U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

MONDAY, APRIL 11, 2011

The committee met in the Polaris Room of the Ronald Reagan Building and International Trade Center, 1300 Pennsylvania Avenue, N.W., Washington, D.C., at 9:00 a.m., Thomas Insel, M.D., Chair, presiding.

PARTICIPANTS:

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

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

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

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

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

PARTICIPANTS (continued):

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

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

GERALDINE DAWSON, Ph.D., Autism Speaks

LEE GROSSMAN

GAIL HOULE, Ph.D., U.S. Department of Education

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

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

JAMIE KENDALL, Administration for Children and Families (ACF) (representing Sharon Lewis)

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

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

CHRISTINE MCKEE, J.D.

PARTICIPANTS (continued):

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

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

DENISE RESNIK, Southwest Autism Research & Resource Center (SARRC) (attended by phone)

STEPHEN SHORE, Ed.D., Adelphi University and Autism Spectrum Consulting (attended by phone)

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

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

PETER VAN DYCK, M.D., M.P.H., Health Resources and Services Administration (HRSA)

TABLE OF CONTENTS

Call to Order and Opening Remarks

Update on New IACC Publications and the Combating Autism Act Report to Congress

The Combating Autism Act: HRSA's Investments

Update on the State of the States for People with ASD and Report on State Services of Individuals with Autism Spectrum Disorders in Nine States

Launch of the New AutismNOW Web Portal

PROCEEDINGS

9:03 a.m.

Dr. Insel: Okay. Good morning and thanks to all of you who have joined us from far away, either by phone or webcast or here in person.

We're getting a little bit of feedback on the mics, so let's see if we can fix that before we go further. Perhaps as we go along we can get the feedback controlled a little bit.

I'm delighted to be able to get all of us together today. It didn't look like this was going to happen late Friday, but fortunately cooler heads prevailed and by literally the eleventh hour we were kept from being furloughed this morning. So, good to have all of you here.

Okay. And in spite of being able to move forward this morning, as some of you may know, there was an accident on the Metro system here in Washington, so a number of people, including Susan Daniels, who is our Acting Executive Secretary of the Committee has been delayed, but I think some people will be coming in over the next few minutes.

We've got a number of things that we wanted to focus on this morning, and this being "Autism Awareness Month," thought this will be a good time to hear from some special guests who we've invited.

I wanted to take you through a quick rundown of recent research highlights, as we do every meeting at the very beginning, but I think this time, maybe we'll hold off on that until later in the morning because I don't want us to get behind schedule and I want to make sure there's adequate time to hear from our guests, and also some time for you to be able to talk with them, either through questions or comments.

So, I think, given the full agenda that we have and, my goodness, as I look at this, it's going to be a challenge to get through it all.

Why don't we go ahead and get started with their comments, and then what we'll do is go around the table when a few more of us have arrived through -- through either taxis or through the now-renewed Metro system, and have a chance to hear from the whole committee, and we'll do introductions at that point in about half an hour.

So, let me begin by introducing Michael Strautmanis, who is the Deputy Assistant to the President and Counselor for Strategic Engagement to the Senior Advisor of the Executive Office of the President.

So, though I think the President was otherwise engaged this morning, we're delighted, Mike, to have you come and represent the White House and the Administration. Thanks for being here.

Mr. Strautmanis: Thank you.

I just wanted to come by and make a few comments. The first thing I wanted to do was just come by so I could see everyone and say thank you. I've been following your work online and through the written word and I just am incredibly impressed with the work of this Committee.

And, Dr. Insel, you have really dedicated so much time, energy and effort to this. I just -- I appreciate it. So, that's a personal thank you from me to all of you.

I also want to say hello to the entire community on behalf of the President of the United States, the First Lady, Michelle Obama, Senior Advisor, Valerie Jarrett and the rest of our team.

If there's anything that we want to say to you all this morning, is that we see you -- we see us. I think, as many of you may know, I have a son who's now 14 years old who is on the autism spectrum. And I thought about that this morning as I thought about coming to address you. And many of you I first met when he was -- when he was just a little tyke running around.

And I think many of us -- I know I did -- felt invisible and we felt like we had to, in many ways, keep our son invisible. You know, he was such a challenge, such a handful. Out in public you always had to be prepared with a set of explanations, or create a set of boundaries for him to operate in.

But, you know, over the years I've realized, as this work has developed and as he's grown, I have two other children and many times I've had to make explanations for them in public. They are not on the autism spectrum.

My wife and I are setting boundaries for them. And I think you all have really taught me, the entire community, that the most important thing is for us to be seen and for us all to be visible.

It's such a difficult issue to try to put into a box, and I think the lesson is we should not be put in a box. There are parents like me, there are children, there are now -- there are adults. They are teenagers. There are expectant parents. There are new parents.

They are medical professionals, teachers, public service officials. People who have dedicated their lives to creating organizations, often fighting lonely battles, people who have created enormous institutions and have partners at the Federal, state and local level to try to deal with this reality.

And so, you know, we all see you and we're working -- we're going to work through this. We're going to make mistakes along the way. We're going to find new heroes. We are going to discover new things and I -- I am looking forward to continuing this march, this walk with you.

So, thank you all so much for your dedication, your work, and your sacrifices.

I have just a few more formal

things that I wanted to say. The first is that I want everyone to know that this Administration, the Obama Administration, will support reauthorizing the Combating Autism Act and continuing the work of the Interagency Autism Coordinating Committee.

I think we all recognize that there are things that need to change. We aren't the same organization. We aren't the same Government that we were when the Combating Autism Act was passed and when the IACC was created.

And so, true to my job, true to my title for strategic engagement, we want to work with you and hear from you in the process of deciding exactly what changes we're going to support and how we're going to move this work forward.

So, I'm looking forward to that process. I'm sure it's going to be -- knowing all of us, I'm sure it's going to be loud. I'm sure it's going to be a little bit messy, but it will be honest.

And I think, in working together, we may not, again, come out with the perfect bill. We may not come out with the perfect committee, but we'll come out with one that reflects and represents as best we can this community and these set of challenges.

I also want to speak not just to those on the autism spectrum who are dealing with issues around the autism spectrum, but to all people with disabilities, including those in the autism spectrum and their families.

