outcomes. And so we certainly recognize the importance of research and the incidence numbers that were discussed earlier today are critical to showing, demonstrating need, showing change that has occurred over time but really looking at more than a million people who are out there right now living, and struggling, and looking for services that are restricted due to funding, restricted due to availability, all those kinds of things.

I was very pleased to hear this morning, I am not sure which Committee members said, that I really want IACC to be activists. I really want us to involve the Department of Labor, because it really is such an important thing to our organization and to our constituency. And we think that the coordination is critical to really bringing about outcomes and that it does need to go

beyond the people sitting presently at this table and include Department of Labor, include Housing.

And again, the presentation about employment and so many of the questions were really excellent of, you know, how do we delve down into the numbers that we are seeing. And so those measurable outcomes that are really improving the quality of life is something that is just so important to the Autism Society.

So that is my summation. Thank you for the opportunity.

Dr. Insel: Thank you. And again, I think all of you have the comments in your packages. And if you haven't looked at them, I would strongly encourage that you do. In this case, there are some very important recommendations related to insurance and the Affordable Care Act, and as it says here, the haves and the have nots. So this whole issue about disparity is incredibly important for the IACC.

Thank you so much for coming today and I hope you throat recovers.

Eileen Nicole Simon.

Ms. Simon: What I was going to say is in your packets, and I just quickly rewrote something else, mainly because I want to thank you for today's focus on language and the language disability of children with autism.

In the past, I have tried to point out the vulnerability of auditory centers in the brainstem to injury at birth. Impairment of auditory centers in the brainstem has two effects. First, difficulty in auditory scene analysis. Two, brainstem damage prevents normal maturation of target areas in the cerebral cortex, the language areas in the case of language disability.

Today I came prepared to point out one possible reason for brainstem injury at birth, which is clamping the umbilical cord within seconds after birth, before full transition of respiration from placenta to the lungs has

taken place. My comments are in your folders and I submitted many comments in the past. Special thanks to Dr. Koroshetz for pushing for auditory system and language research in the past, and to Dr. Insel for pointing out the research showing highest blood flow and metabolism in brainstem auditory nuclei. Otherwise, I keep submitting comments that are never discussed.

I am here in person today to once again try to be heard and hopefully to promote discussion of auditory system injury at birth.

Dr. Insel: Thanks very much. And again, I know that your comments are much longer than what you were able to say here. So I want to encourage people to look carefully at what is in your packages.

Dena Gassner.

Ms. Gassner: Good afternoon. Last month I introduced myself as a private practice social worker working with transition-aged teens and adults with autism. I didn't mention my

professional expertise as well. I am also an advisory board member for GRASP and for ASA.

Today, I wanted to approach you to address a lack of accessibility in three current programs. I know the IACC is charged to find new and creative research options out there but I am here to say that there are other options available that are inaccessible to our community that could immediately enhance the quality of life and financial outcomes for individuals with autism spectrum differences.

Both Social Security and vocational rehabilitation offices are environmentally assaultive. Interpreter services provided to other disability communities are not provided for ours. Our individuals experience tremendous difficulty to communicate under pressure, even those of us who, like myself, are very articulate, when it is personal and when it is intimate, and when it is shame-ridden, sometimes, it is very difficult to

communicate on our own behalf.

Asking for a private place to wait is often responded to with outrage and the need to fully disclose that is uncomfortable for our population. In the four states in which I have served this community in over 25 years of work, adults wait anywhere from 2 to 4 years to obtain Social Security benefits. The automatic first denial protocol must end. We must exit a medical model for determination and incorporate into that medical model inconsistency with work history, relational issues, prior misdiagnoses, and the implications of that, and the failed outcomes and determination protocols.

The fact that a treatment has not been used is not necessarily a measure of need. It is more often a reflection of a lack of diagnostic and management supports.

The voc rehab inconsistencies and state interpretations of the Federal regulations do considerable harm for our community.

Eligibility determination based on observation is permitted. A bias against our community, when many more have invisible expressions of their autism. The stats we saw in the first slide show this morning said that parents report 6.9 percent reported severe, 34.8 reported moderate, and 58.3 reported mild expressions of autism. If our eligibility is based on what you see, the vast majority of our community will not be recognized as having a disability.

Timelines and client self-determination desires are ignored. Post-secondary programs are frequently denied, despite Federal regulations that mandate that no SSI client can be asked to financially contribute to their post-secondary goal.

My son and I are both on Social Security. Last year that non-contribution factor cost us \$13,000 for a summer and a fall semester of college because our in-state program does not accept him because of his ACT score. So they

should be funding the full program.

By the way, they explicitly do not fund the Autism Support Program at that college either, which is absurd.

Self-employment is a delay-ridden red tape burdened protocol, complicated by difficulties with PASS plans. The executive function demands of these options result in the person's capacity being whether you can manage the systems, not whether you can do the work. So, too, is it with Schedule A hiring.

According to the website, Schedule A hiring is a hiring authority for Federal agencies to tap into a diverse and vibrant talent pool, except that hiring process is so complex, so language-driven, and so systems-burdened as to prohibit people with autism from even attempting the Federal Government's most highly distinctive accessible protocol.

Dr. Insel: I am concerned about fairness here because we are really trying to hold everybody to 3 minutes.

Ms. Gassner: Okay.

Dr. Insel: So it might be best just to get to the request.

Ms. Gassner: Okay. So what I would like is for us to make a request through the IACC that these Federal agencies do provide accessible offices. It is not very expensive to make it more sensory sensitive. Enhance training for case managers and one highly qualified person who can communicate with people on the spectrum; a cap on eligibility and appeal time lines for a humane existence; terminate hidden automatic denials; and the rest of this is all listed.

But mostly what we are looking for is technical assistance support to help us with hand-over-hand direct systems navigation. Thank you very much.

Dr. Insel: Thank you. And thanks for coming this long way to share this.

Dawn Loughborough.

Ms. Loughborough: Good afternoon. My name

is Dawn Loughborough. I am the mother of three great kids and one has autism.

In my handout that you have, I will go through that briefly to give you the 3 minutes, but I want to preference my comment by acknowledging a different view of autism as being medical.

And last week was spring break. I traveled back to our farm in the Midwest to meet with a child with severe gastrointestinal problems and autism. And while I was there, I had a plumber come to the house to do some repairs and I asked him, do you know any children like this with autism. And he said, doesn't everyone? So I am really impressed by that, in the sense of I also last week during spring break had four moms I know who traveled three-plus states to take their children to GI and mito specialists.

One mom called me the other day saying she got delayed at the grocery store because a child was having a seizure. A mom friend of

mine with four children with autism and GI disorders, bowel disease-diagnosed, texted me that she was exhausted. She is taking care of all of their medical needs and she needed to go to an appointment for herself to investigate concerns of cancer. You can see the complex situations that these families are in.

And last week, my father came home from church and said another grandparent lost his grandchild with autism. He had bowel disease and the doctors did not know what to do for him.

So I brought a photo of bowel disease with me today and I would like to pass it around. Normally, this would be a very pink healthy-looking tissue and as you can see, it is highly diseased. This is from my friend, Gina.

So, you have my written comments. And basically I am here to say that the current care paradigm for autism care is missing the

physiological care pathways. Currently, the pathway for autism diagnosis channels children into behavioral therapies, speech and occupational therapy and psychiatric models.

Autism parents also want to have a special patient population defined for the medical needs of our children. We have one in 50 children with autism. And I request that IACC look at the environmental causation, the iatrogenic regressive autistic children medically need.

So if you look, I created eight points that have to do with physiologic needs. One, is to develop a strategic objective. Two, is to enable our existing healthcare delivery system to regard autism as physiological. Three, is to overhaul over the long-term, reduce the costs of autism care by treating the underlying causes of autism. Four, is that autism is treatable. Five, that there currently aren't the protocols for these physiological approaches in hospitals. We need

to put that in place. Six, it is time to legitimize the existence of the cascading effects of vaccines on our children's health and society. Seven, we need the media to start covering this in full examination. And eight, we need vaccinated versus voluntary unvaccinated studies to get a baseline for what is happening with our children.

Make 2013 the year to address the medical needs of our autism population. Thank you very much.

Dr. Insel: Thank you.

The next person on my list is Linda Varsu.

Dr. Varsu: Hi. First of all, I am Linda Varsu Papadimitriou. Typical Greek name. And my son, after many years of Kennedy Krieger, he is sitting there. And some of these are the special education schools. Now he is an honor student at a Baltimore City Community College.

So being here today means that no one in this audience is in denial, which is not a

river in Egypt but a psychiatric term, a totally normal reaction of parents after the shock of the initial diagnosis of autism. But it becomes pathological when it lasts longer or forever by denying the diagnosis and/or they expanded the severity of autism.

A parent far into denial is often highly educated, successful in profession with some narcissistic and/or traits himself, and usually the father.

I also say that the effect denial is always second to the diagnosis of autism, as the result of things are detrimental for the person with autism and for the whole family. The early interventions or at least the collaboration of the family with the professionals faced, services and funds to help the person with autism are wasted. Family dramas are the results and also the research protocols become biased and don't have authority when there is only one parent to give the information to be on the test and

everything.

How common is the problem of denial in the United States? There is no research on that. I did extensive research and nothing to find. I can tell you, I can convey to you information from the Autism Society in Greece from professionals over there that the prevalence is as high as 50 percent.

Okay, now we have the people are the ones who ask the government to do some research. Now we found a set of people who found the posting in the blogs over the internet. And I would like to read one which says everything. It is from the Autism Key, a comment on an article saying consequences of autism denial can be far-reaching, and this a mother. Let me read that.

"The denial so awful, especially on the parent, who is not in denial. My 27-year-old son is autistic and has a seizure disorder. I am divorced. I could not deal with my ex-husband's behavior and take care of our son. I

am currently in domestics, trying to get support for him. He would rather hire a lawyer and have the court believe there is nothing wrong with our son, that I just want money. I do not have the money to hire an attorney, so I am not doing too well. He has always tried to make our son look normal when we would be out. This is impossible, so we would have big meltdowns, et cetera, et cetera. I share this to hopefully help others."

So we talk about a drama, and in my written document I put some solutions. I propose fast and low cost solutions to start right now, if it was not possible yesterday. From now on, every ongoing research to have absolutely some small description of the extent of the denial, which one is on denial, and psychologists have very nice diagnostic tools for that, to be on every study starting from now on.

For the ongoing research, we can add this factor of denial, evaluating which one of the

extent. For past research, if result, if contacts are already phone numbers are resolved and the contacts will be the families, they can go back and ask questioner about denial and then put out a new updated article, which could be different from the initial paper.

Dr. Insel: Dr. Varsu, I will have to ask you to sum up.

Dr. Varsu: Thank you. I think in this month of 2013, it is time to start looking seriously at this issue, which is devastating and tell you only second to the importance of autism. Thank you very much.

Dr. Insel: Thank you very much.

Allison Hoffman.

Ms. Hoffman: Thanks for the opportunity for public comment. This is my first IACC meeting and I am really glad to be here.

My son, Matthew, is 8 years old and was diagnosed with regressive autism after a viral infection at age 2. After his diagnosis we

experienced great difficulty in accessing further medical care for him. Once he was diagnosed with autism, everything else went to the side.

We expressed concerns to our physicians and we heard kids with autism do have X, Y, Z, but we just don't know what to do. We were left alone and unsupported with a very sick child, unable to access his life and his recommended therapies.

We set out on a path to find physicians that would help Matthew and we were successful. Six years later, Matthew is finally receiving treatment for his disorders. He has seizures, gastrointestinal issues, and a prime immune deficiency.

His life has greatly improved in development, language, attention, growth, and just overall happiness. We are grateful we are on the right path.

We need help. We need somebody to step in and allow everybody to have a standard of care

for kids with autism. They should not be denied a medical test because the first diagnosis code is autism. They deserve treatment, just like every other child who can express that they have a headache or a stomach ache.

So I came here to ask that we look into that. I don't know if that is even something that you can, but we would look forward to the support. Thank you.

Dr. Insel: Great. Absolutely. And I think you will hear in the discussion period there is a lot of interest in just these issues about standard of care, comorbidities, issues around medical complications. So there will be a chance to get back to much of that.

Jake Crosby.

Mr. Crosby: Hello. My name is Jake Crosby, a master of public health candidate studying epidemiology at the GW School of Public Health and Health Services.

I am diagnosed with Asperger's Syndrome.

Just recently, another study was released by CDC attempting to whitewash away an autism association with vaccines based on what the paper defined as a quantity of antigen exposure from vaccines, not the quantity of vaccine exposure. Since the whole cell pertussis vaccine contained the lion's share of antigens among routinely given vaccines, the study was basically comparing who received this vaccine as opposed to the acellular pertussis vaccine across groups of children with and without autism.

However, the vaccine schedule and the autism prevalence both increased at the same time the whole cell pertussis vaccine was being replaced by acellular pertussis vaccination. So whole cell pertussis vaccination and the new acellular pertussis vaccination did not cause the autism epidemic. The so-called research was completely unnecessary and was produced for PR purposes.

To make matters even worse, Autism Speaks

so-called Chief Science Officer, Geraldine Dawson, misrepresented the study as exonerating the number of vaccinations received as a cause of autism when this study did nothing of the sort. Obviously, she has not earned one red cent of her six-figure salary as an Autism Speaks executive.

Coalition for SafeMinds Vice President Lyn Redwood is another such person tied to Autism Speaks, who is deserving of criticism, having made a total of \$27,500 as a SafeMinds officer during the years 2010 and 2011. She is supposed to serve on this Committee as an advocate for those who contend that vaccinations, especially mercury vaccinations, caused the autism epidemic. Rather than fulfilling her role, she has willingly chosen to be the token mercury mom in Tom Insel's pocket. She has the unique opportunity to question some of the people most responsible for the cover-up of autism epidemic causation by the vaccine program, people like IACC Chair

Tom Insel, CDC's Coleen Boyle, and former CDC insider, Jose Cordero. But does Ms. Redwood? Not even close.

At the last IACC meeting, Lyn Redwood asked Jose Cordero about the breakdown of age for autism prevalence in Puerto Rico. What she should have asked him is how he can expect to be taken seriously when he has asked the *Journal of Pediatrics* to fast track the notorious study by international fugitive Poul Thorsen. Principle Investigator Thorsen and his colleagues used fraudulent autism statistics to make it look like autism was going up after thimerosal was removed from vaccines in Denmark, even though the opposite happened, as revealed in the email correspondences uncovered by biochemical engineer and autism parent Dr. Brian Hooker.

Dr. Hooker would have spoken about this and other instances of malfeasance at Congress but he is prevented from doing so by Lyn Redwood's Coalition for SafeMinds.

After SafeMinds Government Affairs

Committee Chair Mark Blaxill got the scoop on the Congressional autism hearing from someone working closely with Dr. Hooker on getting the hearings going, SafeMinds hired scientology-tied lobbyist Beth Clay, who misrepresented him to Congressional staff and changed the hearing topic from autism causation and the vaccine program to the so-called Federal response, opening the door for autism deniers to be invited to give testimony as representatives on the autism spectrum.

After supported testifying by Poul Thorsen to Congress and contacting Dr. Hooker for more information about Thorsen, SafeMinds President and Lyn Redwood's boss, Sally Bernard, killed the idea of SafeMinds testifying about him before Congress, flat out preventing such issues from even being addressed. She said the cover-up should be resolved behind the scenes, in effect kept covered, up and that SafeMinds needs to make

demands that are "much safer and easier for Issa," the Congressional committee chair.

Sally Bernard remains on the Board of Autism Speaks, even after it has endorsed the IOS 2011 pre-emptive whitewash of vaccine autism link and after Geraldine Dawson's recent misrepresentation of CDC's latest PR to absolve vaccines causing autism, tacitly endorsing these positions while pretending to be on the side that is critical of vaccine safety.

In January, Lyn Redwood claimed in an email to me how sad she was that Thorsen got left out of SafeMinds testimony when trying to talk me out of writing an article that exposed how SafeMinds gutted the hearing. I don't buy it. If she was so sad, she could have testified about Thorsen before Congress himself. Instead, she gave up her position slot to Mark Blaxill, who turned SafeMinds testimony into his own personal self-promotion and book pitch, systematically avoiding

vaccines throughout his entire speech. Her excuse was that she was picking up her son from his first quarter of college on the day of the hearing but the hearing happened 2 weeks after her son's college quarter ended. Even if she had spoken, she would probably have been no more effective than she is as a token on IACC.

Meanwhile SafeMinds' assaults on vaccine safety science continues with its recent dissemination of the hit piece against Dr. Andrew Wakefield to thousands of followers on Facebook and on Twitter.

Thank you.

Dr. Insel: Thank you.

Lori McIlwain.

Ms. McIlwain: I have to speed through this. The video is 3 minutes long.

Dr. Insel: Is the video cued up?

Ms. McIlwain: I am Laurie McIlwain. I am with National Autism Association. This is part of our Video Advocacy Initiative.

In 2011, we were here. We spoke about the need for our kids to have a visual presence here at the meeting. A lot of our kids are unable to attend because of their behaviors and their challenges. Last year, we spent much of the year traveling around the country training first responders. This is data that we collected over the past year - that is over 200 cases of wandering incidents reported by the media. What you see in yellow are the casualties.

These are the children 10 and younger from September 2011 to September 2012. As you can see, the females were at higher risk there of lethal outcomes.

We made a lot of progress. This was a cover story for FBI Magazine. What we are hearing is a spike in calls. We are hearing search and rescue experts talking about seeing higher numbers in search and rescue cases involving children with autism.

We worked with the National Center for

Missing and Exploited Children last year to create new Federal guidelines for search and rescue.

I want to warn everybody because this video is hard to watch. If you are a really sensitive, I would ask that you leave the room. It might startle you a little bit. It took me some time to watch it, but the reasoning is that our children and adults who cannot be here deserve a visual presence at every meeting. It keeps them from attending these meetings that are about them and they are unable to describe their pain, discomfort, and daily challenges. Their caregivers are unable to attend. And it is incredibly difficult - and I want to commend these parents because it is incredibly difficult to pick up a camera at the worst time, and it happens every day to these people, and I can't even pick up a camera to record my son's meltdowns. But at some point, you have to show the physician. So this is what you are going

to see.

(Whereupon, a video was played.)

Ms. McIlwain: That was Brandon's mother who took that video because she was told by a doctor that perhaps it was just his behavior because they were not picking up seizures from the EEG. These parents need support and this is our worst fear. So we have many abuse cases that are being sent our way, and exploitation cases from NCMEC, the National Center for Missing and Exploited Children, and a lot of abuse stories from schools and school buses.

Dr. Insel: Ms. McIlwain, again, I am just concerned about the time.

Ms. McIlwain: Okay.

Dr. Insel: So it would be good to summarize.

Ms. McIlwain: All right. First of all, our abuse needs to be covered but it is not even mentioned in this book. Okay, so that is number one.

We need programs for our caregivers and

our siblings. We are hearing from siblings that we are at the end of our rope, parents saying I don't know how much more of this that I can take. We need to support these parents and not judge them but offer them support. Our suicide hotlines are not trained to speak with individuals with Asperger's and autism. They are not trained. So we need training and access, training and access, training and access. That is what we keep saying over and over again.

Federal autism strategy, that is our goal. We are hoping that we can speak to you guys a little bit longer. National advocates have a day where you can listen to us because we have a lot of constituents so we are seeing the trends out there and we need more of your time. But overall, we are not prepared for what is ahead. We need qualitative data. We need autism.gov, which is a - we need literacy-friendly information, easy access, centralized information for our parents out

there who just want information on how I can stop my child from hitting themselves, basic stuff.

This is what we need. So I am hoping that we can at least start the discussion on that. Thank you.

Dr. Insel: Thank you. And the last person on my list is Karen Heffler.

Dr. Heffler: Good afternoon. I am Karen Heffler. I am speaking as a physician trained at the University of Pennsylvania, a parent of an autistic son now 21 years old, and as an individual involved with the special needs community.

I believe that the research community has overlooked a potential contributing cause of autism that needs urgent attention, and I share this concern with several clinicians who independently have reached similar conclusions.

We urgently need to investigate the potential adverse role that TV, video, and

electronic screen time has on the developing infant mind and the neurodevelopment of autism. The infant brain is exquisitely sensitive to visual stimuli. As an ophthalmologist, I know that there is a critical period for visual development in the first few months of life. For example, if the child has a severe cataract or other visual opacity and this is not corrected or removed in the first year of life, the brain loses the capacity to develop vision from the eye. From this, we know that the brain has a critical period of heightened response to visual stimuli during the first months of life.

Video, TV, and other screen-time exposure in an infant or toddler is an environmental, dose-related exposure. According to studies, infants are exposed to 1 to 2 hours of TV or video per day on average, and in some cases, much more. We do not know what effect this visual exposure on the developing brain that does not have the capacity to understand the

lights and images and sounds and may be making neuronal connections to try to make sense out of the onslaught of images.

We do know several things. And included in the statement is the references - the research that was done to back up everything that I am saying.

First of all, brain changes in autism are found as early as 6 months of age. Some of these brain changes affect the pathways connected to the occipital cortex, which is the visual part of the brain. Videos and repetitive viewing of TV programs began to be available in the late 1980s and early 1990s, when autism rates began to rise. Before the 1990s, this type of environmental exposure was not available. The availability of screen image exposure, such as video, cable, DVR, computer, car VCR, tablet, and smartphone has continued to increase during the time coinciding with increasing autism rates.

Positive effects of early intervention

suggest that there may be an environmental exposure that is either negated or affected by early intervention. Screen-time electronic exposure fits this model.

A 2011 scientific article by researchers in Thailand found an association with autism and earlier television viewing and more time spent watching television than children without autism. Those with autism, on average, started viewing at 6 months of age, compared to those without autism who started viewing, on average, at 12 months of age.

Research has found an association between watching DVDs - to 16 months each hour per day of viewing baby DVDs and videos was associated with lower scores on a communicative development inventory.

The American Academy of Pediatrics recommends that pediatricians should urge parents to avoid television viewing in their children younger than 2 years of age. Despite this, 90 percent of parents report that their

children younger than two watch some form of electronic media. Twin studies show that environmental factors account for a higher percentage of autism risk than genetic factors.

Dr. Insel: Dr. Heffler, we just need to get you to sum up.

Dr. Heffler: Okay. I am urging the IACC as an agency that sets priorities for autism research to look at this as an urgent need and to set the priority that electronic media viewing in infants is an environmental factor that urgently needs to be assessed with researched instruments and our surveys in our National Children Study and the Autism-SIDS Consortium Study and to bring this to the attention of the research community so that other studies can investigate this environmental exposure.

Also, in view of the articles above that I discussed that show that TV, video and electronic viewing in young children with

adverse outcomes with regard to language development and autism and no research to suggest otherwise, the American Academy of Pediatrics' recommendation regarding media viewing in young children - in children younger than two should be more widely publicized and parents urged to exercise caution.

Thank you, very much.

Dr. Insel: Thank you. And to the Committee, Dr. Heffler's references that she referred to are in the package.

So let's - well, thanks to all of you who came to the meeting to share those perspectives. We have heard a wide range of ideas from the need to bring in Labor and Justice and to work on issues around employment; the need to focus on auditory centers; the lack of access and the long wait for SSI; the need to focus on medical and GI problems; the issue of denial, which we haven't really talked much about here before;

developing standards of care; concerns about fair representation on the vaccine issue; wandering and injury as an issue, with a potential of developing something like autism.gov; and then the role of TV and video exposure. So this is a pretty broad range of issues for you to think about.

We have a few minutes for discussion and I am going to just open it up for anybody to follow any of these threads. Geri?

Dr. Geraldine Dawson: I just wanted to follow up on the comment that was made about the need to attend to the medical issues that individuals with autism struggle with. And it is an area, among many, that the IACC has identified as a very high priority area. And the Subcommittee on Basic and Translational Research has recently talked about what would be some of the high priority topics that we would like to, first of all, have presentations here at the IACC about and also consider, again, in terms of research

priorities.

And the issue of medical comorbidities came up and then very closely related to that is the issue of developing standards of care for physicians so that they are recognizing these.

And I will say that there is some progress in this area. Certainly, it is just a step and it is not where we need to be, but both HRSA and Autism Speaks have been working together to try to address this very issue, which is helping physicians to not only recognize these medical conditions but to develop guidelines that are empirically derived that then can be used more broadly.

And I should say that we are in the process of re-competing the Autism Speaks Treatment Network right now, and in the next iteration of it there is going to be a very strong emphasis not just on having Centers of Excellence, but a stronger emphasis on disseminating that information out broadly to

communities so that we see more physicians in the community recognizing these conditions and, hopefully, providing the treatment that kids and adults need.

Dr. Insel: We will just go around the table. So, Idil?

Ms. Abdull: Hi, first I want to just commend Mom Laurie. You speak to many of us that are parents and I think because I heard the last time that you were here when you talked about the wandering. So I was able to get from my son and that squeaky wheel, I had to keep squeaking that wheel in order to get that, it is called Life Project. It is a little thing they put in his ankle and God forbid we will hopefully never need it. But I just wonder if this Committee if there is - and we are only one of eight. I was one of eight in the whole county that was able to get this. And I know I wouldn't have gotten it if I didn't meet you and if I wasn't just as vocal mom.

And so how can we help parents who might not know? Can Medicaid pay for it? Could we make sure that it is on the IEP so insurance pay for it? Can we maybe put it on that Autism NOW website? If we can put what states have it and what it is called because it is called different?

And I was able to get it through a waiver but again, I had to be the squeaky wheel. I just wonder, Dr. Insel, what we can recommend because wandering, especially children who are minimally verbal, if they leave and you don't know where they are, you would rather die than go through that.

So it just breaks my heart that we are still here and still there are so many kids that need that.

Dr. Insel: So this is an issue that the IACC has grappled with quite a bit in the past and maybe Alison wants to speak to this because you and Lyn have led the charge on this. And I know there has been some recent

publicity about it as well. Do you want to sort of get us up to speed with where the wandering initiative is and where is the policy at this point?

Ms. Singer: So I just want to say also, Coleen. Coleen was instrumental in using the data from the wandering study to create the ICD-9 sub-classification that enables physicians to discuss the potential for wandering with parents. That, in and of itself, was a major public policy win because now at least parents can be made aware of the fact that one in two, 50 percent of children with autism will likely wander at some point.

And I think of that 50 percent, I think 60 percent of them will be gone for long enough to cause great fear, not only in their parents, but to have to - the parents to have to make contact with first responders.

So there is still a lot that we have to do. Every time that Laurie comes and speaks to us, it really lights a fire under me because

when she puts up that list of all of the children who have wandered since the last IACC meeting, and highlights the children who have died as a result of their wandering, it is just heartbreaking. It reminds me that we cannot lose site of the most severely challenged children with autism, simply because they can't be at the meeting.

I think when we think of the hierarchy of needs that our children have, safety has to be at the top of the list and we are still at the point where 50 percent of our children with autism are not safe, even when in their own homes.

So I think we have to revisit some of the additional public policy goals that we had talked about, including trying to create the autism alert. Because I think as many of you know when children with autism wander, they are not covered by the AMBER alert because technically they have not been abducted and they are not covered by the Silver Alert,

which although it focuses on a sort of dementia-related wandering, it is only for senior citizens. So our kids fall through the cracks when they wander. There is no way to initiate first responders until they have been gone for long enough to meet with real harm.

So at one point, the IACC was talking about deputizing some of us to go and speak on behalf of the IACC to the Department of Justice and see if it were possible to create or try to create an autism alert that we could implement when children with autism wander. That maybe one thing we should talk about trying to reinvigorate.

Dr. Insel: Are there thoughts about this?

Ms. Abdull: I am sorry, Alison. I also wonder, though, so alert and making sure that we have something similar to AMBER Alert is good. How do we prevent it? How do we get this Life Project that only one of eight that got it? How do we make sure that parents know, teachers know, doctors know, and that it is

covered? I mean it costs hundreds of dollars per year.

I guess as the rookie here, I am just asking what can we do so parents like Laurie don't keep coming back to us with please help.

Ms. Singer: Well, prevention is the key. I mean you want to prevent children with wandering so you don't have to go and retrieve them. And one step towards prevention was to get the sub-classification code from medical wandering so that parents can at least be made aware and they can take precautionary methods, like always assigning a person to watch their child when they are in either a large family situation or when they are out in public, so that there is always eyes on.

And then the other step to prevention is there are some technologies that can be employed for prevention, like alarming doors and alarming windows but prevention is the key.

After prevention, then you want to have

opportunities for retrieval, if they do wander. And that is when you start to get into the technologies of the ankle bracelets or the wrist bracelets or the GPS tracking systems and also trained first responders.

You know, unfortunately, many first responders are still not trained to work with our kids and sometimes kids who are nonverbal don't respond to their name when first responders are searching for them. They don't necessarily understand that not everyone is their friend.

I mean my daughter has wandered. And one time she wandered and she was brought to the police station by a woman who was truly an angel because I sometimes wonder if she had been found by someone who did not have good intentions, what might have happened.

So this is a real issue. I mean, this is something that those of us who have kids who wander fear every day.

Someone else needs to talk.

Dr. Dawson: Thank you for sharing that, Alison. And I think it just brings home how important this is and also reminding us of the statistics that this is such a prevalent and also such a serious issue.

And I am trying to think whether - I mean, this is just one piece of what needs to be multi-pronged strategy. But in the Strategic Plan for research as we think about revising that Strategic Plan for 2013, we might want to really think about when you were talking about prevention, because we know that - and I have, as a clinician, worked with parents who have kids who bolt and it is just so hard when you have a child who really wants to get out of the house, despite your best intentions. It is very hard but I think one thing that would be terrific is to actually develop some prevention and intervention programs for parents that might be effective and to understand risk factors and to really try to do more along the line of understanding

what can we actually do for parents when they are coming to us as clinicians where their child has this particular problem. So we might just want to prioritize that this year, I think, in the Strategic Plan.

Ms. Singer: So I think that Laurie's group has those materials, and you can correct me if I am wrong, and it is just a matter of dissemination. And perhaps endorsement by this organization to try to help them get into the hands of the physicians who can implement them.

Dr. Dawson: I think so but I actually think there is more work to be done in terms of developing systematic approaches for parents. I think that what we have now is great, it needs to be disseminated but I actually think that we could do work here to develop even more effective programs.

Dr. Insel: Lyn and then Anshu.

Ms. Redwood: I am wondering, I know that we wrote a letter to Secretary Sebelius about

this issue and we had asked at one of the last meetings, I think in July, for a response from her. The original response was somewhat cursory and there were several things that we had asked for in that letter that we didn't get any guidance.

But I also think we should consider writing to the American Academy of Pediatrics about this issue as well because they are sort of the gatekeepers of information, especially for parents when a child is newly diagnosed. And I am just not certain that they are even aware that that diagnostic code exists. I think if we could get something that was in their guidelines, if they when a child is diagnosed to be sure that they ask the question about safety and wandering and elopement and let them know that these resources are available, I think that would go a long way in helping this, too.

And I would like to formally ask that Alison and I be given the opportunity or the

endorsement from the IACC to meet with members of the Department of Justice, along with the National Autism Association representatives to discuss specifically the feasibility of getting some type of nationwide alert system.

Dr. Insel: So let's come back to that request in just a moment.

Anshu?

Dr. Batra: As a physician, I didn't know about this ICD-9 code, so thank you. And I agree that that information needs to be disseminated to my organization.

As a parent, again, this is multi-tiered here policy and prevention, et cetera. But as a very simple thing that I have done as a parent and my son was a wanderer under my watch, so it is heart wrenching and you want to die, but for my son and for all the kids in my practice who are wanderers or elopers, I helped my families get ID tags for their kids to be worn around their neck or a bracelet similar to diabetes tags or epilepsy tags, so

that if, God forbid, the child were to wander, at least if they were found, they can be brought back.

So a simple - again, multi-tiered process but a simple thing that I have found that has worked and I have been able to implement.

Dr. Insel: So I would like to stay on this topic because Lyn has got a proposal on the table. Matt?

Dr. Carey: This kind of touches on two of the points that Alison brought up, which is we are talking about a population that is often not very verbal or not communicative and the worry of - how do you balance that against the worry of there being not good players out there that may be out there? But to give you an idea, my son has a cell phone, which he will never dial out of, or at least not for the next 2 years I suspect, which he carries with him. Cell phones have GPS on them now. His ring tone is my wife's voice saying "I'm right here." And it is cranked up really loud.

So I mean but we shouldn't have to do that and not everyone can. But the other question is when you dial it, do you worry? You know, are you basically saying, here is a victim? So that is always there. But I mean that is - the bracelets or whatever else that can track a child, I am not exactly sure how that technology works or how much you get to control it.

But I mean with a cell phone or something like that, you need to have that control right away so that you can say now. You know my kid is gone for 10 seconds, I can't see him. Now, I am calling. I am doing something to get that kid on a smartphone or something else and start tracking. And I need to be able to say start making noise. And if the kid doesn't do it, then start making that happen. Because it is that first second, that first minute that can make all the difference in the world.

And some of these technologies I think, like I said, if you have to call a center,

have them start tracking, get you back, that can take way too long. And so, like I said, we have done that. We are fortunate enough we can make that happen. Not everyone can. So I mean as Idil says, we need to have that capability. It shouldn't be like eight people. You shouldn't have to be the squeaky wheel. People should be saying your kid is in danger of this.

I mean I think it goes along the lines of what we were hearing earlier. Sometimes we have false economies and we say this is expensive. Well, it is not. It is not expensive. If you save one life with this, you have paid for the process entirely.

Dr. Insel: Well so to get back to Lyn's proposal, I must say I am tempted to have you and Alison together go anywhere because I think you could do anything. It is a great idea.

The other possibility would be to have the Department of Justice come to us at the

next meeting and actually dig deep into this issue. Shall we do that? And make sure that we have the right person. That is the thing that I have always struggled with is making sure we have the person who actually has both some responsibility and authority for this topic. So we may need help in identifying who that is.

Ms. Singer: I know who the person is - at the Department of Justice?

Dr. Insel: So you have already been there on that?

Ms. Singer: We identified the person.

Dr. Insel: Okay.

Ms. Singer: And we were scheduled to meet with her and then it was canceled and the IACC sunsetted.

Dr. Insel: Okay. So why don't we have her, if it is still the same person -we will find out -

Ms. Singer: I can find out if it is the same person.

Dr. Insel: With the sequester, one never knows who is here and who is not here. But let's see whether there is somebody who is truly responsible for this issue who we could talk with. And then really put some time aside at the meeting to think with them about what the options are.

What I am hearing here is some of it is policy. Some of it is technology. Actually the issue we haven't gotten back to Idil brought up was around coverage as well and who would pay for it and how one gets access. So there are a bunch of things that are mixed in here that I think would deserve a little more time.

As I recall, it was the National Autism Association that brought us this issue 4 years ago or 3 years ago that started this whole discussion. So it is interesting that they are back and bringing this to us again, but now with a little more urgency.

Lyn?

Ms. Redwood: Can we also - I would like

to have the National Autism Association, since they have taken on a leadership role in this issue, to come back and do a presentation with the Department of Justice.

Dr. Insel: Exactly. I think that is actually what we had done last time - was to use their information. So let's make sure that we have someone from there as part of the panel.

Sally?

Dr. Burton-Hoyle: I might ask, too, because schools are open 9, sometimes 12 months a year. And might we ask for more enhanced involvement from the Department of Education in this topic? Because schools are in communities and also then to go with the IEP coverage to talk about special education policy but they need to be involved. I don't know if the man is still on the phone.

Dr. Insel: You are looking up at the ceiling in the way that all of us are tempted to do.

Dr. Burton-Hoyle: I'm looking at the ceiling, right.

Dr. Insel: Is Larry Wexler still on the phone or maybe on the phone but on mute? Neither, okay.

Well it is a great idea and we could think about making that part of the discussion.

Ms. Redwood: And that is also a place where our children oftentimes wander from.

Dr. Insel: Yes.

Ms. Redwood: My son was lost at school for close to an hour.

Dr. Insel: Great idea. So we can work that in.

Geri?

Dr. Dawson: So to make it more efficient, perhaps we should also invite Jim Perrin as the President of the American Academy of Pediatrics to that meeting so that he could listen and we could start that process as well.

And then I do want to emphasize the idea that I think it would be wonderful to implement a study in the context of schools, for example, on prevention of wandering involves, for example, training of teachers. And then assess it to see whether it is actually efficacious. And think about developing systematic manualized programs that could be used in schools and other settings that could potentially have an impact on this. So I just don't want to lose that research focus because I think it is really important because we have a lot of great suggestions but to package something and to make it systematic and to show that it actually works I think would have a lot of power.