The President is a staunch advocate of you and an advocate on your behalf. As you know, this Administration has expanded at a time when we've had to make very difficult cuts and very tough choices where we need to treat the taxpayer dollars so preciously.

We've expanded investments in autism research, detection and innovative treatments from early intervention for children and coordinated family services to improved support for adults.

And just last week for the first time -- although not for the last time -- the President issued a proclamation celebrating World Autism Awareness Day.

Our Department of Justice has been working hard to protect the rights of persons on the spectrum. The DOJ recently settled a lawsuit filed to enforce the Americans with Disabilities Act against Nobel Learning Communities, a private, for-profit entity that operates a nationwide network of more than 180 preschools, elementary schools and secondary schools in which DOJ alleged that the Nobel Learning Communities, Inc., violated Title 3 of the ADA by excluding from its programs children with disabilities, including some children with autism.

So, across this Administration and across this country, people are striving every day to improve the lives and future for those dealing with the autism spectrum disorders, and we're thrilled and pleased to have the IACC's valuable insights and contributions as a part of these efforts.

The work that you've done in developing your strategic plan is impressive and pushing us and pushing the Administration to -- for better results is your job and I commend you for it.

I also have been incredibly impressed with the amount of unity that I've seen through the -- within the autism community around Autism Awareness Month.

I think that the more that we can find common ground, the more that we can see each other -- in each other’s eyes, the more that we can get that same that reaction from people who aren't dealing so directly with these disorders.

I think finding that common ground in each other will allow others to help find that common ground between us. I think that's the way we're going to continue to move forward.

I'm impressed and pleased with the spirit in which this Committee has worked and, really, I'll talk less as an Administration official and more as a dad and just say, thank you for everything that you've done.

Thanks, Dr. Insel.

Dr. Insel: Thank you, Mike, and it's -- whenever I remember the moment when President Obama came to the NIH and he talked about his priorities for biomedical research and the three things he mentioned were cancer, heart disease, and autism, I thought maybe he was listening to you as well, and being able to keep that very much a focus for the Administration. So, thanks for all that you've done.

We'll have a chance for you to talk with and hear from the Committee. As I say, just in a few minutes we'll go around the table and do some introductions but, first, we would like to hear from Anand Parekh who is coming to us as the Deputy Assistant Secretary for Health in the Department of Health and Human Services.

And, Anand, thanks so much for being with us.

Dr. Parekh: Thanks, Tom. Thanks so much. I'm very happy to be here on behalf of Secretary Sebelius and be with all of you today.

Let me first start by thanking Tom for your dedication as Chair of this very important Committee, and also to thank all of you Committee Members.

This is an important way to serve our country and to serve the public, and you all have tremendous expertise.

And I want to thank Mike, because the support of the White House and the Administration is critical. The importance of raising awareness at that level is so critical and, as Mike said, the President's proclamation, really calling upon all Americans to learn more about autism and what they can do to support individuals with autism spectrum is critically, critically important.

I want to make just five points this morning, if you will. The first is, as you know, I want to acknowledge just the tremendous energy and activity around the department around autism spectrum.

You can look at the NIH with its $122 million of new autism research projects because of the Recovery Act, really helping us better understand, come up with new diagnostic screening tests, trying to understand the risk factors behind ASD, initiating new clinical trials to test early interventions is, as you all have called for, and also adapting many known treatments to older adults with autism spectrum.

There's fantastic work going on at AHRQ. As many of you know, just about seven or ten days ago AHRQ sponsored comparative effectiveness research. Findings were published which shed more light on medical and behavioral interventions for individuals with autism spectrum, and it calls for more research to determine what works for who and when.

You can look at CDC, or Centers for Disease Control and Prevention and HRSA who continue to promote their new developmental behavioral pediatrics curriculum, to educate the next generation of pediatricians so they can quickly identify individuals with autism spectrum and intervene early.

And you can look at CMS with Ellen Blackwell here, who just in the last several days, CMS releasing the report on state services to individuals with autism spectrum disease, really a snapshot of nine states, and Medicaid services and how they are providing services to individuals with ASD and the challenges they're facing.

So these are just a few of the agencies within the department. Other agencies, including the Administration on Children and Families or Office on Disability or Substance Abuse Mental Health Services Administration, and even outside of HHS, the Department of Education and others all doing terrific work, really supporting services across the life span.

The second point I want to make is, in conjunction to all of this excellent work going on across the Federal sector there is really essential coordination and leadership being provided by all of you and this Interagency Autism Coordinating Committee, as well as NIH's Office of Autism Research Coordination.

And there's no better way to look at that than just looking at this report to

Congress that all of you, the department and NIH just recently released which provides really a comprehensive overview of all the different efforts across the Federal Government, provides prevalence information on autism spectrum, provides expenditure data, provides best practices information and really summarizes the important coordinating role that all of you do.

And particularly I want to acknowledge your work with the *Summary of Advances in ASD Research*. I mean, this is a really critical point because, for members of the public, oftentimes, medical research is quite esoteric.

It's hard to really understand these studies and the ability of this document to really put in layman's terms really cutting-edge research is really, really important to the public.

And also your *Strategic Plan for ASD Research* is really a roadmap for NIH and many of our research agencies on where we need -- where we need to focus.

So, given all of this good work, as Mike says, the Administration, the department supports the reauthorization of the Combating Autism Act and the continuation of the Interagency Coordinating Council, the amount of research, surveillance, education, services that's ongoing right now, the work of all of you to coordinate is really pointing us in the right direction.

The third point I want to make is to express Secretary Sebelius' appreciation of your recommendations from your previous meeting. You all focus on a very important public health challenge related to autism and wandering, this is an area that we all agree we need better epidemiology.

We need to better understand how frequently this is happening, under what circumstances this is happening. We need better data to determine the subset, perhaps at highest risk, really to identify important preventive interventions.

And we applaud the formation of a safety subcommittee and we all want you to know the Secretary and the Department will give serious consideration to all the recommendations that you made at your last meeting, as well as acknowledge your goal of bringing to light other important quality of life issues, because we know quality of life is so important.

So, issues such as bullying or neglect and abuse or homelessness, issues like this that affect many people with autism spectrum disorders.

So, thank you for continuing to update the department on these important issues and bringing these issues up to light, and it's very important.