Dr. Insel: But I love the idea of having Jim Perrin come because he could, in his new job, it is interesting that the new president of the American Academy of Pediatrics is somebody who is so focused on autism and behavioral pediatrics. So we really should

leverage this opportunity to involve him much more.

Jose?

Dr. Cordero: Yes, I think that there is a general issue here. I think they are wondering what is a good focus on it but it is someone mentioned the importance of having standards of care throughout lifetime of children's autism. And just sort of looking at the Academy of Pediatrics have done this for Downs Syndrome and it is very well established in terms of what is actually done in terms of health supervision at different times. And it goes from some of the medical issues to the behavioral issues, too.

But I don't see that the Academy has done that in terms of autism.

Dr. Insel: Well actually that is so in October or November they put out -

Dr. Cordero: Yes, and having Jim here would be great.

Dr. Insel: Yes and Jim is very interested

in this and it is also something that the Subcommittee, as Geri mentioned for the translational research has also talked a lot about. And I think one of the things we will hear in a few minutes when we go back to the Subcommittee business is how to do better on the whole question of medical care, health care for people who have an autism diagnosis. And that turns out to be a very urgent question that comes up at almost every meeting as it did today.

Scott and then Jim and then we will have to move on.

Mr. Robertson: On the whole notion just quickly of standards of care, I mean that is something that I hope can get more into how folks have access to healthcare. And one of the things that was mentioned earlier was, for instance, like and I think that is maybe in the comments, I can't remember whether it was the written or oral comments, is about access to like - I think the ASA had it about access

to health insurance laws at the state level.

One of the problems, too, that I think should be out there is that - even when laws like that get put in place in states - they don't always get implemented that well or continually implemented. And just to show you an example from Pennsylvania, we have an autism insurance law and would have been able to give folks a lot better access to services in Pennsylvania but it is not being fully implemented because we shifted administrations. And there is a lot of concern on that that we have that law but it is not being enforced and that. So that is something that should be thought of, too, is not only do we need standards around there but we need to have mechanisms to get people on page, not only at the national level, but trickling down to the state and local levels that there is a consistency of thought and buy-in to a lot of the problems that folks face and the need for continuous access to supports and services and

addressing some of the things the health care access and standards around that to address first some of the medical challenges that the adults and children on the spectrum face.

Dr. Insel: Great point. Jim?

Dr. James Ball: Yes, thank you, Tom.

My thought is I whole-heartedly agree with Lyn and I think that criticism of the IACC over time has been lack of impact in services. And I think that this is an ideal way to actually bring that to fruition through all of the things that we have been doing through the IACC. So I think that is an excellent idea.

Great. So we have got an agenda item for our next meeting and maybe we can turn to several of you, Lyn especially and Alison just to make sure we get the right people to the meeting and that we frame this in a way to go back to Jim's point just now that it is action-oriented and not just informational. I think we should go in with an ask, with saying

how do we get this done. Help us make it happen. Okay?

You get the last word, Lyn.

Ms. Redwood: There is so many other comments that we heard from the public that I want to respond to you but one of the ones or two of the ones that we hear over and over and over again is this issue of undiagnosed medical problems. And you know, the one Allison Hoffman who came and spoke today and talked about how once the diagnosis of autism was in place, all the other medical comorbidities were completely overlooked. And that was the exact same experience that I had with my son. And it took years piecing together these different medical comorbidities and finding doctors to treat them on our own. And each time we did, it was like we peeled another layer and we saw improvement in cognition and behavior. And it is such low-hanging fruit that is completely overlooked that it is at the point where I think it is a

violation of human rights that our children are not receiving appropriate medical care.

And you know we have in our Strategic Plan here with regard to these comorbidities that we need to assist with the development of multidisciplinary health assessments and effective treatment guidelines. And I just think that is so incredibly important because we have enough research now that documents the immune system abnormalities, the gastrointestinal abnormalities, the oftentimes overlooked seizures that our children have that I think it is time to have an entire workshop on those issues, similar to the way the American Academy of Pediatrics and I think Autism Speaks you were involved with this from the GI workshop and to get some guidelines published to really help clinicians to look at these things when they seen these abnormal behaviors in children because I think so much of the self-injurious behaviors are because the children are in pain.

I don't know there could be a dry eye in here watching that video of those children posturing and screaming and saying their bellies hurt and their heads hurt and we are ignoring it, in a way. It is just not getting the attention that it needs.

So I am pleading again. I have been doing this for years now in this Committee that we please look at these comorbidities in the children because it is such low-hanging fruit and there are guidelines of care already established for treating these conditions.

So, please, if we could have a workshop. I know we are planning something for the next meeting but I think we need more than a panel. We need something that is more action-oriented as Jim said.

The other thing that we hear over and over again is the frustration over the vaccine issue. And it is something that I don't feel as though the IACC has really addressed. I know it was in our Strategic Plan at one point

in time to work with - gosh I forgot the other agency - the ACCD. But we know we have case after case after case, I think there is over 80 cases now that have been compensated through FICA where children regressed after vaccines and then were subsequently diagnosed with autism. Now they were diagnosed with other things in the interim but ultimately they had a diagnosis of autism. And I think to overlook those children, I am not saying it is all cases of autism but it offers clues. And I believe there is a subset of children that are more vulnerable. We need to try to figure out what that is. I know we have a few objectives in the plan but they are not getting funded and the studies are not getting done. And the parent community is getting and more frustrated.

So I am asking that we please look at that issue with the 2013 plan as well.

Dr. Insel: Well we have a chance to get back to this in a moment when we talk about

the strategic planning process and how we want to go forward with that.

On the comorbidity question, Alan, there is a meeting that is in discussion for September or what is the status of that?

Dr. Guttmacher: Tom's right. Sometime this fall, and I think that is the right way to phrase it, it is in discussion, Tom and IMH and myself and part of NICHD, and some of our staff met with Tim Shriver recently from Special Olympics and some of his folks to talk about the issue of comorbidities for those with intellectual developmental disabilities in general, not specifically focused on autism but certainly including folks on the ASD spectrum.

And so we are in the early stages of planning something for this fall and trying to get our hands around exactly how you can make something that broad useful at the same time I think will be the challenge with it.

Dr. Insel: So one option would be to

carve off a major part of that for specifically for ASD. One of the pieces, and I won't have time to go through it today, but one of the pieces that we can bring to the table are the data that are now emerging from large studies of healthcare systems to look at what are the healthcare issues. And they are exactly what we are hearing about, GI problems, and in some cases more than anything else is what people with an autism diagnosis end up with, making you wonder if it is really a comorbidity or whether it is actually part of a syndrome that we should be recognizing as unique.

But there are other issues as well, whether it is seizures or neurological problems or others. So we have some pretty, I think, compelling data at this point that could at least focus that discussion. The question I think that Lyn keeps coming back to is how do you change practice? How do we get physicians, how do we get dentists to be able

to recognize the issues for these kids and be able to provide the kind of healthcare that you want for any child? And that is turning out to be an enormous challenge.

Walter? Okay.

Dr. Guttmacher: Let me just say, Tom, I think sort of a procedural question for us is to be optimally useful to the autism population is whether it is better as part of this larger meeting as a temporally next to or how we do that, but that is something we should certainly talk about.

I certainly agree with the discussion that if we forget this other meeting we are talking about that it is time for IACC to pull together, to have an involvement in some kind of meeting on this.

Dr. Insel: Yes, I just think what we are looking for is impact and we always come back to that, sometimes doing something that is larger and leveraging something else is going on.

And Special Olympics globally has an enormous impact. So it is not a bad idea to work with them. But I am open to suggestions if people think of better ways to do this. This wouldn't happen until probably September at the earliest. But I am not sure how quickly we could pull anything together now.

Dr. Batra: Tom, I have one suggestion. You know again, it goes back to everyone recognizes the need. There is anecdotal evidence to support it as well as the NOW research. Again, it goes back to the professionals, the pediatricians, the dentists, et cetera. And again, I am a parent but I am a pediatrician and the way you capture my profession is you tie it in with a meeting that is for pediatricians where they are involved and you have an afternoon on autism-related comorbidities. And that you have a captive audience of general pediatricians who then will get that information and, like Alan said, we all want a

pearl that we go home with and then we can apply it to our patients. So I think that would be an effective way to do it.

Dr. Insel: Go ahead.

Dr. Dougherty: The American Academy of Pediatrics NCE, National Convention and Exhibition is in October. I think it is in Orlando. So that might be -

Dr. Batra: Yes, that is a good place to start with.

Dr. Dougherty: - sort of piggy backing onto that meeting.

Dr. Insel: Yes, so this does raise the possibility that maybe we should reach out to Jim sooner rather than later and get his advice about the best way to do this. Because I take your comment to heart. I think changing professional practice is not easy and it is usually a mix of carrots and sticks and finding out what those should be for this would be useful.

I think Jim would know that. I have met

with him in the last 6 weeks and talked about these issues. He is very interested in trying to figure out how to change practice. So, I think he would be very engaged with us, if we started to ask him to help us on some of these.

Laura?

Ms. Laura Kavanagh: I would just encourage us to not only look at changing pediatric practice but look from an interdisciplinary perspective as well. So we fund training grants throughout the country that have an interdisciplinary focus and bringing that perspective in as well because it might not be the pediatrician who sees the child first.

Another connection with Jim, as Geri mentioned earlier, he is the PI for our Autism Intervention Research Network on Physical Health. So there is all kinds of great connections, I think, with multiple issues with Jim here.

Dr. Insel: Yes, Cindy?

Dr. Lawler: Sure, I think there is another dimension as well to sort of consider some of these comorbidities, not just in terms of making sure that we meet the full needs of individuals that are affected but having a better understanding of this distribution of these comorbidities I think could give us some real clues in terms of etiology. So I don't know if those kinds of implications are going to come out of the workshop that Alan was sort of describing but I think there could be sort of some benefit to thinking about standard ways to kind of capture that kind of information, you know to perhaps perform meaningful subgroup analysis in the context of etiologic research as well. So it goes, I think, beyond sort of care provision but this is something we could consider with the next version of the plan.

Dr. Insel: Okay, so what I am hearing in terms of and I think this has been a great

discussion. Actually it is so much better to keep our discussion right after the public comments. I think it does generate activity.

So a couple of things that will come out of it. One is the next meeting there will be a focus on the issue of wandering and safety, involve who we think are the principles in actually deciding on how to make that an action plan. The second issue is the comorbidity focus and Linda has brought that up several times. I have to say I think we have heard about this in almost every public comment that we have had over the last year. So it is certainly well overdue for us to get some kind of an event going or some sort of a process.

I would like to explore what Jim would recommend how best to do this. Laura, I take your comment to heart that we probably ought to be thinking beyond pediatrics but at least as a starting point, if we can get that group of clinicians onboard and figure out how to do

that, that might be a good idea.

And then Alan, we will turn to you to see if we can get some clearer plans going for a large meeting that could be very public and very high profile so we make sure that even though it may not be uniquely autism, at least it hits this issue very clearly.

Last couple of comments, John and then Walter. Then we need to move on.

Mr. Robison: It seems to me that last year one of the objections to the wandering legislation proposal was that it would prevent people who were in abusive situations from escaping, if you will, and seeking help. And I guess that raises the question if we are going to seek to have insurance coverage and wide availability of electronic devices to protect people from inadvertent harm when they wander away and allow us to track and find them, don't we have a similar and equal duty to provide a rescue device to people at the opposite end of the autism spectrum, where we

might not have a fear that they would wander away but where we would have a recognition often based on evidence and observation that they are at risk for bullying abuse and should such a thing be available?

And if we are going to push for that, should we cooperate with other groups where populations could be at risk of abuse and wandering? We are talking about this as if we are only seeking to protect people with autism but I mean really there are probably quite a few populations where people are at risk for wandering off and where people are at risk of abuse and we should be protecting both. I think they are both equally deserving of protection.

Dr. Insel: So why don't we just bookmark this for now and if there is going to be a chance to talk about this much further at the next meeting, plan to bring it back to the table at that point? I think it would make for a really interesting discussion because you

raise a counterpoint that hasn't been in the conversation yet. And it would be good to do that maybe with the DOJ folks and others who are there.

Walter, last comment.

Dr. Koroshetz: So I was just wondering, in discussions we have had similar to this in the past, self-injurious behavior has been one of the other items that we thought need to be addressed. So is that something that is a separate thing? It is not quite a comorbidity. There is a lot of overlap for some of the other disabilities. I'm not sure if it would come up in that area but I think that that is probably what drives the parents to the point of exhaustion more than anything else, if I had to guess.

Dr. Insel: Allison?

Ms. Singer: So when we had this conversation on the conference call, I think where we landed was that at the July meeting we wanted to have a panel that looked at self-

injurious behaviors and looked at basically the challenges of the most at-risk individuals with autism, including those with self-injurious behaviors and medical comorbidities and that we would then, from that panel, see which issues emerged as the critical issues and then use that to develop a workshop.

I know Susan was going to start to make some invitations for that because it is in July. Is there any update on who has been invited or who may have responded?

Dr. Daniels: No invitations have been made. I received a large number of proposals of people who could possibly speak and, obviously, we are going to have something that is 90 minutes or less. We can't have 15 speakers. So we would have to look more carefully at the number of speakers. And I have heard that there are other people who also want to send in more speakers as suggestions. So we will have to look at this a little bit more carefully.

Dr. Insel: But that is on the agenda for the next meeting, for the July meeting?

Ms. Singer: Okay well I thought on the conference call we had whittled it down and we had agreed that there would be three or four speakers and we had agreed on the topics and that when we solicited additional names, we would keep those sort of on a list for as we started to develop the workshop but that we had come to a decision with regard to the topics for the panel. Is that how others remember the conversation?

Ms. Redwood: I don't remember that we had actually made decisions exactly on who the panel members would be.

Ms. Singer: But the topics.

Ms. Redwood: So the topics -

Dr. Insel: Let's plan to do that through a phone or email and come up with a final list, since this is already April. So we will need to get people invited fairly soon. And it might be actually a good idea to have both of

those topics at the same meeting, both the wandering issue and the self-injury issue.

Ms. Singer: And then Jim Perrin could hear both.

Dr. Insel: And Jim can be at both of them. We need to move on.

Dr. Ball: I'm sorry. I just ask that when we do do that, that we have specific asks for those people so they know exactly what it is what we want so we don't drop this.

Dr. Insel: I think that is a great point. Rather than simply having these as informational discussions, I think we should go into them as a group that is trying to get something accomplished and we can let them know that as well. And so that as we come out of those discussions, there is a plan.

It is one of the things we talked about when this IACC got formed is whether Justice and Labor, other agencies should be on it. It turns out that they are not but we have reason to make sure that they are really engaged with

us because so many of the issues that we care about are in their purview. So let's plan to do that.

I want to move on because we have got to get our own business done as well. Some of the things we have been talking about are relevant. I am going to actually skip the science update to save time. I will mention in one minute the one thing that I do want to make sure you know about, which was the President announcing a new BRAIN Initiative. He actually mentioned autism as part of the reason for doing this. It was mentioned in the State of the Union address and then again he talked about this last week on the second of April. I know that Allison was there in the East Room and Alan Guttmacher, and I am not sure who else from the IACC was in attendance. But it was really an extraordinary event with a couple of hundred scientists and advocates who came to the White House to hear him launch this new initiative, which he called the next

great American project, which is an attempt to map the human brain and its dynamic activity to understand, as he says here, how we think and how we learn and how we remember. And his promise that this would not only help us understand something much more about what it means to be human but also what happens when people have problems, whether it is Alzheimer's or autism and he went through a long list of disorders for which this could be extremely helpful.

So this is, at this point, a White House proposal, NIH, and DARPA, and the National Science Foundation are involved, as well as several private foundations. He has proposed a \$100 million dollars, actually a little more than that in his - we think in his 2014 budget. The actual budget hasn't come out yet. It should come out tomorrow. And we will be eager to see what the numbers really are, but in his message the term he used was a \$100 million. So we will see what is there.

In this environment when all of us are facing five percent reductions in virtually everything we do, it is nice to see a new proposal on the table but it is certainly coming at a time of pretty strict fiscal austerity in the Federal Government. So these are tough times.

I am not going to take you through all this. What we will do is just Susan, I think will just distribute these slides so all of you can see them. We have gone through and tried to give a sense for most of the questions in the plan, what is most exciting. So this is from Question 1, Question 2, Question 3. I mean, there is every reason to think that there is a lot of activity. And I know some of you are concerned about the slow pace of science. We get concerned about how to keep up with all of the things that are happening, right up through Question 7.

And I just should mention then before closing that that middle one, SHRINE which you

moms sure have never heard of is an approach by Isaac Kohane, who is the last author there. They have taken on autism as a sort of test case to find ways of doing analyses from medical records. And they have been able to us this now to look at tens of thousands of records of kids with autism and so actually have looked at that question of how many of these kids have to be seen for GI compliance or for other sorts of complaints. And that has been published. It was not in this slide because it was the original findings were published last year. I think they might have even been one of our success stories. I can't remember if it was in our updates or not.

But in any case, it is a new window, rather than the kind of epidemiology we talked about this morning, which is doing phone calls. This is looking into the healthcare system, so it is a different kind of data but it has a couple of advantages, one of which is that it can be longitudinal. Usually it is

family-based, if you are looking at kids and it is often much deeper and it takes you places - it may get you to look at questions you wouldn't think to ask because you can look at what the data themselves will tell you about the kind of healthcare that both children with autism, adults with autism, and their families are receiving. So it could be extremely helpful. Of course, it also has things like pregnancy record and all of that.

So this is just the beginning of what I think will be a very exciting new opportunity for us. And the technique he has developed called I2B2, I think you will hear much more about it. It matures and it gets used for many more questions. We will send you the slides. We will make sure you have them. And again, this is not a comprehensive accounting of all of the research over the last 3 months but we tried to capture some of the things that were most relevant to the Strategic Plan. And even looking at this list, I have to say that some

areas like the treatment questions I think are pretty thin. There is not a lot to say. But in other areas, it is remarkable how much is actually getting done.

So I won't go into this any more deeply but you can take a look at this on your own time. And of course, we can provide any of the papers that any of you want to look at that are available.

I am going to turn this over to Susan and we can start to talk about some of the actual business that we have to accomplish today.

Dr. Daniels: I don't know if you would mind going back to the comorbidity panel issue because I would hate to plan another IACC meeting just talk about planning another meeting because it does take us work to plan meetings and to put those on the calendar and plan *Federal Register* notices. So it might be something we could resolve in this room that would be easier.

So there were a number of suggestions

that came forward for a panel talking about comorbidities, pain-driving behavior and some other issues. Can you crystalize what it is you are looking for from that panel and what kinds of questions you want to answer that would help us in trying to figure out if we have three people who those three people should be, given that there were a lot of suggestions?

Dr. Insel: I think one of the issues that comes up over and over again is the particular kinds of syndromes that show up. And we heard today about gastrointestinal issues but there are others as well that, well as we keep hearing, they are not getting the attention they need, either from the standpoint of what they may mean about the pathophysiology of the disorder or in terms of getting the kind of treatments people need. But I will open this up to others. Anshu?

Dr. Batra: So again, comorbidity, many issues there surrounding that. The two that I

find are the most consistent and the most difficult for families to handle and most destructive for families is number one, sleep, and number two, GI. And of course, neurologic issues and allergy, and autoimmune, et cetera, et cetera, I mean I could spend all day talking about those. But sleep and GI I would say are the two big ones.

Dr. Insel: Lyn?

Ms. Redwood: The ones that I experience most with my son and I hear from the community and maybe I am just sort of targeting in on these but again, GI, I think immune system abnormalities are big. I think there is a lot of opportunity there for treatment. Also metabolic. We have literature now on mitochondrial injury. We have a lot of information on methylation defects, low levels of glutathione has been replicated in 30 studies now. So I think targeting metabolic.

We have got treatment studies using N-acetylcysteine, which again helps with a lot

of those metabolic pathways with behaviors. And then the fourth one, I would say, is neurologic.

And again last night during dinner we had a lot of rich discussion. And Tom, I agree, it is hard to keep up now with the science because it is coming out very fast. And as Cindy said, I think there is links between all of these. And if we could use some type of systems biology approach, I think we could find common pathways or common links between these different abnormalities. And as you said, it may not be actually comorbidities but what is actually driving the disease itself. So it is something more than just a workshop.

And I think from what Walter, you were saying the document that was distributed, it was a PDF and it was on comorbidities from the Autism Trust, I think it was, pointed out all these cases where these children had self-injurious behaviors and then they were found to have these underlying medical problems. So

that is where I think the link to the self-injurious behaviors come in because they are nonverbal and they cannot tell us. So all we see is the behavior and it looks bizarre and so we medicate them with Risperdal or something and we are overlooking the root cause.

Dr. Dawson: So I think what Susan is asking us to do is to really think about what do we want to do for this panel. And so one idea would be to have at least one presentation on prevalence. And there are some different statistics. So you have talked about this particular study and also the Autism Speaks Treatment Network and with the AIRP, we have close to 6,000 patients that every single one has been screened for these comorbidities. So you really do, at least with that population, get a sense about the prevalence of these kinds of things. But there could be other speakers but prevalence.

And I think it might be interesting to

have at least one or two speakers that gets into pathophysiology. So there is some interesting work. There is no way you could do the entire landscape but maybe something in GI or immune, just so that people are thinking about that these have perhaps etiological or biological significance for understanding.

And then the third would be something about practice. So where do we stand in terms of practice guidelines? So what is the AAP doing? What has been developed through the AIRP. So we get sort of a benchmark of where are we in practice guidelines on this. So it actually would be prevalence, pathophysiology and practice.

Ms. Singer: So at our last in-person meeting we had a mother who came and spoke during oral public comments, who stood up in front of us and very bravely showed us photographs of her son with the injuries that he had inflicted upon himself. And I think afterwards we talked about on the conference

call that this was a highly underrepresented population - that this is a population that is in psychiatric inpatient facilities or on waiting lists for psychiatric inpatient facilities and that we knew very little about the treatment options for this population.

And so we at that point I suggested that we try to get a representative from one of those inpatient facilities to talk about the experience of those individuals and their families, including the fact that at some of these facilities they are using treatments like ECT and that that is something we need to really to shine a light on.

So I would like us to move forward with continuing the discussion of I think a population that in the 7 years that I have been on the IACC we have never really talked about.

So I would like to see maybe the medical director from the Kennedy Krieger is the closest, the Kennedy Krieger Institute, the

inpatient facility, the medical director there is Lee Wachtel. And perhaps Dr. Wachtel could come and speak to us about that population.

Dr. Insel: Is the theme here self-injurious behavior or comorbidities? I know that there is a bridge between them but it seems to me that those are different topics. We talked about building a meeting around comorbidities more broadly in September/October but having a panel at the next meeting on self-injurious behavior.

So I am not sure. What is it that the Group wants to do for the next meeting? Is that what you are asking?

Dr. Daniels: That is sort of what I am asking because I heard so much feedback and it was, as you can tell, a little bit broad. And I just wanted a little bit of guidance as to what people really wanted to focus on, which is probably everything. But if we could divide it up a little bit or make it a little clearer - that would help.

Dr. Insel: Scott?

Mr. Robertson: So one thing I just wondered is there seems to be a natural inclination at times to be only focusing on these issues in the childhood population of autistic people. Like I mean I think it is welcome to have a pediatrician there but it would be nice to be able to also have at least one expert who could speak to issues around medical challenges that autistic adults experience and healthcare kind of experiences and not limit it just to younger children, which I think usually that is - and I think the literature tends to focus on that not only because the literature on autistic adults across many different areas is already pretty scant but I think there is a perpetual notion and a vicious cycle that these issues people only want to think about them around younger children.

And I know many, many tons of autistic adults who are not able to get their

healthcare needs met or have trouble going in there and with the communication, social aspects, sensory aspects of even connecting with healthcare providers. That is one of the reasons why we developed ASAN in conjunction with ASPIRE has been developing the toolkit for autistic adults.

So I just hope that it will be possible to have at least one of the experts who could speak toward issues and challenges and barriers that autistic adults face with co-occurring medical and healthcare conditions, not just autism-specific things but just also getting their health needs met to ensure a quality of life and being able to connect with providers on that. Because I really worry there is a bias towards exclusion of issues that adults face often in the discussion around co-occurring medical conditions.

Dr. Insel: Denise.

Dr. Dougherty: There is a Secretarial initiative that a lot of different entities in

HHS are involved in on adults with multiple chronic conditions. They call it people, but it is only adults.

But it might be useful to get the - sorry. I am the Child Health Advisor at AHRQ so I get very annoyed when people use the word people and they only mean adults. Sorry. That is a whole other story.

But it might be useful to find out who is the lead on that. I am sure it is somebody at NIH, too. And here how they are dealing with this kind of chronic condition as well.

Dr. Insel: So I'm not sure we are getting any closer to a clear message here.

Ms. Abdull: So I am going to see if I can suggest something to what Dr. Daniels had said and what you were saying, Dr. Insel, that comorbidity is sort of like the top. And then you have got the self injuries or you have got the GI issues or the sleep, they are all part of that. And how do we make it so that we are focusing on issues that just a few things

because it is very difficult to focus on everything, I am finding out from the outside to the IACC people. And I used to think what the heck do they do all day? They talk for a few hours. But when you are on the inside, it is very, very hard.

So I would suggest if we could say the comorbidity but then not only just get somebody to tell us what it is, but as Dr. Dawson was saying, the prevalence and then how can we make sure what they are telling us, we take that information and recommend something that helps the patients on the ground.

So people with authority, for example the pediatricians, if we know this exists, because a lot of pediatricians are in denial. I know from my own son when he would touch his tummy or he would put his tummy on a corner of a table, he would say that is okay, that is just boys. And so I think getting the information of the prevalence and then also making sure that doctors understand and listen to the

patients.

And then how do we make sure it is always paid? We always have to come back to this payment thing. And with autism we are always saying it is a behavior. So we get behavior intervention, all of this, that we don't really get the medical intervention.

So it is going to be maybe a lot but if we can focus on the comorbidity and then within the self injuries and what have you would come up but then also, how do we make sure that we are getting information to the patients and the parents on the ground and then what happens?

So the doctor tells you that your child has GI problems and autism and then what do I do? So giving parents information that they can take from us and use it in their own life.

Does that help, kind of?

Ms. Redwood: I agree with Allison. There is so much that has to be done to think of narrowing it down to a workshop or a panel for

an hour at an IACC meeting is crazy.

So I think it is great we are doing that but I think we need to do more. And I think this would be something that would be perfect for a workshop because I think it is going to take at least a day to really drill into this to the level that we need, if we are talking about establishing guidelines.

So maybe as an alternative for the next meeting when we have the President of the American Academy of Pediatrics here and we have the panel, we try to engage them to partner with us on a workshop or something to try to address these comorbidities.

I liked what Geri said in terms of prevalence and practice guidelines. I forgot what was - I thought they were all three Ps but I think that is a great focus. But I do think it is too much for a quarter of a day at an IACC meeting and it really demands more of our time and thoughtful attention.

Dr. Insel: So again there is a lot of

things bubbling here. This self-injury piece, which is what we were talking about for next time, are you saying you want to put that off and put that into the comorbidity discussion or is that a separate enough topic that it is worth going after that at our next meeting as part of a panel?

No question, I think everybody agrees that the comorbidity question itself is too big to do in 90 minutes or 30 minutes. We need much more time for that.

Do you want to take time for this corner of it next time or just build that into the comorbidity workshop or whatever it is that happens later? Dennis?

Dr. Choi: It might be helpful to parse the comorbidity universe into those which are truly unexpected symptoms of disease outside the nervous system and those which are symptoms of disease within the nervous system.

So in a sense, that latter category is somewhat artificially called the comorbidity.

I mean you have a diseased brain and the diseased brain produces most prominently disturbances in behavior and cognition, et cetera but it also produces disturbances in sleep, self-injurious behavior, seizures. And maybe while those are all important and worthwhile to examine in and of themselves, I think that would be useful construct to think about this. I mean, there really would be considerable merit in looking very specifically at signs of disease outside the nervous systems. Those are potentially very powerful clues to some underlying biology, so GI, immune system, whatever.

Whereas, I think also looking at other ways of examining the disordered brain, besides the most prominent sort of behavioral and cognitive symptoms would also be worthwhile but they are somewhat distinct. That might be a useful way to go at it.

Dr. Insel: Okay, good comments.

So Susan, where are we?

Dr. Daniels: So does it sounds like for the next meeting if we had a panel that talked about self-injurious behavior and then sort of allowed the comorbidities piece to be handled maybe in the bigger event later, that that would work? There have been some suggestions that would have to do with self-injurious behavior and pain sensory issues, et cetera. And I think, based on those suggestions, we would have enough to maybe do a panel of three people. I mean, if we're going to try to cover GI, sleep, immune abnormalities, metabolic disorders, et cetera all in 90 minutes, I don't think it would happen.

Dr. Insel: Geri?

Dr. Dawson: So the only thing I want to mention is I am a little concerned about folding this into a general large meeting in the fall for two reasons. I think it is great we should do that but I do think it could get a little lost. And the other thing is that we have a very short window when we have Jim as

the president. And it is a very - I think we want to move on this as quickly as possible, even if it weren't the big definitive panel on comorbidities but it was having Jim here and talking about where do we stand with practice guidelines and raising this as a really important issue that the IACC wants to take on and how could we could with the American Academy of Pediatrics.

I guess I just like to see not wait so long to move forward.

Dr. Insel: So what if take some time in the July meeting just to sit down with him around many of these issues? Actually it is several things that we have talked about here the American Academy of Pediatrics has some stake in. And we could use some - since he is coming for another reason anyway. We could use this as a chance to get his input about the best way forward because I think where a lot of the questions come up is not so much on the science, it is more on the practice. And he

would be a good resource for that purpose and then advise us about the best way forward. And maybe you are right. Maybe what we should plan to do is not a joint meeting on developmental disabilities but to just focus on autism. I am not sure about that but it would be interesting to get some reflections.

Ms. Redwood: Could we not have two panels at the next meeting?

Dr. Insel: We certainly could.

Ms. Redwood: Because that would be one way to deal with it. I know that we have a lot of other presentations but if we cut down some of the presentations and just focused on action items that we could do and have two panels.

Dr. Insel: Sure. I guess what I am trying to understand is what is - I know one of them, as we said from the beginning would be about wandering and safety. What is the other one? That is what Susan was asking, I think.

Ms. Redwood: Can we have three panels?

(Laughter.)

Ms. Singer: Well if Jim Perrin is actually going to be here, I think that is the time to talk about the practice and the comorbidities. And so if he is going to be here, maybe we put off the panel on self-injurious behaviors until the next meeting to take advantage of the fact that his term is short because I agree with Geri there.

But I would rather do that than try to lump it all in and do everything in 90 minutes and then nothing actually.

Dr. Insel: And maybe so what you are saying is to start on this question and then we can, at a later time, go deeper into the question about the other two Ps that Geri brought up, the prevalence and the pathophysiology, which actually would take a fair amount of time to get into. There are lots of interesting scientific questions but that is not actually what we want to engage him on, which is much more about how do you

change behavior.

Okay, I am okay with that, if others do.
Tiffany, you haven't said anything yet.

Dr. Farchione: I was just going to mention that if we are going to focus on practice at some point, it may be worthwhile to engage folks who are involved in graduate medical education, too. Because they are the ones who are going to help modify future practice.

A lot of what this sounds like to me, it reminds me of when I was in med school and we were learning about cultural competency. You know, different ways to listen to people to try to understand what they were really trying to tell you. And a lot of times our kids, they can't - they don't have a way to communicate with us what is really going on and so they do it through self-injurious behavior or other things. So if we are - I mean we are probably a long way off from this but at least to figure out a way to educate future physicians

so that they don't just write people off and ignore them and say oh it is just part of the behaviors. You know, really listen to what people are saying, regardless of how they are saying it.

Dr. Ball: I know I am harping on this but it is very valuable to me and I think the community.

I want to be real specific about what those action items are that we are actually going to engage him in so that we are not over-burdening him with a lot, asking him for specific gets that we can have really good success with, so we actually impact families and adults and children on the spectrum. So be real careful about muddying the waters into a variety of different things, being very specific about what it is we need from him, want from him, and want to engage him in.

Dr. Insel: I think that is great advice. Idil?

Ms. Abdull: I was just going to ask

something just - the AAP is not part of here. Wouldn't it be nice, because we take our children to the doctor, so wouldn't it be nice on the next IACC if we can have a member from the AAP and, I don't know, maybe make the public a little less? I would rather have that.

And then in terms of educating the doctors, I wonder if HRSA can answer a little bit maybe because you guys do train tomorrow's not just practitioners, but also therapists?

Thanks.

Ms. Kavanagh: So as I mentioned before, the Health Resources and Services Administration funds leadership, education, and neurodevelopmental disabilities, training grant programs, which are interdisciplinary in nature. So 12 different disciplines, physicians, OT/PT, nurse, nutrition, psychologists and others, as well as developmental behavioral pediatrics training programs. We would be happy to come talk about

those training models and practice models that emerge from those training models as well. But I don't want to muddy the waters and expand it further.

Ms. Crandy: So are we asking him if he can make this issue or training or the guidelines be part of this October conference that the AIRP is having? That is one of the asks that we want to happen?

Dr. Dawson: So the AIRP, this is all they are thinking and doing right now is trying to develop guidelines around medical comorbidities and physician guidelines. So I don't think that is the audience. But I think it is the American Academy of Pediatrics meeting. So to have an emphasis on this at that meeting.

And then I think the second specific asks had to do with wandering and getting wandering into guidelines and pediatric training as part of - you know they do have their own guidelines on the treatment of children with

autism, the American Academy of Pediatrics does but I don't think wandering is included in that.

Dr. Boyle: So they do have information. They do have fact sheets on wandering which came out of our work a couple years ago. They have a toolkit on autism. They have just - we have helped them just update the information on wandering. So they do have that.

Dr. Dawson: Okay, excellent. Well, very good.

Dr. Insel: But the question, again, is how do you disseminate it? How do you make sure? What happens when people don't do it? And who is responsible? And where is the accountability and the practice system, all of those issues?

So I think the questions in terms of the action or the ask will be to say to him something like now that we have guidelines, now that we have a code, how does it get disseminated? How does it actually happen? And

to get his best ideas about where the roadmap would be for that. Coleen, last thing.

Dr. Boyle: Last thing. So just with the wandering code, so the wandering code is really it is for essentially data. So it would be a way to identify how many children would essentially get this code for wandering. But my challenge would be with reimbursement in terms of thinking about counseling or services or whatever. To me, that would be the question to apply or take to Jim. So these codes can be used for reimbursement but I don't know how that works in practice.

Dr. Insel: Right. And actually it goes back to Idil's initial point of when we got this whole conversation started was who is going to pay for this anyway.

I am going to suggest that we maybe have beaten this horse enough and we take a ten-minute break. We have a lot of business that we still need to take care of related to OARC, related to the Subcommittees. I want to have

you come back in 10 minutes and we will zip through some of that and get you best ideas.

(Whereupon, the Committee members took a brief break starting at 2:59 p.m. and reconvening at 3:11 p.m.)

Dr. Insel: So you are going to take us through the business and we will talk about Subcommittee actions as well.

Dr. Daniels: Okay. So I wanted to give you a little update on what the IACC has been up to in the last few weeks. We have had four meetings in March on the phone but they are meetings and we have discussed a lot of business and done a lot of things. And OARC is also working on some things so I wanted to take you through that quickly.

First of all, I wanted to show you the IACC Summary of Advances that was released today. It is on the IACC website. This is an annual publication that we do to meet the requirements of the Combating Autism Act to publish an annual *Summary of Advances*.

The lay-friendly summaries of the 20 most significant advances in ASD biomedical and services researched selected by the IACC are in this document and it covers a wide range of topics that relate to the areas of our Strategic Plan, the seven critical questions of the plan. And so you will be interested in looking at this.

Unfortunately, I wasn't able to get these bound before the meeting and so you have photocopies sitting at your places but we will have the bound copies ready in a couple of weeks and we will mail them out. And if anybody wants extra copies, just let us know. And any members of the public who also want a bound copy can just to write to our office and ask. And the PDF is up on the Web as well.

Anyway, thank you so much to all the Committee members for your work on this document.