The fourth point I want to make is, as we mark National Autism Awareness Month, as the Secretary called for, we need to rededicate ourselves to addressing the challenges of ASD, whether that rededicating ourselves to pursuing multiple avenues of research, causation, prevention, treatment, NIH leading the Federal Government efforts, but also the private sector heavily involved.

We need to rededicate ourselves to educating a broad array of health professionals, not just clinicians. It really takes an interdisciplinary team of health care professionals to care for individuals with ASD and not just individuals who have the best training, but those who can show empathy, compassion and can -- can relate to individuals with autism spectrum disorders.

We need to rededicate ourselves to building on the promise of the Affordable Care Act. As you know, because of the Affordable Care Act now children with autism spectrum disorders can be -- or all individuals can now be screened for autism if they're in new health insurance plans without any kind of cost-sharing.

Children with autism spectrum disorders can remain on their parents' plans until age 26, so guaranteeing access to health insurance.

Autism spectrum disorder can no longer be considered a preexisting condition for children, and there could no longer be any annual or lifetime limit on benefits.

So these are all important elements of the Affordable Care Act that can -- that can help individuals with autism spectrum, but it's not good enough that it's just in the Affordable Care Act. We need to make sure that people realize these benefits and we need to get the word out.

We need to raise awareness. We need to make sure that families and parents and individuals with autism spectrum realize these benefits that have accrued from the Affordable Care Act.

And we need to rededicate ourselves to addressing quality of life issues beyond health, issues related to education, job training, and we need to continue to address issues across the life span.

For example, as individuals with autism spectrum get older, the more and more likely they will have additional chronic conditions.

Already half of Americans have chronic conditions. One quarter of Americans have multiple -- two -- two or more chronic conditions, so we need to better understand how the presence of additional conditions and comorbidities affect the management and treatment of ASD as well as vice versa.

So this area of ASD and comorbidities will be an important area of focus, moving forward.

And finally, let me just conclude by thanking the community and all of the stakeholders. Many of you are here today are sort of uncomfortable speaking to many people who are behind. We apologize for -- for the setup, but you all bring attention to so many critical issues related to autism, and you give voices to so many people around -- around the nation affected by ASD, as Mike said.

And I think, very importantly, you remind us why we've chosen to do what we do day in and day out, and that's to make a positive difference in the health and lives of our fellow Americans so that they can all realize the American dream.

So, thank you so much. It's an honor to be here, and thanks, Tom, for letting us provide a few comments.

Dr. Insel: Great. Well, it's great to have both of you here, and I think the important part of this dialogue, too, will be for you to hear a bit from the Committee.

What I was going to suggest is that we first just go around and do a round of introductions so our guests will know who is here, and then we can look back and have a chance for a little more discussion.

So, can I ask Henry to start?

Mr. Claypool: Sure. Henry Claypool, Office on Disability.

Ms. Redwood: Hi. Lyn Redwood from the Coalition of Safe Minds.

Dr. Lawler: Cindy Lawler, National Institute of Environmental Health Sciences.

Mr. Grossman: Lee Grossman, President and CEO of The Autism Society and also the dad of a 23-year-old son with autism.

Dr. Mamounas: Laura Mamounas, National Institute of Neurological Disorders and Stroke, and I'm sitting in for Dr. Walter Koroshetz who is at the annual neurology meeting this week.

Mr. Ne'eman: Ari Ne'eman, Autistic Self-Advocacy Network, and autistic adult.

Dr. Houle: Gail Houle, U.S. Department of Education, Office of Special Education Programs.

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

Dr. Kau: Alice Kau from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. And today I'm sitting in for Dr. Guttmacher who is the Director of the Institute.

Dr. van Dyck: Good morning. Peter van Dyck, Maternal and Child Health and HRSA.

Dr. Janvier: Yvette Janvier. I'm a practicing developmental behavioral pediatrician from Central New Jersey and I just wanted to let you know one of the projects I'm working on now is identifying autism in underserved communities throughout New Jersey.

Dr. Boyle: Good morning. I'm Coleen Boyle with the Centers for Disease Control and Prevention.

Ms. Singer: I am Alison Singer. I'm the President of the Autism Science Foundation and the mother of a beautiful 13-year-old daughter with autism.

Ms. Kendall: Good morning. I'm Jamie Kendall with the Administration on Developmental Disabilities. I'm here for Sharon Lewis.

Dr. Dawson: Good morning. I'm Geri Dawson, and I'm the Chief Science Officer for Autism Speaks.

Dr. Battey: Good morning. I'm Jim Battey and I'm representing the National Institute on Deafness and Other Communication Disorders.

Dr. Solomon: Good morning. I'm Marjorie Solomon. I'm representing The

M.I.N.D. Institute.

Ms. Blackwell: I'm Ellen Blackwell, Centers for Medicare & Medicaid Services and I'm also the parent of a 24-year-old adult with autism.

Dr. Insel: Thank you. So this is a very -- as you know, a very hard-working Committee. We've been together for going on four years.

We -- one of the concerns of the Committee is, of course, reauthorization. We are due to sunset September 30th of this year and so it's reassuring to know that the Administration is committed to making sure reauthorization goes forward in the Congress.

Mike, I'd like you to comment about this being a messy process. At times it has been, but it's been a, I think for all of us, a process of learning a lot about the complexity of autism and the -- both the opportunities entailed with this.

And so, your comments, both of

your comments were, I think, right on target for much of what we have been doing for the last four years, and the kinds of things that we've been thinking about going forward.

But I think, rather than my taking any more time from the Committee, I'd like to just open this up and find out if there are comments or questions that anyone wants to raise from the Committee.

Geri.

Dr. Shore: Stephen Shore. I don't know if you can hear me.

Dr. Insel: Stephen, welcome. Is anyone else with us on the phone from the Committee?

Dr. Shore: I think there may be about four or five of us.

Dr. Insel: Okay. Let's go around and, Stephen, why don't you start with introduction.

Dr. Shore: All right. I'm Stephen Shore. I'm an autistic adult, Assistant Professor, Special Education at Adelphi University and on the Board of the Autism Society of America.

Dr. Insel: Anyone else on the phone from the Committee?

Ms. Resnik: Good morning. This is Denise Resnik from Arizona and I'm the co-founder of the Southwest Autism Research and Resource Center and the mother of a 19-year-old son with autism.

Dr. Insel: Anyone else on the phone?