We also, in the last few weeks, sent a letter to the Secretary of Health and Human

Services on Health Coverage for Early Intervention. And I couldn't cover all of your points in this one slide but just as highlights that you talked about the strengthening evidence base for effectiveness of early interventions as justification for recommending support for coverage of and broad access to these treatments for children with ASD and recommended that this coverage be equitably available to both children who are insured with Medicaid and to those who are under private insurance. And this letter is posed on the IACC website under IACC publications, if you go there.

Dr. Insel: Can I take a moment -

Dr. Daniels: Sure.

Dr. Insel: - to say thank you especially to David and others who worked really hard on this. It seems like there were probably 400 emails and you never lost your patience with this process. But I think that the product was worth the amount of labor. You did a great job

and I know it wasn't just you. It was several people but I really appreciate your leading the charge.

Dr. Daniels: Thank you so much David, Denise, and others who helped with this letter.

I also wanted to give you an update on OARC and some of the ongoing projects we have in the office. So we are working on the research portfolio analysis for 2011 and 2012 data. And just to give you a brief status update, we have collected some of the data. We are still collecting other parts of the data and are in the process of verifying all of the data. And so for those of you, many of you have organizations and agencies who participate. You have seen what our spreadsheets look like. We collect kind of detailed data and as we go through these spreadsheets we always find mistakes, information that has been left out or is unclear. And so we go back and verify every

piece of data before it is finalized and we start doing the analysis. And so we are in the process of doing that right now and we will be releasing the final report probably towards the fall.

When we have the data from 2011 and 2012 completed, then we will put it into the web tool. And right now we have 2010 data and 2009 data are in the web tool which released last July, which many of you hopefully have visited on our website.

And we have the data from 2008 but we had never had a chance to format it for the web tool and so we are in the process of doing that. So that all is going to be available there, hopefully soon.

We also have a project coming up where the ORAC has been asked by the Department of Health and Human Services to gather data and complete the Combating Autism Act Report to Congress that is due on September 30, 2103. And you saw a previous version of this report

from 2010. I think that we may even have some copies of the 2010 report here in the room. It covers, at the program level, what all the different Federal agencies are doing on autism, talks about budget numbers and kind of larger programs, a little bit about results, although obviously it is not going to be something that covers every single project that has been funded and detailed results but sort of highlights from every agency.

And so OARC will be beginning the process of gathering the data for that report and that will be publicly available after it has been submitted to Congress and so that the IACC will be able to access it in October so that you can use it for anything that you may have going on related to updating the Strategic Plan.

Something that I haven't discussed before with you all is that in ORAC we have had an ongoing project to try to create a searchable database for the public comments because we do

have written statements that go with our oral comments, as well as the written comments that are received every time that we have an IACC meeting and we wanted to make a way for the public to be able to see these in a searchable format and so we are in the process of creating a database for those. And it is a laborious process but we are getting through it and it is moving along pretty well.

And then the last item I just wanted to mention on this list of things that we have going on in the background is obviously the planning of IACC meetings, which is continuously ongoing because we have a lot of meetings.

Dr. Insel: Can I interrupt for a moment?

Dr. Daniels: Sure.

Dr. Insel: One of the issues that has come very occasionally but it came up today and I have received some emails about it in the last half hour is when there are public comments either about people who are in the

room or who are not in the room that are highly offensive or interpreted as being attacks on someone's - essentially hate speech and how we should deal with that. And we haven't talked about this as a Committee but I do think we need to have an approach going forward to decide what is the best way for OARC or for the Committee to deal with that and to what extent do we want to tolerate anything that feels like intimidation or hate speech to either people who are on the Committee or even outside the Committee. Some of the comments today were actually directed at people who aren't associated with the IACC at all.

Scott?

Mr. Robertson: Yes, when I have seen some of the comments since I have been IACC, I have been really, really concerned about the times where I have seen comments that were real like direct attacks, ad hominem and kinds of things and things that were beyond - because I could

see - I try to be flexible in my thinking that when I see things that are relevant to informative kinds of things that is important but I have seen things in some past comments. And I am not going to point out anything on specifics that were really worrying.

And what concerns me is as much as folks have a right to free speech, they don't have a right to kind of lobby, kind of slanderous or libelous kind of attacks on folks. And I worry that by not having some kind of discussion or agreement or maybe loose policy or something on this, that we are implicitly accepting that it is okay for folks because we haven't, the IACC as a body has not said anything about this before.

And sometimes these types of attacks are sometimes repetitively coming in from the same persons, at times, continuously. And I think they are because there hasn't been anything set by the body about how to handle when these things happen.

So I think we should at least have some kind of loose-working framework about what we should be doing when these things come in. And at least my suggestion is that either out there with guidelines for the comments that maybe there should be something around that so when people send those in, they should be aware. And maybe it comes down to just not accepting things that are not - you know they are not accepting things that are filled with things that are kind of a hate speech nature or at least if not that route, then maybe asking folks to maybe make changes or edits or something that can take out those parts. Because those parts really worry me that I see things that are, as I said slanderous, libelous kinds of things that I think most other bodies would not be so accepting of such attacks pretty blatantly on folks.

Dr. Insel: John?

Mr. Robison: As much as I find some of our regular commenters offensive, I am a

strong believer in free speech and I guess I would just remind all of you that when we join a Federal Committee like this, we place ourselves legally in the position of being public figures. We are just as subject to being called fools and incompetents and tools of Big Pharma or whatever else it is with impunity as a U.S. Senator is by Rush Limbaugh or some other radio commentator.

And as offensive as I find some of the comments and expressions, I would be very careful starting down any kind of slippery slope of censorship because I think that is something that we are not about here. We have taken a lot of steps to make our meetings open and transparent. I think that, in some cases, I would be inclined to speak up during these things and maybe I should stop keeping my mouth shut politely because I have the same right to answer back. But having said that, I don't feel right about a discussion of muzzling commenters unless they truly cross

the line into something that is patently racist or offensive and I haven't really heard that.

Dr. Insel: Some of the comments, in fact some of the comments today were not about people in the room but people who are associated with -

Mr. Robison: You know, I understand they weren't but those comments came in in the context of speaking before a Federal Committee. And one of you made a remark about libel or slander and I believe, I am not positive about this, but I believe that people do have protection from that when speaking before a Federal Committee, just as they do in a court and other venues.

Dr. Insel: Alan?

Dr. Guttmacher: I am also of the opinion that we should tread - I was going to say tread carefully but I would say probably not tread at all in terms of saying what kind of speech is allowed and what isn't.

One person's terribly offensive and inappropriate is somebody else's passionate point. And I think it is very hard to have any kind of objective standards by which one said gee this is in and that is out.

And I think for lots of reasons we are - I mean we all serve here while we are on the Committee, particularly, as extensions of Federal government and I don't think - I very much identify with the comments that John made.

I do wonder, however, partly because of this context and partly because seeing how many public comments we often have to go through because there are so many people that want to speak to us, which is great and it is part of the reason for our being here, whether it would be appropriate to say that there should be some periodicity of one comments. That is, no one - that we will only take comments from folks once a year or twice a year or whatever it might be in terms of the

public session, to allow people to submit any written comments because they are really unlimited. But in terms of oral comments to say that we ought to expect people to be able to make the point. I know that there are some people that would object to that saying yes but you didn't hear me and you haven't reacted to my comments. Well, if we didn't hear you the first time, it is not that likely we are going to hear you better the second time.

So it is a little bit different from what I think was being proposed but I think I would be more comfortable with that.

Mr. Robison: I think we would have to do something like a lottery thing or something, Alan, to be fair with that. Otherwise, I think we would be very open to suggestions that we are targeting and discriminating.

And you make a very good point that like in the case of the one fellow earlier today, I think that as much as I and maybe you disagree with what he says, it is obviously his

passionate belief. And I don't believe that his expression of a passionate belief is going to be followed by his attacking me in an alley when I leave the building. You know I would rather he didn't feel that way but he does and he is entitled to it.

And I also feel like a lot of the very angry comments that I read from parents in the written comments are, in fact, an absolutely valid expression of frustration that as a government we have not served our constituency very well in this cause. And I know that is not our personal responsibility here but we are the lightning rod because we are the autism Committee.

Dr. Insel: Jan.

Ms. Crandy: And I believe the public is our checks and balances. It makes us do our job, what we are supposed to do here and why we are here and who we are representing, although some of the personal attacks probably hurt and I am sorry that it is happening. And

I think that people at this table are here because we genuinely care and we want to be here and we are trying to make a difference. But I don't think we should stifle anybody from their opinion.

Dr. Insel: Geri?

Dr. Dawson: I absolutely concur that we should avoid limiting public comment in any way, unless it crosses some line that I actually don't think it has crossed yet, as painful as it might be for some people.

And I think, you know at least for myself personally, I mean, I honestly don't take the comments personally. I think it really is about somebody feeling very frustrated and that we are symbols of something that is perceived as a barrier to achieving what somebody things is important and fair.

And so for me, I don't - unless it cross the line farther than it has, I would prefer not limiting it.

Dr. Insel: Well so, just to be precise,

the particular email that I received within the last hour was about someone who is not on the Committee and in no way associated with us and felt that there was hate speech directed at her, based on her religion and the way she was identified by a comment today. And she feels that we should be putting some limit on that kind of speech and there should be some protection from those who are not on the Committee from being attacked in the public comment period.

Sally?

Dr. Burton-Hoyle: What are the standards for other committees such as this in the government?

Dr. Insel: Yes, FACA is very open. The whole idea of having a FACA committee is that there is complete transparency and there are few limits.

For instance that kind of thing we were just talking about of having either a lottery system or limiting the number of times

somebody can speak is not within the FACA guidelines. So there is really the whole point of having a FACA committee is to make sure that it is transparent and it is publicly accountable.

Allison?

Ms. Singer: So a lot of us have worked together for a number of years. And even though we don't always agree with each other, I think it is hard to listen - it is harder to listen to that hate speech towards you colleagues than it is to hear it directed at yourself.

I felt for Lyn. I felt for Geri. Again, to Geri's point, when it in the past has been directed at me, I didn't feel it as much as I felt it today for those who were named.

So you know, I think it is nice that we all care about each other on this Committee. Even though we don't always agree, I think we find a way to try to work together and be respectful within the Committee. But I agree

that I think it is a slippery slope if you start to put limitations on the speech. I think we should just all try to be supportive of each other and supportive of the important work that we have to do. But I think it is almost giving it too much weight that we are even having this discussion. I think that is sort of negative reinforcement of bad behavior that we are having this conversation.

So I would hope that we could come to an agreement. There seems to be agreement that we don't want to limit speech and move on to the important business that the Committee has in front of it.

Dr. Insel: Okay, I am going to take that as advisory and I don't think there is a lot of reason to spend more time on this but I did want to make sure it was on the table because it seems to me it was hanging and it may come up again. And I think it is useful to have this discussion, rather than doing it after the meeting by email or something like that.

Dr. Koroshetz: Okay, I suggest we actually talk to get some information about what is the legal rights of the FACA committee with regard to this issue because it hard for me to imagine that there haven't been much worse things that have happened in other FACA committees and if we can't draw the line here, then there has got to be some places where you have to draw the line just for decency's sake. So I think we could just explore that and see what has happened in other places.

Dr. Daniels: So we already have some idea about that. I am pretty familiar with the FACA guidelines.

And so the things that we could do, if the Committee were interested in having us do this is we could issue in the *Federal Register* notices when we are having public comment, just a guideline about the expected conduct. It doesn't mean people have to abide by it but it is something that we could put in the *Federal Register* notice as advisory. And if

you feel comfortable with that, we could put that in. It doesn't mean that anyone would necessarily follow it.

We are required to allow public comment at these meetings. However, the format of the public comment is not specified. So it doesn't have to be oral. For example, if an oral comment came in that we were concerned about, we could move it to a written format, if people didn't want to hear it orally, because it is still allowing the person to give comment. But it is making a decision about that and so we don't have to do that. That is one option that we would have.

Otherwise, we could just put in a guideline that states the values of the Committee about respecting for each other and having consideration even when we disagree and leave it at that.

Dr. Insel: So that maybe the easiest resolution is simply to provide that, along with the other information about how to submit

public comment.

I do want to say for the sake of the Committee, as your Chair, I am not going to allow anybody to intimidate or threaten anybody on the Committee. And if you feel in any way endangered or threatened or intimidated, you need to let me know if I am not picking it up because we can't do our work under those circumstances. And it is really important that we have an environment where people feel safe to disagree and follow the very values that we set out with when we started with the plan.

So let's leave it at that and let's move on to other business. Thanks, Susan.

Dr. Daniels: So on to the next slide. So we have two Subcommittees, the Basic and Translational Research Subcommittee, the Services Research and Policy Subcommittee, and then we have the full Committee. And I wanted to quickly just lay before you some of the projects that have been proposed in the last

few weeks before we get into discussing any of the projects, just so you can see them. And today, this afternoon, a few additional projects have come up. Because in my previous slide I told you about what OARC is doing. So those are our projects that we have going on in the background. There are also these projects that are coming up.

So the Strategic Plan Progress Review Process, this was something that we talked about on the last Basic and Translational Research Subcommittee call, talking about what kinds of preparations we would make for doing the next iteration of the Strategic Plan and taking a look back over what progress has been made but in a different way than we have done in the past. And I will let the Subcommittee chairs talk about that in more detail.

But just as a quick overview, if we were to do this, first the question - a Planning Group has formed around Question 1 to try to do a pilot of this. And this Group is active.

It has already met once. And if they come up with a strategy, then we would potentially split into seven groups and the BTR Subcommittee would have five of those Groups, if we went by question, unless we collapse some of the questions together into other Groups. So then we might have five Planning Groups there.

There is also the *DSM-V* Planning Group that is meeting in 2 days on the phone and Geri Dawson is chairing and she can talk in our discussion period a little bit about that and the goals of that.

We also have the SRP Subcommittee - and I am sorry I didn't mention it, the BTR Subcommittee is led by Tom and Geri. They are

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(Laughter.)

Dr. Insel: We want to say Geri and Tom.

Dr. Daniels: Geri and Tom, maybe.

Dr. Insel: It just sounds better somehow.

(Laughter.)

Dr. Daniels: I guess we need a little comic relief here.

The Services Research and Policy Subcommittee led by Denise Dougherty and David Mandell and so they have a number of projects they are also considering.

So the letter to the Secretary regarding early intervention, that one is completed so we can take it off list. I just thought I would put it there so you can remember that we just talked about that one.

The letter to the Secretary regarding adult services and research, this is one that came up on the most recent SRP Subcommittee phone call and that is one of the projects the Subcommittee would like to do. They also discussed possibly preparing an adult services roadmap document and so that would require the whole Subcommittee or Planning Groups or something to try to work on that.

They talked about some kind of a Health Disparities Project. And then if there is a

Strategic Plan Progress Review Process going on, then there would be two planning groups for that.

And then the full Committee, by the end of December 2013, needs to do an update of the Strategic Plan and that is required by law under the Combating Autism Act. And then we talked about - and this slide was prepared before this afternoon's discussion of a collaboration with an NIH workshop on co-occurring conditions or maybe this would be some other session at an AAP meeting or some other kind of a workshop.

So as you can see through these three slides, there are quite a few projects and if you include OARC projects, we have a lot of projects possibly proposed. And so we wanted to give you all plenty of time to discuss this and come up with some plans and possibly some prioritization about how to accomplish these things. Maybe the timing so that it can be done. And I know that you all want to have

projects that are going to be useful and have some impact and be completed.

Dr. Insel: Susan, maybe we should go back a couple of slides and just start with the - so this one, on the Planning Group because we have to update the plan and we have to decide how we will do that. And last time the recommendation that we made that when we met as a full Committee was to do something a little different than last year but not like the year before when there was a full revision of the plan. This was to be more of an accounting or accountability exercise to look at what has been accomplished.

And there was a Planning Group that met a few times, at least there has been a lot of email back and forth. I'm not sure I have everybody on it. I know Allison and Lyn and Coleen and Walter, Anshu, and Matt. That is the Group.

Geri and Tom have not been in on those conversations but we have followed the email

with interest. Maybe - it would be useful I think to get some feedback from the full Committee about that process but it turned out to be harder than I think anybody thought. The original idea was to look at the questions, look at the objectives, and to come up with a fairly quick way of saying have we done it, have we not done it. Where are the barriers? What needs to be done?

And I think getting into it and trying this out with the first question, which is probably the easiest in some ways, it looks more difficult than one might have thought. We can just sort of summarize and Coleen or others, correct me, Geri and Tom if we don't have this right, but where we thought things have ended up, and maybe this is our construct of where things have ended up is we need the portfolio analysis done for 2011 and 2012. And that is really going to be critical to know what has been funded and what has been supported with respect to every one of the

seven questions.

We can use that to do an actual accountability in the sense of what have we done with respect to what we said and needed to be done in 2009, '10, and '11. And if we have all the data, that should give us a pretty good quantitative analysis of what has been accomplished. And also what has been neglected, which hopefully would come out of the same analysis.

I think that the Group felt that was sort of a useful way of looking at what grants were funded. What it didn't tell us, and this is what we talked about last time, is what have we learned? Because obviously it is even better if you can get the answer without having to spend as much money as we originally proposed.

So was there a way to get the outcomes or to get the new knowledge coming from this research? And I think that is where things got very complicated as we discussed in the small

group. There are whole branches of science that try to do what is called the science of science and to figure out about the return on scientific investments and most of the time that is a 10- to 20-year outcome study because it just takes a long time for research to pay off in terms of changes in practice, changes in policy, or even changes really when it comes to therapeutics, changes in new treatment.

So what we thought might be more feasible would be to do something a little bit like what we did last year around having expert panels, having a more qualitative look at bringing in experts but also bringing in some consumers and bringing in members of the IACC to say for this particular question, what has actually been accomplished not last year but since 2008. And at that point, we should have the whole portfolio analysis and be able to see what investments have been made, what is paid off, what hasn't, at least in a very

short-term framework, knowing that a lot of the funding, a lot of the grants that were funded in 2011 and 2012 are still getting going or still in their earliest stages. But the hope was that if we put those two things together, the panel with a qualitative assessment, the portfolio analysis with the quantitative data that we might be able to provide something that would be a useful kind of update to the plan and a reflection on the accountability question. And especially perhaps highlighting the areas that haven't gotten the attention that they deserve.

Is that kind of - so let me turn this to the five of you or six of you who have been involved to see if this is getting to the meat of it. Allison?