Dr. Shore: And I have one request.

Dr. Insel: Go ahead, Stephen.

Dr. Shore: And that is -- well, my request is, if somebody could email me information to access the webinar, if there is one, so I can get the visuals and, two, I appreciate all the work the Obama Administration is doing in support for those of us on the autism spectrum and the community.

Dr. Insel: Okay. We'll take care of the email. Just to reassure you, you really haven't missed much, in terms of the visuals.

Dr. Shore: Yes. I figured that.

Dr. Insel: There are no slides yet, but we'll connect you that way.

And, Denise, do you want to say a word about why you're not here, because I think it may be of interest to your fellow Committee Members.

Ms. Resnik: Certainly. Thank you, Tom. I'm not here -- there, because tomorrow we are hosting Stephen Hawking at the Southwest Autism Research and Resource Center.

He's speaking to our Grandparent Support Group as a grandparent. His daughter, Lucy Hawking was recruited by ASU to serve as a writer-in-residence for their Origins Program, and a big decision for her about relocating from Cambridge where she does work with her father quite a bit and lectures and writes with her dad, was what type of services were here in Arizona for her 13-year-old son with autism.

So, SARRC has been working with Lucy and her son William and even is coming tomorrow to thank us and to also share some thoughts with our grandparents.

Dr. Insel: That's terrific. Well, thanks. And you get a pass for not coming today.

Ms. Resnik: Okay. Thanks, Tom.

Dr. Insel: So, let's open this up for comments. Geri.

Dr. Dawson: Well, I want to begin by expressing on behalf of the community and Autism Speaks how grateful we are for the support of the President and for the Secretary of Health.

And last week, when the President made the proclamation about World Autism

Awareness day and also when the Secretary of Health sent the letter responding to our letter to her, those things mean a lot.

It does mean a lot to feel that you're listened to and that the work we're doing has the attention of people at such high levels.

So, I want to thank you for that. And I also want to thank you for the President's support of the reauthorization of the Combating Autism Act.

In many ways, I feel like the IACC is just beginning to hit its stride, and we have so much work to do. And this was really brought home to me when I read the three publications that came out in "Pediatrics" last week from AHRQ.

And a tremendous amount of work went into that. I was part of that process, but I looked at what we really know about treatment, and it was really quite paltry. It was amazing how we only have two medications that we know have any kind of efficacy and we have early intervention, but still there's so many questions that need to be addressed, even about that.

So, I just want to express the urgency and the tremendous need that we have to continue doing research and to develop services to address what really is a public health crisis at this point. Thank you.

Dr. Insel: Ari.

Mr. Ne'eman: I just -- I wanted to, first start by thanking Michael, in particular, for his comments and for the President's statement. And, in particular, the part of the President's statement that recognized the contributions that autistic people make to our country and to our society.

You know, I think that -- those issues of language are very important. You know, I also really appreciated your comments here today where you connected the issues that affect autistic people with the issues that affect all people with disabilities.

So, you know, I know, for one, I'm very appreciative of the fact that we can count on the administration's support, not just for the reauthorization of autism-specific legislation, which is important, but also for coming reauthorizations of the Workforce Investment Act and the Elementary and Secondary Education Act and the Developmental Disabilities Act, and other critical pieces of legislation that impact autistic people by impacting all people with disabilities.

So, you know, I get to, once again, thank the Obama Administration for its support.

I also wanted to direct a very quick question to Dr. Parekh, if you don't mind. Last week the National Health Disparities Plan was released by your department, and I'm wondering if you can speak to what degree people with disabilities, including autistic adults and other people with developmental disabilities are included in that, you know, in addition to racial and ethnic health disparities.

I know that's an issue a number of the Members of the Committee have a definite interest in.

Dr. Parekh: I think the best way to answer that question is, there are elements of that plan that address all different types of disparities, whether it's for racial and ethnic minorities, whether it's for individuals with disabilities.

Certainly, the focus of the plan was to raise awareness of some of the disparities that exist along those racial and ethnic lines but I think, again, many of the levers that are called for in that plan I think can help other areas of disparities.

So, the Department and the Secretary is very conscious, with the leadership of Henry here, of the importance of raising awareness and having a game plan for addressing disparities that exist in the disparities population, and to the extent that we can use that strategic action plan to reduce racial and ethnic health disparities, we will, and to the extent that we need to do additional things, you know, there's full support to do that.

Henry, I don't know if you want to add at all.

Mr. Claypool: Oh. I think we're mindful, Ari, of where individuals with disabilities fall in terms of the data that we need to really ascertain where the disparities exist for the population, and I think there's quite a bit of work that we're looking at and we want to engage the rest of the disability community to try and form a strategy around how we go about documenting and addressing these issues.

So, we'll definitely be in touch

with you and others that have interest in fleshing out what -- from the disability community perspective are perceived to be health disparities and figure out together how we can move forward on those issues.

Dr. Insel: Other comments?

Lyn or Lee? Okay.

Mr. Grossman: This is Lee Grossman. I want to thank you for your comments. It was truly excellent to hear what the Administration is doing in light of all the priorities that the President is dealing with.

It has been a breath of fresh air over the last few years to see how this Administration has stepped up to address issues regarding not only autism, but the entire disability community.

We kind of took some steps backwards in the early part of this past decade and I now see us catching -- catching up again and moving that forward.

I particularly appreciated the comments about quality of life issues and how we need to address other issues such as bullying, homelessness, poverty, education, job training, et cetera.

With all that said, there is a tremendous crisis going on right now in this country with the budget cuts. The impact on the autism community and the disability community has been actually shocking in terms of people losing the minimum services that they've already had.

Letters are going out from the states to individuals where people are losing their housing, they are losing their jobs, and actually we're sitting here watching this happen, and the calls that we get into our office are absolutely horrifying and they're coming at a volume that we just simply can't ignore anymore.

My question to you is, in our role as an advisory committee, and knowing that this is happening, what would be most impactful for us to provide to you to have the Administration respond to this now crisis and it's even -- and ongoing, growing crisis? How can we best address this?

Mr. Strautmanis: Lee, I appreciate that question and I appreciate the comments and the spirit in which you ask that because I know you're on the ground, and you're -- you and your organization are, as well as other partners, are trying to respond to the growing need.