Dr. Boyle: No, I was just going to say that is a fair assessment of where I think we had a lot of discussion about how to do that qualitative piece and just bringing everybody up to speed in terms of thinking about

requests for information from both the scientific and the consumer community, trying to really get a sense of what the impact of the plan has been for the autism community, people with living with autism and how to best do that because we want to know is today better than it was 5 years ago. You know, and obviously reflecting on what you said, Tom in terms of the time period it takes to see change, the decade at least, actually sort of changed the culture of how we do things and what are doing.

So I mean I think that we were trying to be very ambitious in a short period of time and maybe thinking about that process moving forward in our next round, I just I guess - you know how best to get that - I think everyone was very concerned how to best get that qualitative piece. That is the real challenging piece.

Dr. Insel: Allison.

Ms. Singer: Yes, I agree that is a good

summary. I would just add that we also talked about using the panelists to help us prioritize the objectives. I just wanted to make sure that didn't get lost.

Dr. Insel: That is a great addition.

Lyn, comments?

Ms. Redwood: Yes, I think the summary is nice. It would be wonderful to have that more qualitative analysis. The concern that was also voiced by staff and by some of the Committee members is just the time crunch that we are working under to be able to accomplish that.

I think it would be good if the group of us sat down and started going through it because the other thing that I think can happen when we look at some of these, we may be able to answer them their selves because the objectives were written to be smart. So they are measurable, they are time bounds. Some of this we can actually say yes, we did it. We had a workshop and we can scratch that

off and that could come off of the plan when we do our updates. But the more question is did that workshop really toward the vision and mission of this Committee. And that is the one that is a little bit harder to quantify. And I do think bringing in some stakeholders in the community and some experts in the field would be helpful to perform that type of analysis.

And I think Anshu had said even with pediatricians, if there was an objective I think the first one is to come up with existing tools. Do pediatricians really feel like they have what they need? Do the families feel like they are getting what they need? And then what is missing?

Dr. Insel: You know, I think we have a lot of expertise on the Committee itself. So while I think it will be great to bring in stakeholders, we can look to you do some of the heavy lifting on this as well just around this table we have so much talent and so much experience. So I would say that part of that

qualitative assessment could happen here.

Other thoughts about this? Geri.

Dr. Dawson: I really do like this combination of the quantitative and qualitative assessment. And I think the key will be thinking about how to put together the panels that do the qualitative assessment. And I really do like the idea of a combination of IACC members, experts, both in the field and maybe even outside the autism field but have the expertise to kind of have a distant look without having a personal investment. So I remember, for example, I was on years ago a consensus panel around PKU and the guideline there was to bring in people who had enough knowledge to be able to make - come to consensus. This had to do with when testing was done for PKU and things like that but didn't have a stake in the game. And it is kind of an interesting perspective.

I do think that bringing in people with a stake in the game is important, too, because I

think they do have a very deep grasp of what progress has been made but having that some of that perspective. And then finally maybe the voice of a practitioner. So over the last 5 years, any of the research that has been conducted, maybe it is a representative from a professional society or something has an impacted practice to your knowledge. So maybe those are the different perspectives we might bring in to those panels.

Dr. Insel: A few of the panels from last time, much of that we did by phone, and it was surprisingly effective within 90 minutes or so if we kept the phone calls very structured and very focused on specific questions.

Walter was on a couple of them as well and I remember that there were lots of tough questions but we could then do the research in-between calls and then come back and resolve things pretty quickly. So I think that it did work for last year to get at what do we know, what do we need, and we could build on

something like that. Walter?

Dr. Koroshetz: So I agree I think it is really important to actually look at research, even though the science of science is not where you would like it to be. There is no formula you can use and plug in these to get your answers.

I think that a group such as this has value if they can be a realistic mirror to the investigative world. And by that I mean we have the plan which has things in which I think everybody agrees are good. We have money that went out to fund the research that people thought was good research. But getting from the research to the goal is not as easy as just giving out money to grants. So I think the value that we could play at some point, maybe the timing is wrong, is to look at what the research in a question is, see how far it has got and then the issue is if we are on this trajectory, we are going to get to where we want to get or if we are not, what is

missing. What is the problem?

So I think that is - I mean I think you can - I am less interested in the historical record than I am in okay, this is what we did so far and did we need to - are we on the right track or do we have to do something different?

And then maybe, especially when you come to implementation, there may be some really big things that you have to do, that the research actually hit the pediatric practitioners. That may be a gap that is, if we recognize it, we can potentially bridge the gap.

So I think that would be the value of going through a review process is not historical record but identifying where are we and are we on track to get to where we want to get. But it is a lot of work and I think to do that for every question I mean I think it is just not possible. But I think that is the value of this process. The question is, how do

we do it for every single question. That I don't understand.

Dr. Batra: Yes, and Walter that was very well said. And I guess am I learning researchese, as I was mentioning last night, from my standpoint, I think we have wonderful science. I have learned that this last 9 months going through all the research. But again, from my standpoint, it is how do you translate that to the real world? How has that affected me as parent? How has that affected me as a pediatrician? What tool have I been able to implement now to the babies and the young adults? And that is the piece I don't understand how to quantify. You know, how do we create a report card for ourselves and for ongoing research?

And I think Susan was explaining yesterday, in the research world, it just means number of papers that have been published but that doesn't help me. You know you can tell me there have a hundred papers on

Question 1 but how then has that translated to how I practice in my clinic?

So I don't know. I would love to hear some suggestions on that.

Dr. Insel: David.

Dr. Mandell: So we have scores of objectives. Right? So almost four score -

(Laughter.)

Dr. Mandell: - and 7 years ago when the IACC started - sorry it goes just too far.

But I think that it might be useful if we were to tackle something like this for all seven questions. I'm actually not really sure we should in a systematic quantitative way, when we think about the resources that are available to do it, unless we were going to outsource it. Maybe part of the challenge is selecting representative objectives from the questions. And then trying to sketch out what would it look like from knowing nothing about this issue, such that the objective had to be stated in the first place, to having some sort

of successful implementation of a product, a deliverable related to the objective and you were talking about the study of science or the science of science and certainly one can sketch out what that pipeline looks like and then you could sort of mark where you are along that pipeline and the deliverables that have accompanied that process up to that point.

I think your point about the fact that normally when you do this, it is 20 years out, 30 years out is very well taken. And I don't think the expectation should be that with each of those objectives we would be all the way at the point of having a deliverable that is implemented in the community.

And so it is scorecard more than a report card in that it tells us sort of where we are and what we have left to accomplish, rather than grading our success in some ways so far. But I can't envision doing that kind of task, given the means that are available to us for

the entire IACC report in a meaningful way.

Ms. Redwood: See I think we have to. I think we really have to do that for all 78 questions in terms of updating the plan because there are some of these objectives we have accomplished.

And some of them are going to be really easy, David but how do we update the plan if we don't look at all of them? And I think some of them we can look at and say okay we were overly ambitious but we are on track, like Walter said. So we are going to keep this one going. But then we may look at another and go you know we really were asking the wrong question. So to really be able to dig into this and to do an update that is required by Congress, I think we have been existence how many years now with both IACCs, it is time versus just each year giving the updates for that particular year. We need to really look at this and see if it is the right document.

Dr. Mandell: So given other things that

were on that list and certainly on the Services Committee, we have really decided as a Group that we want to be very committed to the issue of research and services and policy that affects adults with autism.

So given the other things that are on that list, what should the process be for that kind of update that will allow us to have a meaningful update but still set aside time that would allow us to address those issues that we, as a Subcommittee, think are really important.

Ms. Redwood: Could the people who were on

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Dr. Insel: That is why Susan has said that what we need to do is set some priorities here because we can't do everything. And we have to figure out in the time we have left how we want to spend that time and what we want to use our resources for. And that is really up to the whole Committee to figure this out.

I'm sorry, Lyn. I didn't mean to interrupt.

Ms. Redwood: No, I was just going to recommend that we have already established these Groups that updated the plan that was required as part of the Combating Autism Act. So those people are already somewhat intimately familiar with the objectives and the research. So but if those same core people were tasked with looking at each of those questions because 78 sounds like a lot. But when you break it down into seven, it is only maybe ten and some of those could come off really fairly easily and have that be sort of the update process for this year. Then we take that information at the beginning of next year and then go through the whole plan in terms of this one is done, this one is done, this one is done. I am just throwing that out as a possible solution.

Dr. Insel: I thought that is what I was recommending because we can go back to the

Group, we probably will add to the Group with some additional people. It is seven Groups but if you are talking about virtual meetings and these are people who have already done this one time but only for a 12-month or 18-month period, if they could look at much broader time frame, it seems like it might not be a huge amount of work for them, particularly if you are taking people who are already expert in the area and they know what is being done.

Scott?

Mr. Robertson: So one thing to think about, and I think this might have been mentioned in a comment by David is that at least from my perspective what concerns me a little is there seems to be maybe two different things in terms of prioritizing for the Subcommittee on the Basic and Translational Research, that approach may not necessarily work as well for the other Subcommittee. And do we have to adopt uniform approach to both? Because it sounded like we

almost needed to do that and it concerns me because the Services and Research Committee is still trying to get - we already know that we haven't tackled those things. We have these review studies coming out saying like there is nothing major happening in terms of things on employment and stuff like that and we already know that.

I think if the Services and Research went and did the same thing that the Basic and Translational Research Subcommittee was going to do, I don't know how beneficial it would be. I think it would tell us the same thing that we already know now and that we don't really -

Dr. Insel: But it might be quick. It probably wouldn't be that much -

Mr. Robertson: Oh, it would be really quick.

Dr. Insel: In fact what we said last year when the Group started doing this is we couldn't understand why this would take more

than 15 minutes because there is just not a lot of literature there. And it is pretty obvious what you have to review. It is a little better now than it was a year ago. A little better but I am not sure that it has to become a 24 or a 36 hour project. It is something that probably could be knocked off if you have the right group of people together pretty quickly.

I think what happened last year was people wanted so much else, they wanted to do this project on adults. They wanted to do a number of things around employment and around coverage and all of that and we weren't taking that on. And so people were saying let's use the Strategic Plan update to get at those issues. And what we would like to do this year is say no, no, no, the Strategic Plan update is just an update. Look at the objectives. Look at the questions. Look at the portfolio analysis. What has been done? What hasn't been done? What do we know? What don't we know? And

those other issues, let's get on to those and not try to make the update part of that. That is kind of where we are doing here.

So for the Questions 5 and 6, it might be a relatively straightforward, relatively simple process, with the idea that your Subcommittee is going to be working on something that is quite different and needs a lot more attention.

Denise?

Dr. Dougherty: Yes, my original question was how many resources are available and how much time and other resources do we have. But I am really thinking about the Services Research and Policy Subcommittee because when we first did our process last year, we have a lot of experts. We got together a wonderful new Strategic Plan because we said the heck with the old Strategic Plan because that wasn't a Research Strategic Plan. And really I think we still have the documents.

And so if you give us permission to like

say the heck with that old Strategic Plan, let's not even go back because that wasn't a Research Strategic Plan. It was kind of a mishmash of stuff. And so I think we are in a different situation where we are trying to maybe look at objectives that nobody really cares about.

Dr. Insel: So you know what you could do? So we have to do an update. That is required by law. And it has to be done by December. And we can't have two different flavors of updates. We have got to do one update.

So but you could do this relatively quickly, I think. It is clear, I'm not sure that Susan intended it this way but I think these are probably listed in priority order or something like that. I mean, it is clear that there is a whole other agenda that your Subcommittee is going to have to get engaged on which can be a lot of work.

So for you the Strategic Plan update, especially if these are objectives that you

are not particularly enthusiastic about anyway, maybe a relatively brief process but we do have to get that done. It has to be done by December and what we would probably do is engage a smaller group than what we did last year. We had an army of 100 or so involved. I think you are talking about 600 of 700 people. Look at this, look at the objectives, figure out what has been done.

In this case, you will have the portfolio analysis. We already know there is not actually very much investment in this area so you can answer the questions fairly quickly and then get on to some of these other things, which I think everybody feels are much more substantive for services and research or for the services piece of this and the policy part.

Geri?

Dr. Dawson: I mean I think the good news is that we actually did do this before and it worked quite effectively. And so if you think

about it, it is just a longer look back now in the same kind of process. I think it will be very informative.

One idea in terms of the individual objectives, rather than thinking about 78 objectives that you are looking back on would be for each question to ask the Group to say are there any objectives that have been accomplished and list those. Are there any objectives on which very little progress has been made? And list those. Are there any objectives that this Group uses very high priority moving forward? And are there objectives that are considered low priority moving forward?

So at least you would have sort of a sense of something related to the objectives itself but it really has to do more with this prioritization process that Allison has mentioned and also being able to check off, okay we actually did this one.

Dr. Ball: I think that is a great idea. I

would just like to see it go a little further on the ones that we know we have completed. Take it to the next level and really look at how did that impact the quality of life of individuals and their families on the spectrum. Because I think at that point we would have measurable ones that we have completed but how did the rubber hit the road? How was the impact felt by our families and our individuals?

Dr. Insel: Yes that I think was the reason for doing more than what we did last time, which was, so this time including within the qualitative. Because I don't think we will have real data about that but we can get a qualitative read on this if we include providers, consumers, have a somewhat broader group on each of these questions. And it would be question-based, so we would have seven such Groups.

Susan, you had a comment about this.

Dr. Daniels: I had a comment about

defining completion. And I think there are a couple of different - at least two levels of that that you can think about with the Strategic Plan because most of the objectives are written such that they say we will support projects on X, Y, or Z by a certain date.

So you can say the projects were supported but does that - but I think that you all are also talking about did the science get done and those are really different questions. So you might have to have a level of checking off whether the projects got funded and then the next level is did the science get done. And then the next level is, was there an impact. That would be minimum three levels but that is three levels of analysis. So that would take a little bit of time, depending on how you arrange yourselves.

Dr. Insel: But I think what I am hearing, Susan, is that people want to use the portfolio analysis to answer the first question. Did the science get funded? And you

could have a green light, yellow light, red light, as we have done in the past.

Dr. Carey: We do have it.

Dr. Daniels: We have that.

Dr. Insel: So we could do that.

Dr. Carey: It is year by year but I mean we have something like that. And if the 2012 version comes out this year, we will be up to date. So we will have three levels.

I think that is what the discussion was. We have got that level. We were asking let's take another level no top of it. Right? That is kind of where we were last year, last session.

Dr. Insel: And I think what we are trying to convey is the best we will be able to do with that is a kind of qualitative assessment, if we have the right people taking a look at this.

What we are hung up on right now is we don't have the 2012 data yet. And just in terms of our timeline, as much as it would be

great to charge ahead with this in May, it sounds like we won't actually have the NIH data until -

Dr. Daniels: Actually, I have not checked the RCDC website but I thought the data was going to be released soon. Is it released?

Dr. Insel: It is not out.

Dr. Daniels: No, so NIH has not even released their 2012 data yet.

Dr. Insel: It is supposed to be mid-April.

Dr. Daniels: So that is obviously a huge part of the portfolio and that would be holding us back. We have received data back from a lot of the funders. There are a few funders who still haven't returned their data to us so we are waiting for those. But I mean we are not sitting around waiting. We are analyzing what we have or verifying what we have but the NIH piece is the biggest outlier.

Dr. Insel: So realistically though, I mean because you would want the portfolio

analysis in your hand to start this process. So that gives you the first part about what was funded. Because if nothing was funded in the area, it is probably not likely that the science has gotten done, although maybe.

Dr. Daniels: So you have got 3 years of data, though to look at already. So you could look at the first 3 years while you are waiting for the next 2 years.

Dr. Insel: That is possible. I am just thinking about how to schedule this. The final report is due in December. Last year I think we started in September, something like that. Should we think about launching the effort in July and then using July to October to have the meetings mostly phone by that time we should have the portfolio analysis for at least everything up to 2012.

Dr. Daniels: And you will have the Combating Autism Act Report if that is useful to you at all for this exercise.

Dr. Insel: Right. Okay.

So at least the information about what is funded would be in our hands by then. We could begin putting the Groups together even in the next couple of months, thinking about who should serve.

And to go back to Lyn's suggestion it makes all kinds of sense to at least go back to the people who helped us last year because they are very familiar with the issues. And that worked pretty well.

I think we just want to expand each of those Groups except on the services side, where we may want to contract about 80 percent because that wasn't helpful to have 70 people on the phone at the same time.

So we could probably do this so I would think over the next couple of months we could come up with what the Groups might look like and we will need your recommendations about who else to include. But again, I am going to rely heavily on the IACC itself because there is so much experience right here.

Okay, so anything else on that first piece? Because the other piece is the *DSM* and I think it is useful to hear about what is going on with that.

Dr. Dawson: So do you mind if before we do that, I would like to know did we ever hear anything back from the Secretary regarding the letter that was sent.

Dr. Daniels: On the coverage letter?

Dr. Dawson: Yes.

Dr. Daniels: No. No, we haven't received anything so far.

Dr. Insel: It did not come back unopened, no.

Dr. Daniels: Certainly the Committee would find out about it very quickly. If you received a response, I would send it out to the Committee. I have not received anything thus far.

Dr. Dawson: I think that was the expectation on one of our calls but that this is nothing the secretary can really do

anything about, the essential health benefits package. The Secretary of HHS has said what is going to say about essential health benefits packages. It is really up to the states.

But there were people on the Committee, and Idil is nodding, that felt that having that letter would be useful to them in going to their states who are - the states and the components thereof who are responsible for setting up the essential benefits package.

Ms. Crandy: And I can say that I already entered that letter into testimony. We are trying to increase coverage in our bill for coverage for autism to add on to the mandate. And we used the letter already. So I appreciate the letter.

I do hope that the Secretary will issue a directive, though, that advises states to include the mandate and expand the coverage in a level of intensity that is research-based for dosage.

Ms. Abdull: So you are right, Denise,

that that letter was mostly for people here or around the country to use it for states. So we also did use it for State of Minnesota. And the reason I think it is better for states is because states also fund the Medicaid portion.

And so as someone who always advocates for people who are on Medicaid, what we have been saying to the governor is that if you are going to dictate an order a private company you don't even own to pay for services, you better be willing to pay for it for the children that you are responsible for.

And I think that has worked well so far. So in Minnesota we might get this year signed by the governor a public coverage for an intervention and a private coverage at the same time because that should be the goal that we don't want to create two-tier system. So I think the letter while we didn't get a response, it is working well.