You know, this probably doesn't have to be said, but I think it's important to put this in context, you know, individuals with disabilities, individuals that need those services, were needing them before the recession hit.

This was not a situation where we had -- we were taking care of all who needed taking care of before the recession hit and obviously, when the recession hit it hurt everyone, but it hurt the most vulnerable the most.

And so, that's why the President rushed to pass the Recovery Act and -- you've heard about here today, even, I know you're all aware of what we're able to do through the Recovery Act, and efforts since then.

But, you know, as -- and this is not a surprise. You know, that time is over the ability of the -- part of the Recovery Act was to give an infusion of funds to help the states serve the most vulnerable and -- and obviously that is going to be difficult to -- to repeat.

We're -- a couple things I'll say that I think would be very helpful. Actually, through our office we also manage Inter-Governmental Affairs, and so Valerie Jarrett, the President's Senior Advisors and Cecilia Munoz who runs the Office of Inter-Governmental Affairs is spending a lot of time talking to the states, talking to governors, talking to local officials about their needs and the ability to have this Committee whose work I pay attention to, lift this issue up, gives us one more tool to add to those conversations.

And look, as we're, you know, talking with those governors and we're talking with those state and local officials, they are aware of the needs and they are trying desperately in a situation where they have to balance their budgets to serve the needy, but to listen to that is important, but I think what this moment should teach all of us is the importance of partnerships.

None of these problems could be solved by the Federal Government alone before the crisis hit. None of these problems can be solved by the private sector alone.

I think we need -- I think we need partnerships. One of the areas that I work in is with the President's Council on Jobs and Competitiveness. I believe the issue around giving individuals -- individuals with disabilities the opportunity to live as full a life a possible and to be able to contribute to this society as far as their minds and hearts and bodies can take them, is a competitiveness issue. It's a jobs issue.

You know if we're going to win the future we need everybody to be able to participate in that effort. And so, making sure that we're talking to folks in the private sector, our philanthropic community, nonprofit organizations, our national organizations, our civil rights organizations is something that's important.

So, I think this Committee lifting this issue up for the Federal Government to recognize and the Administration to recognize is important, but I think this Committee reaching out and serving as ambassadors to other institutions, to other organizations who may not realize that this work can be and should be a part of their efforts will be important.

And, look, you know, at tight budget times, I think everyone can get into a bit of a zero sum game mentality because, you know, there's only one piece of the pie out there and either I'm going to get it or you're going to get it.

And I don't think the people that you all represent and work with can afford that. I think we need to be reaching out and bringing more partners to the table, traditional and nontraditional to meet the very serious needs that you addressed, and just lifting them up is important and I -- I appreciate your work, Lee, on the ground, and I appreciate that question. Thank you.

Dr. Insel: Lyn.

Ms. Redwood: Hi. Thank you. When I received the agenda on Friday afternoon and saw where representatives from the Administration were going to be here to address this today, and there was an opportunity for comments and questions, I was excited.

And as a public member of the IACC, I turn to the public. And I've read through all of the public comments that we received for this meeting, both written and oral.

I turned to an internet blog and went out to the blog saying, "Please send me information. What do the parents need?" And what I heard as a common thread in almost every comment is that we need to be doing more and we need to be doing it faster.

We appreciate being seen, but we also want to be heard.

Mike, it was over ten years ago since we first met and it was ten years ago that I started coming to these meetings. I met with the Director of NIMH.

Dr. Insel, it wasn't you at the time, the Director of NICHD, the Director of CDC, and we've been asking for this urgent situation of autism to be addressed.

And, you know, hundreds of millions of dollars to date have been spent, either through the Combating Autism Act and research before, but as Geri points out, we still have very little in terms of effective treatments and we still are at a complete loss for what is causing one percent of our children, and closer to two percent if you look just at boys to come down with this devastating disorder.

Forty percent of those also have intellectual disorders and are unable to speak or communicate or be at these meetings here today. It really is a silent epidemic.

So, from where I sit, reading these comments from the families, there's a disconnect between celebrating autism because they feel as though there is really little to celebrate in their lives.

A young man that I know just turned 22 and he is aged out of the school system. He was just approved for Social Security income, Medicaid and Food Stamps. He's never going to be able to live on his own or be employed.

And 80 percent of the population right now with autism is under the age of 18. How are we going to deal with this epidemic when it hits us in a few years? States are already struggling.

So, I think that, since our last meeting, another thing that's happened that we mentioned was we sent a letter to Secretary Sebelius regarding the urgent need to address wandering and elopement in our community.

In that short period of time, four children have died from that issue. I could go on citing example-after-example of the urgent, unmet needs that we're not able to address on this Committee.

I think the IACC was a great start, but the reality of this Committee is it is formed by directors of national institutes of health, and people who run large autism organizations are full-time Federal employees, and we only meet maybe four to six times a year.

There's no way we can address this issue. We're the ambassadors to go out to raise awareness and do all the wonderful things that you're asked for.

So, I'm asking -- you said it was our job, Mike, to push for better results, and I'm asking for help from the Administration to establish some type of task force that really addresses this issue with a sense of urgency, the same type of urgency that we put forth toward H1N1 where Secretary Sebelius was in meetings every single day to try to address that outbreak. We need that type of concerted effort.

We need to develop a comprehensive policy that can address all these critical needs of identification, treatment, education, services, prevention, safety, bullying, all the things you mentioned, but we need somebody to head that up.

And what I'm suggesting is that we establish a task force within the White House the same way as was done for obesity. And I know, Mike, when you and I spoke back before President Obama was elected, there was a press release that put out that there was going to be an appointment of a Federal ASD Coordinator to oversee all Federal ASD efforts, and that this coordinator would be tasked with eliminating bureaucratic obstacles that may be delaying implementation of important ASD measures like wandering, and ensuring that all Federal dollars are being spent in a manner that prioritizes results.

So, I'm asking for your help, because we're doing a great job and we really appreciate the support, but we really need more.

Mr. Strautmanis: So, Lyn, one of the reasons why we met back when we did is because you're passionate, stubborn and committed, and it's one of the reasons why I admire you.

And you're right. I think we do need to be pushed. I will -- I stand by my comments around the work of this Committee and I stand by my comments about the ability of this Committee and Dr. Insel to do the coordination, and the prioritization that the Secretary of Health and Human Services, the Secretary of Education, the Attorney General, the President and others in the Administration have placed on it around this issue.

But, I agree, it's not enough, and I think that -- you know, I can imagine that those comments were written by parents who were up at midnight or one a.m. or two a.m., just like my wife and I often are, searching through the blogs, trying to find somebody who's experienced the latest thing that, you know, we're experiencing that we can figure out a way to deal with for another second, much less another day, much less a decade.

And so, I appreciate your sense of urgency. I take your comments at face value. I take them seriously, and I'll take them back -- as I said, as we talk about reauthorizing the Combating Autism Act, the work of this Committee, we don't want to move forward until we've heard from the public, until we've heard from you.

So, I'll, you know, just leave it there and just say I take your comments very seriously. I'll take them back and we'll put them in the middle of the discussion as we talk about next steps.

So, thank you for reaching out to the parents in that way so we could hear from them today.

Ms. Redwood: Thank you, and please give our thanks to President Obama.

Mr. Strautmanis: Thanks, Lyn.

Dr. Parekh: And if I could just add to Mike's comment, just three -- three short points. There are, as you've heard, lots of different programs, activities, initiatives underway across the Federal sector in this area, but that in no way is meant to be seen as a sign of complacency, that we're all doing what we can.

I completely agree with you. We completely agree with you that we need to continue to redouble our efforts and progress is great, but we need more and more progress.

I think your second point about the important, again, issue that you all brought up at the last meeting related to wandering, the statistics that you've pointed out are sobering and these are more than numbers. These are -- these are children, these are parents, these are families.

So, you all have alerted us of this important public health challenge and we've promised to quickly continue to review your recommendations and provide some kind of next steps or game plan of what more we can do on that important public health challenge.

And I think the third point is simply to reiterate what Mike said, that we're always looking for better ways -- this is a priority, but we're always looking for better ways to ensure coordination and collaboration on this important issue.

And again, I think the reauthorization of the Combating Autism Act provides us an opportunity to say, "All right. Let's look at what we were able to accomplish for the next -- for the last four years, and how could we do better moving forward."

So, I really think it's an opportunity, as Mike said.

Dr. Insel: If I could pull a couple of these comments together. It's -- it's been interesting. One of the great things about the IACC is we have both written and oral public comment.

So we get a lot of information in and it's a chance to hear from many different voices. And I think there is an emerging theme that is worth conveying to both the White House and to the Department and elsewhere within the Administration.

And it kind of is at the intersection of what Lyn was saying about this -- this tsunami that we're approaching of -- or is approaching us of so many children with autism spectrum disorders becoming adults.

And then these comments about, at the same time that's happening we're seeing the erosion of the social supports and the public supports in states for people with disabilities or mental disorders.

And the figures that we're looking at are, you know, $2.2 billion across the states in terms of losses, the things that were there two and three years ago that are going to be disappearing this year, next year and the year after, just as this wave begins to hit, or as it grows.

And so, we look at this as a

committee and we think, you know, what can we do to help all of us think better about how to prepare. Yes, absolutely, there will need to be partnerships, but there will also need to be better ways of thinking about this in a way that we -- what we do is much more efficient, much more effective.

We simply don't have the answers here, but we're hearing more and more concern. At least, use of the term "crisis," I don't think, overstates the sense the Committee's getting, and I am here speaking on behalf of the Committee, so if someone disagrees, please let me know.

But it is this emerging theme over the last maybe 18 months, 12 months, as we -- as this economic recession which, in some ways the -- as you say, the Recovery Act really helped to forestall the worst parts of this.

And so, it's now coming home and it's part of because we're just coming off the Recovery Act and at the same time, when the --

the needs are beginning to grow, in such a serious and rapid way.

So, it's -- this is one of those items maybe to send forward for -- as part of our congressional mandate, which is to say, we're supposed to let the Administration know when there is an emerging concern, public health concern, and this is clearly becoming a more significant issue.

I think what Lee and Lyn are both trying to convey is, we'd like to be effective. We'd like to be helpful for you and helpful for the community, and we're not exactly sure the best way to capture what we're hearing and to transmit that and to convey it in a way that's helpful.

But any suggestions you have, we'd certainly want to take advantage of.

Other comments?

Let me just say that your being here is an extremely helpful part of this process, and we really appreciate your willingness to join the meeting this morning.

We're hoping the Act will be reauthorized, the IACC will live beyond September, which means there will be hopefully many more opportunities for you to join us and for us to continue this dialogue because at the same time that I think, everyone here is so grateful for all that's been done, there's also a real concern about how much still is in front of us to be done and we want to really watch this progress happen.

As Lyn said, the urgency is a central concept of the strategic plan. It's still very much with us, and maybe even greater than it was when we did the plan three years ago.

So, we look forward to working much more closely with both the White House and Secretary Sebelius and the Office of the Assistant Secretary for Health.

So, can we give our guests a round of applause as a way of saying thank you.

(Applause.)

Dr. Insel: Well, thank you, and you gentlemen are welcome to stay, if you'd like, for any part of the rest of the meeting, but we're going to go on with the agenda.

Mr. Strautmanis: Unfortunately, I am going to have to leave, but I'll read about you, and I'm watching you. So, somebody on my staff is actually watching you. So I'll have my eye on you as you all continue.

I guess the last thing I'll say is I don't -- you know, of all the people that you've thanked, and I certainly appreciate you thanking me and I certainly appreciate you thanking the President.

I do want to say, I don't think Secretary Sebelius gets enough credit for her work. I know you all know how much she cares about this issue and I know you all know how much she's always saying, yes. When there's a need, asking her staff to do more of listening when they bring her recommendations and advice.

But, I've seen her up close and personal work on this issue. I know how much she cares and I know how dedicated she is.

And, look, the last thing I'll say is, you know, I think sometimes we get in these settings and we do a lot of talk, and there is a lot of information that you're getting, there are a lot of reports that come in, and that's important.

I'm not here to talk about this. I'm not here sitting in the White House every day to have a good discussion. I'm here to change lives for the better.

If we aren't impacting people's lives and improving them, maybe we can improve them a lot, maybe we can improve them just a little bit, but every single day we've got to be moving forward finding ways to change people's lives in this country and around the world on this issue and so many more.