Dr. Insel: Well you were amazingly helpful. It was incredible to learn about this

process from you, things that we didn't know from our Federal partners. So this has really been an interesting process for those of us who were involved.

Let me ask the Group about the *DSM-5* Planning Group. What is going on with that and what can we, as a Committee expect?

Dr. Dawson: Sure. So the *DSM-5* Group, first of all, is I am chairing it and the members are Coleen Boyle, Laura Kavanagh, John O'Brien, Scott Robertson, and John Robison, and Larry Wexler.

So the broad issue is how is the *DSM* going to impact both access to services and also prevalence estimates? Those are the two, I think, biggest questions that people have in their mind and that we hear from the community our concerns. And from that, there are other more detailed questions about how could we track changes and how diagnostic systems are used. And how can we track the impact? How will social communication disorder be

operationalized? How will clinicians and how should clinicians use that information in terms of making decisions about treatment recommendations? How will insurance companies interpret a social communication disorder in terms of access to early intervention?

So there are many real life impacts as well as scientific impacts in terms of monitoring prevalence of autism over time that we want to consider and then perhaps make recommendations on. Some of those might be research recommendations. Some of those might be policy recommendations. But in any case, want to kind of sort those through and then come back to the Committee with some ideas and get your input and we will go from there.

Dr. Insel: Okay and so you are meeting this week and we will hear from the Subcommittee at the next IACC meeting.

All right, Scott?

Mr. Robertson: So one thing related to the *DSM-5* Planning Group is at least a few of

the people were not able to make that meeting. And, what I wondered is, is there any mechanism for input? If that is a one-time only if that call is going to be the only - are there going to be multiple phone calls for that?

Because I was going to say if it was only a one-time thing, I would be happy to also send in, for instance, there is some briefs that ASAN wrote on *DSM-5* stuff. So I would be happy to send those along if that can help inform some of the discussion on that. Because it is a tap that we feel -

And if it was like any other time like I would be like happy but I have like another council that I am on that is like meeting at the same time and I kind of have to be there. I can't miss that other meeting.

And the other and I wanted to say this before but I just didn't feel like I had an easy spot to work in as much as my main worry and maybe the other things like the roadmap

and stuff like that account for that is that I do worry since if the Strategic Plan on the adult side and the services side is continuously like for instance the update on accountability this year is continuously like well the things we want to have happen aren't happening but is it really proactive in saying these are the things that could come forward? And I know it does have to mesh so it is kind of consistency with the rest of the plan. But I do know on the other hand, too, that Congress and the Secretary, et cetera, take value in that Strategic Plan in terms of what is put forth there. And I do worry that if some of the things that are, some of the big picture issues for this get shelved only to things like the roadmap, is that going to be taken as equal weight by Congress, et cetera, when looking at these kinds of things and saying things like understanding services needs and the possibility of maybe getting needs assessments for autistic adults and

things like that put out there and done are things that could be put into the roadmap but what negative impact does it have by not being able to be put in the Strategic Plan at some point.

Because I feel like last year when I have brought up some kind of big picture kinds of things, I feel like they kind of got shelved away because of the justification was that we kind of had to hurry things because we had a shorter time frame with the 2012 plan and then I thought maybe with the 2013 that maybe there would be a little bit more space. And I guess I feel just a little bit disillusioned on some of these things. These are important and they are important to the many autistic adults out there who don't feel like there is enough coverage and enough emphasis on strategic priorities on some of these areas that autistic adults are getting missed out on.

Dr. Insel: Well this is such an important point and we have come back to it a couple of

times but I want to make sure that we should be really clear as a group that the Strategic Plan is one of the many things that we do. I am not sure that people on the outside would say it is the only way to have an impact. In fact, arguably, it is not the best way to have an impact.

And so I think it is really up to us to find other mechanisms that become much more visible and have a higher priority both within the Committee and outside. And I think the idea of developing a services roadmap or having effort specifically around adults, if we do it right, could have a much greater impact than putting another objective, a 79th objective into the Strategic Plan.

Mr. Robertson: Can it actually go to Congress in terms of can they be able to see it?

Dr. Insel: If you think that would have an impact. I'm afraid that it probably wouldn't. I am not sure that that is the way

to really make something happen. The way to making something happen is what we were talking about before is to get practitioners to the extent possible to change policies. Arguably, this letter to the Secretary that we just did is the kind of thing that does really have a much greater impact than we developed even through our Strategic Plan objectives. And so I think we have got some models that we have done.

The whole business about wandering is a great example where that was never actually through the Strategic Plan. It was changing a policy very quickly in a very focused way and then ending up with a code that allows us actually they didn't ask questions about coverage, about accountability, getting the prevalence, all of that. So it is extremely helpful. So it is being strategic and not necessarily through a Strategic Plan but figuring out where you can actually move the dials here.

There was another hand that went up over here. I think it was John.

Mr. Robison: No, I just was waiting actually for the adult services.

Dr. Insel: Yes, so let's move to that because I think we are done, unless there is anything else from the other Subcommittee. We are ready to talk about any part of this.

Mr. Robison: I am just very concerned that we continue to really to be child-focused in all of the talk and the research and such.

And I understand that indeed this is a condition that is identified in childhood when kids are growing up. I know that but I guess I feel like one of our duties is to spread awareness. And one of the bits of awareness that I think we have come to largely agree on in the last couple of years is the notion that for every child there is out there that is diagnosed, there are two or three undiagnosed adults. And we need to be talking about that more. And I guess I am concerned that outside

of this letter, which is a fine idea, we need to somehow all work together to get that knowledge into the public consciousness.

Dr. Insel: When it says adult services roadmap, talk to us, to the Committee. What did the people on the Subcommittee imagine? How would that work? What would it look like? How could it have an impact?

Dr. Mandell: Sure. So I think that it is a catchy phrase, this idea of roadmap. And I don't think that we have had the opportunity to put as much thought into what it means as we need to.

I think that there are at least three parts of it. I think there is the issue of fiscal mapping. That is, how do various agencies at various levels make funds available for care for adults with autism. I think there is the idea of the service mapping - that is how are these services organized and delivered. And once that groundwork is laid, I think there is probably the most important

part is what tools do we give to adults with autism and the people who care for them and support them to begin to access those services.

I think often these roadmaps tend to be very vague documents with sort of worn phrases about the need for services to be organized in a certain way or to adhere to certain principles. And I think that we were conceptualizing something that was much more functional that people could use.

Mr. Robison: I think I was a little slow-witted when you asked for this before. I have a specific idea about a roadmap. I started to elaborate on it last meeting. I think that we need a group within NIH as representatives of the government that can somehow issue an implementer of legitimacy or conformance to standards when new therapies are developed and validation studies are done. We need to be able to assert in a relatively expedient manner that they were done in a way that we

agree is workmanlike and proper.

And I think then that what we need to move towards is a cooperative model between the NIH, CDC, Simons and Autism Speaks, where we evaluate all of this research with respect to its probable efficacy with children and adults alike. We determine how these different therapies are going to be used, just as we have a set of guidelines to determine which is the appropriate antibiotic for a urinary tract infection and which is appropriate for a sore throat. We need to be able to give clinicians prescription guidelines for therapy.

Once we have done that, we need to look - as a government group, we need to look outside possible to Autism Speaks lobbying affiliate to take up the case to go and argue this in every state in the country, as we have now learned the hard way is necessary. And that needs to be backed up by both public and private funding to, first of all, do validation studies because nobody thinks that

is sexy and they want to do original research. And then, we need to be doing the training of clinicians. And only with that combined with a successful lobbying effort to get this into the scope of insurance coverage, only with that done are we going to succeed in delivering benefit to the population, adult and child alike.

And I think when we talk about a roadmap, that is the roadmap in my mind. That is the path to delivering powerful positive benefit. And I think each of those organizations who are already the leaders, each one has a role.

Ms. Singer: So the idea of the roadmap came up, I think, the last few years as we were working on the services section of the Research Strategic Plan. And it came up because over and over we recognized that we needed to understand best practices in service delivery, as well as in services research but that there needed to be a place for those best practices in delivery to live.

So this was with regard to housing and employment and social skills for adults in the workplace and things like that.

So we talked about creating a parallel document that would be similar to the Strategic Plan but where the Strategic Plan focused on services research, this would focus on service delivery.

And we, in the first IACC, there was a services roadmap that tried to lay out best practices but the problem with that was it was not at all functional and really not at all grounded in reality. And it was sort of this wish list of everything that we could think of that would be great. And as a result, it was described by the General Accounting Office as one of the worst documents produced by a government agency.

So you know we have to really, when we are working on this document, I think it is really imperative that we be realistic with regard to outlining priorities, given that

there is a difficult fiscal climate and that many states are on the verge of bankruptcy. But really outlining what are the priorities and what are the best practices for delivering services in a way that provides real value to real people.

Dr. Ball: Yes, and to follow up on Allison, I totally agree and it also has to take into account I think already established quality of life indicators for individuals. Because as we look at those, that is the research end that we do as an Interagency Committee in looking at how does this impact those people. So those quality of life indicators actually then hit all the different areas.

Mr. Robertson: One thing related somewhat to what John had mentioned, he was talking about you know establishing kind of guidelines on therapy but the one thing I should emphasize is that like say you look on the adult side. Adults in many cases it is not

like they want therapy. They want jobs. They want to be able to live in the housing in the way they want. They want to be empowered by their families but be able to have some direction what they want in their lives as adults as well. They want access to things like healthcare services. They want those healthcare services to understand autistic adults. I mean, so I think that that is one of the things that has to be kept in mind is that while there is commonalities to some of the things that are thought of for research for instance on kids, when you shade into adult life, some of the priorities are a little bit different in terms of even how society thinks of.

You know, it's not just an autism-specific thing. When we think of kids, it is a completely different thing in terms of how protect to them, et cetera. But when we look at adults, we have a completely set of different things that we consider and as we

get older and into the life span. And I think that is something that should be taken into consideration and that shades back into the quality of life.

Because when you - I did a conceptual paper that was published in Disability Studies Quarterly a couple of years ago on quality of life and autistic adults. And I used the framework in there that was from the broader IDDD and it does look at things like employment. It look at things like employment. It looks like things like healthcare services. It has about eight or nine areas in terms of education, employment, physical well-being, mental well-being. I mean, it looks at those kinds of areas. So if you are going to look at quality of life, I would say, look at some of those kinds of things that shade into there. I know people don't always - they think, oh, employment is something separate. Well, these things all connect around, you know.

Dr. Ball: But I don't' think they are

mutually exclusive.

Mr. Robertson: Yes.

Dr. Ball: I think, when it comes to the child and the adult, is housing going to be a little different? Yes, but it is still housing. Is it opportunities to recreate? Yes, but it is going to be different, depending on where the child is or the individual is on the lifespan.

So there are commonalities to it you are just looking at it at different age ranges. So that is the best way to qualify exactly whether or not the impact has had significant benefit to a family.

Dr. Insel: And most children with autism are going to be adults with autism. So there is every reason to push forward with this sooner rather than later.

Sally?

Dr. Burton-Hoyle: And the Center for Medicaid Services calls for each state when they develop their state plans to have person-

centered approaches. Person-centered approaches and self-determination are quite common and self-determination is mentioned in most state plans for adults.

So I guess I just want to support that adults want to have the same lives that everyone has. Their support needs are different. But when we take a person-centered approach, then they can have quality of life.

Dr. Insel: Geri?

Dr. Dawson: So I am trying to understand whether this roadmap is like a toolkit that parents or people with autism can use themselves. So we are saying it is a best practices kind of document where transition planning and whatever or is this a - this is where we stand now in the United States in terms of how people as adults with autism are doing. This is where we would like to be. What is the roadmap for getting there? So which kind of roadmap is it?

Dr. Mandell: I think it is the first. I

think trying to do the second is what got us into trouble. And I was one of the unfortunate contributors to that - I even have accompanying music as I talk about it - one of the unfortunate contributors to that first roadmap document in my youth.

I think that we can - I think it is two separate documents and I think to mix them is a problem. My understanding of the first part what we were talking about was really a practical document that families could use. I think we could talk about where we are in terms of adult services and where we want to be. I think it serves a very different purpose.

I think we can talk all we want about where we are and where we need to be. But in terms of immediate impact for families, I think the one that has the most effect is the one that individuals with autism and adults and people caring for them can pick up and say, here is what we know about treatment and

here is how you can access it. Here is what we know about vocational services and here is how you can access it.

Dr. Insel: So this is such an important conversation to have. I mean, the whole point of bringing this up here is fairly soon you guys are going to start on a big project that is going to take you probably a year to accomplish. And before you get too far into this, it is really helpful to have the guidance of everybody in the Committee. So we are all on the same page about what this is going to look like when it is finished. I had exactly the same question and I thought you were talking about number two, not number one. So it is helpful to know that you have got - yes, it is very Tom and Jerry, yes. But that is a different - I mean I am not sure I would call that a roadmap but it seems to me like it is sort of a tool kit or guidelines or something that is more around how to inform families and communities about what works,

what doesn't work, what is available, what should be.

Dr. Mandell: And maybe the Services Committee needs to - I mean this was brought up at the last meeting, I think, with seconds to go. And we have not had an opportunity to discuss this.

Dr. Insel: Is there a document like what Geri is talking about as the second option, where somebody says this is the level of employment, this is the level of education, this is the level of independent living. You know, going down each of those quality of life metrics and saying this is where we are in 2013 or '12 or '14 for the people with ASD. Do we have something like that somewhere?

Dr. Mandell: The closest, as far as I know is Paul Shattuck's studies using the PEELS data.

I think that is also an important question. As I said they are both really big projects and so I think that -

Dr. Insel: Just the chance for you to get some feedback from other people on the Committee. Idil?

Ms. Abdull: I was just going to say that because we didn't have a lot of time and I wouldn't say big project because we might scare David and Denise into driving this, but we wanted to do was practical. So how do we make - what do we tell the people that are now adults with autism? While the second one that Dr. Dawson is talking about is a good idea but the first one is a practical guideline for actual people who are on the spectrum that are across the spectrum.

So even what you said, Scott and what you said John, because maybe people that you know need employment right now, right? But then people on the other side there, people who before you get the appointment, you want to make sure that you have the skills and the therapy to be able to get a job.

So we wanted to get a practical guide and

then let the states use it. I mean if we have something like that, we can advocate locally state-wide and it is state legislators and say, well, how do we make sure not talking the talk but how do we walk the walk and help these people?

Dr. Insel: It's not what I thought this was. That's great. Jan?

Ms. Crandy: And my concern was when we brought this up in our Committee, some states have started to do this. Ohio has several documents. I don't want us to spend a lot of time redoing something that somebody has already done great. It seems like we could pull that information in if we want it to have or the Committee could endorse something that is already done. I know even when we are talking about toolkits, the 100-day toolkit that autism speaks does for the younger kids is amazing. Why can't we just endorse something like that instead of trying to re-invent the wheel and do it again.

Dr. Insel: Let me ask for those of you who are not on the Services Subcommittee, is there anything you want them to think about with respect to what this could look like? This is the chance to give them some feedback.

Noah, you are not on the Committee? I thought you were, but go ahead. You may be drafted after this comment.

Mr. Britton: I'm on the Science Committee. I don't know the new terminology. But yes, that is the one I'm on, not the Services one.

It sounds like what you are proposing is on the Autism NOW website, which is probably in need of improvement but it does sound like that has been done already. And I just hope that you look at that when you are designing this.

And Jan is right. Other places have tried and I think, as unusual, when people try to come up with the final solution, they just add one more solution into a huge pile of things

and no one really knows what is going to work. But I do think this is a good idea. I just am skeptical that it will actually make a difference.

Dr. Insel: Scott, did you have your hand up?

Mr. Robertson: If you need to get more comments first from anybody not on the - because I am on the Services Committee.

Dr. Insel: I don't see a lot of hands going up, so go ahead.

Mr. Robertson: Okay, so just one thing related to that, so there was those two things you kind of teased out in terms of what the documents could possible look like of this toolkit or roadmap or whatever it is called. I am just going to say on record that I don't think that we could even come close to answering the question of where do things completely stand by now just by looking at scattered bits, amounts of research.

And this is why, and I do hope to - and I

don't mean to beat a dead horse on this, but the needs assessments for autistic adults. England has done this over the last 4 years. They actually passed a law that required them across the country and they did it very thoroughly. So England knows exactly where a lot of the gaps lie in specific areas of their country.

Here in the states I guess we could look at what has been done on the research end in terms of what publications exist, unemployment, et cetera, et cetera. But until finding out what things actually look like in terms of the state of the existence and support needs, until there is actual assessments out there to look and survey and/or interview, say, hundreds or thousands of autistic adults across the United States, we are not going to have a complete picture in the way that would be most desirable. And I don't think you get to the same spot by looking at some studies that were published on

individual's use of mental health services or whatever systematically for looking at mental health records. I mean, I think you really have to look at the horse's mouth eventually - go to the horse's mouth eventually and be surveying autistic adults themselves to find out where the gaps lie across the country. And that hasn't happened.

Dr. Boyle: So just to bring us back to our discussion very earlier this morning when somebody asked Stephen Blumberg what kind of data is collected by the National Center for Health Statistics and he mentioned the National Health Interview Survey, which is being enriched to be able to evaluate the impact of the Affordable Care Act at the state and larger municipality level. I know they asked about autism. They may not ask about autism among adults, but that might be something that obviously this Committee could make a recommendation towards.

And again, thinking for the future and

thinking about all the rich data that is involved with the National Health Interview Survey and the fact that they are including questions about impact, around the ACA and access to services, I think it would be a great thing to try to help guide them in that direction.

Dr. Dawson: So I just wanted to mention that we do have a few projects that I think are in their second or third year. So they should be coming to fruition. One is in Canada and all of these do involve both a combination of services. So it is to sort of do a landscape analysis of services and employment but also with qualitative interviews around quality of life and all in the adult area. Most of these start in late adolescence. And one of the things that I would suggest is you think about the toolkit is to keep that developmental perspective because everything we know about success and whether it is whoever it has to do with setting the stage

early on for healthcare and things like prevention of obesity and all of that, having that sort of developmental perspective I think is really important, at least starting in adolescence and transition planning and things like that because we know those transitions are so sensitive.

But yes, I think we are going to see more of this work in the next year or two. We could even have - I could check with them and try to get some of that data.

Dr. Insel: So just to summarize what I am hearing, a real interest in something that may be an adult services toolkit or some description of what is available. What you are talking about is something that is very practical that could have an impact for families and communities and would provide enough grain size that people will actually be able to pick it up and run with it.

We haven't talked at all about the next bullet, the Health Disparities Project. I am

thinking about the amount of work involved in every one of these. And yet I think when we discussed that before, there was a real sense that that was very important as well. Is that something we should put on the back burner for now or how to deal with that? Because I guess the question would be: who is actually going to do that?

Well, if this Subcommittee is taking on a services project like this, is there - how does that get done?

John?

Mr. Robison: Well, I guess I just would ask the question that while I agree with a lot of these other ideas in the roadmap and I heard from Scott the idea that some of this stuff is therapy, some of it may be legislation and accommodation, I still think that we have this huge fundamental barrier of having to have both a pool of trained clinicians and a pool of validated studies and then we have to embark on that lobbying

effort. And I feel like unless we make that a very vocal priority, I don't see how we are going to deliver success to the people. And I guess I didn't hear any response to that.

Dr. Insel: So there is a response and I didn't share it with you. But we have another project underway unrelated to autism specifically, because the issues you bring up are actually true across the board for psychosocial interventions. There is no FDA. There is no regulatory pathway. There actually are no standards laid out for what we mean when we say evidence-based.

So the Institute of Medicine has agreed to take this on as a project and we just haven't found people to pay for the project but we are in the process of doing that and the hope is that we would be able to launch that fairly soon. And it is about a year-long effort to do this but what will come out of that, we are still tweaking the final language on the charge, it is almost precisely what you

said before, John. It would be coming up with a way of saying this is what the science actually tells us. This is what we mean by valid science. These are the standards that you need to meet in order to say this is worth paying for. This is worth implementing. You don't have anything like that today and part of the confusion that you hear about in this era when we are supposed to have parity for behavioral health or mental health is that people are saying but there is no parity for the quality of science. We actually know when somebody tells us that this particular drug is effective, we know what that means. But when you tell us that equestrian therapy is helpful for you name it, autism, what does that mean? What is the evidence? And what do you accept as evidence in this case? And how many people have replicated that? And what does the replication look like? And how well-designed were the studies?

I mean, this is sort of extraordinary to

hear earlier today about a study that was being done for language and it was one of the very first adaptive designs ever used in autism. I mean, this is - the field is so far behind here. And yet that is exactly what we are doing in cancer. It is exactly what we are trying to do in the rest of medicine. We have a long way to go in terms of quality of work to be able to say that these inventions are useful or not.

So I am not sure the IACC has to do that but the Institute of Medicine will help us, I think, in getting out at least some language and some basic standards of what can be expected for behavioral interventions or for anything in the psychosocial domain. We hoped that it would have already been launched but we have been held up with getting the necessary funding. If you know of anybody who has \$500,000 they want to spend on an IOM study, let me know and we will sign them up because it is expensive but I think it is so

important to do.

Anshu, do you have - I have a place you can sign right here. You're on.

Dr. Batra: I'm on West Coast time, so I actually had a question regarding the roadmap to Geri. So Autism Speaks has a transition roadmap, right, a transition toolkit just like several other toolkits?

Dr. Dawson: Yes.

Dr. Batra: How is that different from what we are proposing here? And I looked at the Autism NOW website and it is fantastic in terms of all the resources for vocation and housing and all the multitude of other things.

Geri, can you comment on that, the ASD Transition Toolkit?

Dr. Dawson: Right. And so with an Employment Toolkit and there are other toolkits, because adults is a big area of emphasis right now, that are underway and are going to be rolled out. And it does make one wonder, especially when ASAN has great

toolkits and you have got the Autism NOW website. You know, really start by looking at what is out there. Right? And the idea of kind of bringing things together where if you are - and then maybe you will find this is what is missing is these few pieces.

Dr. Insel: I mean, Noah is right. This has already been done, largely.

Dr. Batra: And I think it may just need to be integrated and synthesized into one maybe IACC document so that we have one more thing that we can check off. But I mean, I think that that, I just I feel like a lot of us just in practice I feel like I have already sort of accessed it for myself and my patients.

Dr. Insel: I think we do want to make sure that as we look at what is out there that we look at it with some skepticism and we make sure that what people are recommending does have a scientific basis for one of - again, when we are talking about our core values, one

of them was scientific excellence. And one of the things the IACC can do is to set a very high bar for anything that we recommend. And we have tried to do that up until now.

So I am not sure that other organizations are under those sorts of constraints but it is something that could help to guide this process.

Jose?

Dr. Cordero: I would like to come back to the Health Disparities Project and I think it is a case of calling a spade a spade. What we have been discussing all day long, including many of the presentations that we have from public comments, really point out the disparities that exist in terms of the autism community. From even the letter we sent to the Secretary, it is pointing out the disparity that there is in terms of health coverage for persons with autism.

I think that this is something that maybe doesn't have to be a separate project but as

we look at the call it roadmap or what the key project is in service, we need to really point out that we have major disparities in terms of from access to care, from even how much is devoted to research for autism say compared to cancer but also it is how these disparities are even more pronounced in different groups and that is just another aspect.

But I think that we need to start from recognizing that the autism community as a whole, we have major disparities that we need to acknowledge.

Dr. Insel: So I wanted to follow up on that comment and maybe with our co-chairs here to ask whether in the process of doing this toolkit or whatever we end up calling it, can the disparities issue be integrated in at every level so that you are looking at what may be available for communities in need, where are there particular tools that have been developed for particular communities. I wonder whether you really need to do that as a

separate project or whether it will be the most useful to have it integrated from the get go as you think about what kinds of services are out there.

Again, this is in the flavor of giving you feedback from people who are not going to be doing the work but it does seem to me that it would be a shame to start on this without having some focus on that question since that is a question that keeps coming up. I think Idil is going to bring it up again, probably.

Dr. Dougherty: Yes, I mean I think that makes sense except that when you brought up - my point before was going to be the evidence base for adult services is not going to be high. And I think the breakouts for disparities is going to be even less. So I think by doing the roadmap we get to the letter to the Secretary regarding adult services and research, what needs to happen.

Dr. Cordero: So, if I may, that is exactly part of the point of the disparities,

the fact that we don't have enough evidence out there means the research hasn't been done, focus on that group hasn't been done. Just like you can even argue, think about children in terms of how drugs are tested and they are not included, children and pregnant women are not included in terms of testing. Here, just another example. I think that we shouldn't take the fact that there is no evidence as saying well then we can talk about that. It is actually a point to talk even more about it and what should be the direction should be taken in that area.

Dr. Insel: I guess what I am trying to get at is this is a lot of stuff to do and in terms of setting up priority, would it make sense? The bottom one has to be done. It has to be done by December and we don't have any choice on that.

The others, as Denise was just saying, it may be that you want one of the outcomes to be a letter to the Secretary after the Group has

done the heavy lifting of putting together a plan. I am still wondering whether that plan, even if the data aren't there, should in some way reflect on the disparities issue at the same time, rather than thinking about that as an altogether separate project.

Idil?

Ms. Abdull: I was just going to say that because we hear - disparities, there are two, right? So there is autism disparity compared to cancer or diabetes or all the other conditions. And then there is the racial and ethnic disparities, and that is the one I am very much interested in.

And with that one, we always, everywhere I see, everything I see they will say there is racial and ethnic disparities is high. Black and Latino kids get diagnosed late. They get less services. And then people look at it and then it becomes as normal as Minnesota snow, if you live there. What we wanted to do is concentrate in a way so that we don't just say

racial and ethnic disparities exist because we know it exists. We don't need to ask Jack and Jill that.

What we want it to say is: how do we get there so we can eradicate disparity? Is it the class guidelines? Is it training? I think I was asking you, Dr. Mandell of the U.N., do we need to train therapists that are culturally and linguistically appropriate or do we need to train professionals of color? Do we need to make sure that pediatricians are asking the right questions? So we wanted to concentrate not just does it exist but how do we eradicate that?

And then also go talk about in terms of the payment because it is all about money. At the end of the day it is if the services are only good on paper, then it is worthless. We have to make sure that most low income people, we know this proportionately not most but low income children and adults with autism are disproportionately minorities. And so when we

always are going in and we are saying we want to make sure private covers this and private covers that, we ought to be talking to CMS, whether it is adults or children, and saying that how do we make the best practices that we are covering for people across the spectrum and across the life span through CMS. And maybe that is changing the EPSDT guidelines and adding autism services but we wanted to concentrate and not just in a way that tells us this disparity exists but how do we eradicate it either nationally and state by state. Did I sum that up?

Dr. Mandell: That was good, but it again speaks to the audience and the question Geri and Tom both brought up that seems to be wavering. If we are talking about ethnicity and race and ameliorating those disparities, then the right target audience are the people who are in power to do that.

If we are talking about a toolkit for adults with autism and we want to specifically

address issues that may be challenging to traditionally underserved communities, then the issue is not race but place. And that is if we think that there are services ghettos, that there are places where people who are traditionally underserved tend to congregate and those places tend to be underserved and so that some of the disparity that we see has to do with where they live, then would want to make sure that any document that we came up with specifically targeted and addressed those issues in under-resourced settings.

But what I am hearing from the vacillation back and forth and from the suggestion that maybe a lot of these documents really already exist, that perhaps the Services Subcommittee needs to regroup a little and to do some more research and decide whether the toolkit is the right strategy. If it already exists, why would we want to sully it by putting the IACC name on it. Right?

(Laughter.)

Dr. Mandell: But we can point to where it exists and give people credit. And if it doesn't, maybe that is what we tackle and write it in a way that it will be particularly meaningful to groups that are often discriminated against.

If the roadmap is really for at the agency and government level about helping adults with autism, then I think we can address the issues of disparities very directly in thinking about traditionally underserved groups.

Dr. Koroshetz: Well, the disparities issues is not an adult issue. I mean it doesn't seem to fit.

Dr. Insel: Right. So it is -

Dr. Mandell: But that is still like it is an issue that requires content. It is an issue that requires - we could do it as a separate issue but we could also, as Tom suggested, interweave it in with everything we do and everything we talk about.

Dr. Insel: But it does sound like there is some more homework for the Subcommittee to do. You may want to just put your heads together and figure out how you want to use your time, recognizing that everybody is busy and there is limited resources to get this done. And you won't be able to do everything as well as some of us might want. But you have got to figure out what you do want to accomplish.

Scott?

Mr. Robertson: So one point quickly first to the science-backed thing is it seems to be in conflict with the ability to suggest resources that if we then require they would have to be science-backed, because we already know that we don't have science-backed, because the research hasn't been done. You know, it is like a dog chasing its tail constantly kind of problem. It is a Catch-22 at times.

Then the other thing is like yes, these

things exist in segmented fashion, at times. It is just like service and supports for people with disabilities in adult life exist but in so many disparate places, it is not like there is one document that I can say in terms of a way forward for autistic adults in terms of recommendations. You know, one central thing that I could say, okay, this is the thing. You are newly diagnosed - for instance, newly diagnosed autistic adult. I mean, one of the things that John mentioned that is true is that a lot of adults to this day, I know lots of folks - in fact, there is an individual that I am helping out this individual and the individual's spouse that just received a diagnosis like a few weeks ago. And this individual is, I think, in their 20s or 30s maybe. And that is pretty commonplace among autistic adults. And it is like, what do you do then?

And it was like, if there was something out there that could help autistic adults,

working with their families to support things.

And I think we do have some resources out there on Autism NOW, ASAN has some things. I mean, there is so many other resources out there but it is so segmented that you can't really just point to one thing and say okay, this is what you do in terms of things on employment, things on some of these other areas. And maybe this could help maybe at least address some of it.

Dr. Insel: So I think it is going to require some more thorough discussion amongst the Subcommittee to decide how you want to develop this.

Donna, I think you had your hand up.

Dr. Kimbark: Yes, I just - maybe I lost the thread of the conversation. I might have, so you will have to excuse me. I wanted to go back a little bit to the health disparities and what we actually define as health disparities. I have heard a lot of ethnic and racial mentions about that but I would like to

go back to also including the underserved population.

If we talk about underserved, we might talk about access to care and demographics and if you can get to care and consistency of care as well. One of the things I want to point out that is well-published data is that for the military, one of the things is that we have, I mean, you get a really good cancer diagnosis and care because of the fact that the military families are routinely looked at for cancer, you know, screened for cancer. So they have a really good diagnosis and treatment care and facility.

The problem, though, still exists for families that have children or young adults that have an autism diagnosis, the question is: can they get to care? Yes, they might be able to get to care. They might be able to get the status of an exceptional person within that family but the question is: how consistent will their care be? Can they get to

the right treatment centers to get that care? And will they still have coverage, which is one of the things that I do know that the military is working towards.

So overall, and that is just a little small microcosm of what is happening in the general population. So I want to make sure that when we talk about health disparities, that we include minorities and underserved populations.

Dr. Insel: So just to finish up the conversation then, we are going to - as David leaves - we will make David and his colleagues go back to work on trying to figure out what amongst this list how to prioritize it, how to develop it.

But I think one of the things that hopefully they are hearing from us, those who are not on the Subcommittee, is that there is a lot available already. It may be that there are some shortcuts to provide the toolkit that they want but we want to make sure they do it

well.

Okay, that is most of the business that we had to do. Are there any other issues that people want to bring up, and I include Susan in that question, that we should be thinking about before we adjourn? Are there any announcements that people want to make about their agency or organization that they want to share with the rest of the Group?

Scott? Go ahead, Jim.

Dr. Ball: Just that our 47th annual conference is coming up for the Autism Society. It is going to be in Pittsburgh this year, the 11th, 12th and 13th. And for the first time, we have the ability to provide free attendance for all those with an autism spectrum disorder. So anybody with an autism spectrum disorder can come to the conference and register for free. July 11th, 12th, and 13th.

Dr. Insel: Terrific.

Mr. Robertson: That is most appreciated.

And I know you are not doing that - I know one of the reasons to do that often for the discounts is because of the fact at autistic adults don't always have full-time jobs, income is often a source of difficulty.

So one of the things that I wanted to mention for this particular month, it being April, is that ASAN launched this month four autism acceptance websites. We are trying to put out that going beyond just simple awareness that the population, that the general population has had an awareness of autism for some time now. I mean, most people on the street have heard the word, et cetera but don't necessarily accept and have a good deep understanding of the full issues surrounding autism among children and adults. And so there is blog posts, different events and things like that on the sites. And I think there might be other publications coming out.

There was one little mini kind of booklet kind of thing called straight on into morning.

It kind of goes off after the Neverland, Peter Pan thing, that's, how do you get to Neverland? That is a collection of essays and other articles by autistic adults, moving toward acceptance and understanding and understanding the resilience that autistic adults need to face in challenges.

And I think some of the articles maybe even hint at some of the adversity autistic adults have traditionally experienced in April, where it actually in many cases is felt is not the greatest time of year because it seems to be the time of year where sometimes the similar stereotypes and stigma kind of parades around even more strongly than you see the rest of the year. And you turn on the television and if you are lucky, maybe you see one or two stories about autistic adults where you see 400 on autistic children. And there is a big gap there on those.

So that is one of the reasons that we have the intentionality that the articles that

are coming out, all the resources are by autistic adults ourselves to help educate the public that these issues go through the lifespan and understanding what that means.

So I would highly recommend that folks visit the site at some time.

AutismAcceptanceMonth.com, I believe it is. I can send out the link over email if people would like to visit, take a look at some of the resources and posts and events that are going on throughout the month of April for autism acceptance month.

Dr. Insel: Thank you. Anshu?

Dr. Batra: I just wanted to publicly acknowledge the hardworking staff at OARC once again in all the time they have spent and the dedication and the hard work and the countless hours and midnight emails that we have been receiving to help us to facilitate what we need to do.

And I was thrilled to hear that Susan was able to -- is in the process of hiring more

help to help us with the task at hand.

And lastly, I was looking at the back page of the Strategic Plan and I still noticed that under Susan Daniels it says Acting Director, and I would like to inquire when that is going to become more - when that is going to be transitioned into the next step.

Thank you.

Dr. Insel: It won't be soon enough, I can tell you that. As I mentioned before, hiring is not one of the easier things under the sequester or it is not what the government is really good at these days. So we have a lot of people in acting positions, sometimes for years and years, but we are, hopefully, going to move some of that forward over the next few months when we finally get a budget, which may have finally by the end of this week, one hopes.

Noah?

Mr. Britton: Related to that, this is a very ignorant question, but have we been

extended beyond October?

Dr. Insel: We have the authorization that goes until the end of September 2014.

Mr. Britton: Okay.

Dr. Insel: So you are not off the hook this year but we have another year beyond that.

Mr. Britton: Okay.

Dr. Insel: But there is, at this point, no reauthorization, no extension beyond next October. The IACC will end when the authorization ends. It could be reauthorized and renewed. If it is reauthorized, there will be a whole new Committee put together, presumably. That is what was done last time and that takes surprisingly long, like everything else does these days.

So we will know more about that, I think, over the next year.

Geri?

Dr. Dawson: I just wanted mention briefly that on April 2nd, World Autism Awareness Day,

there was a series of events at the United Nations as there often has been for the last several years and extremely well-attended. Actually Idil was there and others on the Committee and David actually presented. I presented and ambassadors from different countries presented. But it really is truly amazing to sit in a room and see representatives from all over the world who are struggling trying to address issues related to autism. And one of the, I think, really heartening things to happen this year was a UN resolution that was passed, which is requiring every country to report annually on the progress that they are making in terms of both research and services.

So it is a step towards accountability and getting it on people's radar. But we could see the attendance and just the diversity of people from around the world and the Secretary General himself addressing the group about autism, it really did kind of remind us that

this is a global issue and that there is a lot of work to be done.

Dr. Insel: Jan?

Ms. Crandy: And Niagara Falls looked beautifully blue when they lit it up.

Dr. Insel: Other announcements, comments, questions? Susan.

Dr. Daniels: So I will be in touch with the various Subcommittees and Planning Groups about future meetings. We have several different projects that we are going to be working on so I will be in touch about that. And if any of you have particular feedback, suggestions, whatever, please feel free to contact us at OARC as always.

So thanks, everyone, for being here.

Dr. Insel: Yes, thank you. Thanks for those who joined us by webcast or phone. And for all of you in the room, both at the table and outside, it has been a long day but I think a lot of good stuff happened and still a lot of work to do.

So thank you. We are adjourned.

(Whereupon, at 5:08 p.m., the Committee
adjourned.)