And at some point, you know, I'll

drop of exhaustion or my wife will get sick of me and, you know, they'll bring somebody else in to replace me, and I'll, you know, grab a seat on this committee and we'll continue to do this work together from wherever I sit.

So, you're not rid of me. We're all partners, and I look forward to your important and continued work.

And thank you, sir. Thank you, Doctor. Appreciate you.

Dr. Insel: Well, great. We're going to move on with the agenda and let me just do what I was -- generally has been the beginning of each meeting which is to do a very quick rundown of what you may have missed since our last meeting, which was in mid-January.

These are just recent reports out that I wanted to capture very quickly before we get on to information about autism awareness month updates.

So, for each of the themes of the

plan there have been, I would say, sometimes interesting, sometimes compelling reports that have come out under this first theme about when should I be concerned, two interesting reports suggesting that there's now a way of diagnosing autism with a hundred percent reliability as early as 14 months with a very simple video game that distinguishes eye gaze, and geometric patterns versus social signals.

And Cathy Lord and company have now redone the diagnostic interview, revised algorithms for much younger children so that this provides algorithms for toddlers.

Under the etiology question, what caused this to happen and can it be prevented, a couple of papers coming out. One on vitamin D deficiency in women of Somali origin, which I thought was intriguing, given what we've heard about the increase in autism in Somali population in Minneapolis.

Curiously, this is not in Minneapolis at all, but in Sweden, where they've also identified the same sort of increase specifically in Somalis living in the County of Stockholm, and there they have tied this, they think, perhaps, to a vitamin D deficiency during pregnancy in that population although the connection is still not very precise, and there's still more -- much more to do on this.

On the same topic of what can -- what caused this to happen, a lot of interest, of course, still on the genetic side, particularly around the idea of using induced pluripotent stem cells.

We talked about this, I think, in our last meeting, the development of the stem cell technology for beginning to develop both the mechanisms and treatments for Rett syndrome, but in this really intriguing study, the last one on this slide shows that it may be also an important way of being able to look at synapse formation, and in this case, identifying those components that may be most critical for causing autism or at least putting children at risk.

Already mentioned by Anand earlier today were the three papers out in "Pediatrics" from AHRQ that describe the meta-analyses, the reviews that have been done to look at both the role of early intervention in terms of ABA, as well as medical treatments.

And, as Geri mentioned, you know, the upside of this is that there are now a substantial body of literature. The downside is that what we have is just not good enough, and I think these reports which don't provide any specifically new information, but do bring together what has been done over the last decade or so are pretty compelling and showing that, while there's still major questions about what works for which -- which people.

Services. Interesting that in the update of the strategic plan we focused specifically on dental needs. Ellen kept our focus on that when we did the -- this particular objective and, indeed, there are a couple of papers out just recently on how there is these unmet dental needs in children on the spectrum, and using ABA as a way of helping to overcome that.

I am going to also point out the paper by Paul Shattuck at the bottom here, "Post High School Service Use Among Young Adults With an Autism Spectrum Disorder."

This article, quite important, I think, for helping us to identify what is happening at that transition from youth to adulthood, showing a large drop-off in services, about 40 percent, 39 percent of children are no longer getting services as they hit age 22, 23.

And particularly of note that African American children and adults, now young adults on the spectrum, are about three times more likely not to be receiving services of any kind when they move from being covered in the education system and as children with autism to adults with autism.

And this goes back, Lee, to your comment about this growing crisis because it is a crisis, but I must point out this paper because it suggests the crisis is worse for some parts of the population than others.

So that is a recent and I think important paper to look at.

Now, finally, on the infrastructure and surveillance issues, several things have happened in the last few weeks with pulling together resources, particularly for animal studies, work that's happened through the Simons Foundation to create this new database for animal research, particularly mouse research as well as the -- I believe the first publication that uses the genotype of the autism tissue program, brain samples.

As you know, there are well over a hundred samples in the program. We have not had DNA on those samples until recently and this new publication provides information about that.

So, that's a really quick rundown. There's much more that I could talk about. It used to be an easy task to sum up in five minutes what had been published between IACC meetings.

Those days are long-gone. Now all I can do is provide a very incomplete summary and very noncomprehensive summary of what's out there because the literature is almost impossible to keep up with. It's a very active area and these are just a few things to mention.

Just one other comment I should mention, because I think it's really historical, although it's not published in a traditional sense, and that is that about two weeks ago the Allen Brain Institute submitted online the first developmental human brain atlas at the transcriptional level, that is looking at which genes are expressed in which brain areas across fetal and early postnatal development.

And this is an open access tool. It was paid for with Recovery Act money. It's, I think, transformative in the sense that for the first time we'll have a sense of both the genes and environment and where they may play out in the developing brain, particularly in the prenatal brain.

And what's very clear is that that prenatal brain doesn't look anything like the adult brain in terms of patterns of expression, even the genes that are expressed, the proteins that they make are sometimes very different in the prenatal brain than thereafter.

We had no idea about this until the last few weeks and now we have a sense of really who the players could be, where they're playing out in the brain and what things we might be looking for.

So this is, I think, a really

important point in time. It's all available on the Allen Brain Institute website, which is still being loaded up.

There's still much more information to come, but this is the first release of what I think will be an extremely important tool for developmental neurobiology, and particularly those people interested in the etiology of autism.

So that's a very quick update. I'm going to turn this over to Susan. Welcome. I'm glad you made it in spite of all the problems on the Metro this morning.

Dr. Daniels: Thank you.

Dr. Insel: And have you take us through the new IACC publications that are coming out fortuitously during Autism Awareness Month.

Dr. Daniels: So I want to give you an update on some of these new publications as well as one non-IACC publication.

So, congratulations to the Committee on the completion of the 2011 IACC Strategic Plan that was completed at the last meeting. You now have your glossy bound copies on the top of your piles.

And for the public we also have copies available, and anyone who is in the listening audience that would like a bound copy, you can just write to our office and ask for it.

This new strategic plan has 16 new objectives that were added in 2011, and now we have a total of 78 research objectives spread across the seven questions of the plan.

And some of the highlights of the new plan include studies on the use of AAC tools for nonverbal individuals, prevention of related health concerns such as obesity and mental health issues, and safety issues that may increase the risk of injury or endanger life.

There's also another new

publication. We didn't quite get to the presses in time to have your glossy bound copies in front of you, but those will be available within the next month or so and we will be taking them to the upcoming IMFAR meeting and then have them available at the July meeting.

This is the 2010 IACC Summary of Advances in Autism Spectrum Disorder Research, in which members of the Committee selected the top 20 articles and, in this case, there were actually 21 because there were two back-to-back articles that we put into one advance that summarize some of the top advances for 2010, and these studies cover the span of the strategic plan.

On Chapter 6 there was no article that was selected among the number of articles for that chapter, but there were nominations and this document lists everything that was nominated by the Committee as well as those that were finally selected and has really nice lay-friendly summaries of each article, which we hope will be useful, not only to policymakers and the Committee, but also to families.

And this -- I'm not going to read you every title, but these are some of the articles that were listed in the Summary of Advances, and this is available online. It's both a downloadable PDF and an HTML version. And the HTML version has some links to other resources, including right back to the articles. So, those who are viewing this, if you want to go to our website you can download this document.

So, in front of you you also have a copy of the near-complete 2009 IACC portfolio analysis document, and this is a document that the IACC has charged the OARC, the Office of Autism Research Coordination with conducting, to help them with their requirement to monitor Federal research activities related to autism spectrum disorder.

However, this document covers more than just the Federal sector. It also covers many private foundations that fund autism research and it provides a comprehensive analysis of the ASD portfolio, both across the Federal agency and private organizations.

And it gives us an idea of kind of the current landscape and possible directions. We have used those, the IACC has used this to identify gaps and new opportunities and that's helped them with the strategic plan.

Just quickly I wanted to run through a few of the figures from the strategic -- from this portfolio analysis. The total funding for 2009 was $314 million, and we've listed the different organizations that participated and provided us with data.

In this figure you can see that the Federal Government provided about 75 percent or 76 percent of total ASD research funding in 2009, meaning the private sector is providing almost a quarter of that funding.

And you can see the impact on the right-hand side of the NIH-ARRA funding which amounted to almost 20 percent of total funding in 2009.

This is a figure that shows us the ASD research funding by strategic plan questions, so for this total $314 million, how does this spread across the strategic plan, and you can see that Question Three on, "What Caused this to Happen and How Can It Be Prevented," was our largest category with 32 percent, but the other two largest categories are "The Basic Biology of Autism," which is Question Two, "How Can I Understand What is Happening," and the other one was "Which Treatments and Interventions Will Help," Chapter Four.

There has -- and you can see that there's some of the other areas that have smaller amounts of funding.

And this is actually an

interesting figure because it shows across the NIH-ARRA funding. NIH was the only Federal agency that participated in this portfolio analysis that has ARRA funding that was directed at Autism.

You can see that the proportions are a little different from the rest of the -- from the total pie, and that Question Three is greatly expanded in the ARRA funding, and so there was quite an emphasis on looking at causes of autism with the use of ARRA funding and also quite a bit on basic biology and treatments, and diagnosis.

So this figure shows the impact of 2009 ARRA funding on ASD research in terms of its alignment with the strategic plan and you can see in the gold there that the NIH-ARRA funding, how that compares to what was there from -- from traditional funding, and you can see how that spreads across the strategic plan and the dollar figures are there, although I know they're kind of small.

And you can see how new investments are -- this came up at the last -- at the last meeting someone asked about: Can we identify what's new funding? And so we went ahead and did that analysis, too, to try to show you what's new.

And you can see, the dark gold is ARRA and then other new projects. So, if you add the kind of dark gold and the lighter gold, that would be all new. And so you can kind of see how the new spreads across the strategic plan.

So, anyway, but that document -- it's a draft document. It's included in the meeting materials for this meeting and is currently online, but we should have the final product out this month.

And so you can be looking for that, we'll send a mass email around to everyone about that but, for the meantime, you can look at this draft which is pretty much almost complete.

The last document I want to point out here is a document that's not an IACC document. This is a document from the Office of the Secretary of Human Health and Human Services, and this document -- HHS asked OARC to help coordinate this document.

And so, our office did put this document together, but we did it on behalf of HHS, and not as an IACC activity.

It's a document that's required by the Combating Autism Act of 2006, and it describes Federal progress and expenditures made in autism spectrum disorder research and services activity since the enactment of the CAA.

We gathered information from across HHS agencies, including ACF, AHRQ, CDC, CMS, HRSA, NIH, Office on Disability and SAMHSA, and we also got input from the Department of Education.

And this includes the latest information on programs and projects, kind of highlights, because we tried to keep it so it wouldn't become a 300-page document.

We tried to keep it at a high level, but talking about many of the major programs and progress areas for prevalence, age of diagnosis, intervention, effectiveness and outcomes, innovative intervention strategies and adult services and supports.

And it's really got a lot of rich information about different activities the Federal Government is undertaking, and some information, as well, about research results and services that are currently being provided and new programs.

And it also describes some activities and publications of the IACC and its coordination role. So, I would really encourage people to take a look at this document.

It's also on the IACC website and we will be printing bound copies of this as well, and there is a summary document that is much shorter. I think this document is about 80 pages, and then the summary document is more in the range of 20 pages, I believe.

And we developed it such that we hope that families can also read this and understand what's going on with the Federal Government and how money is being spent.

So, with that, I think I'd like to conclude and move on to the next thing. All of these publications can be accessed on our website, and there's the web address for anybody who's watching. Thank you.

Dr. Insel: Great. Thank you, Susan.

Questions or comments for Susan?

Chris?

Ms. McKee: Susan, were we ever able to put together the index of public documents, of published research for -- I think we were actually looking at 2009 originally, but now it would be 2010 as well.

Dr. Daniels: So, the 2010 is done

and it's in this, so we're going to go back to the 2009 and complete that now that this one is done.

Ms. McKee: Okay.

Dr. Daniels: So, what Christine is referring to is the full listing of everything that was nominated by the Committee, putting that together question-by-question and having links back to the original articles.

And so we have that done for this version, but for the previous version we only have links to the articles that we selected, and so we're going to go back and put in the links to the articles that were nominated.

Ms. McKee: Susan, can we actually go broader than that? The year before, in 2008, before we set up this process of nominating articles, the OARC or whoever, put together an entire list of all published research for the year, and I think we had 300, 500. I can't remember what the figure was for everyone to go through.

What I'm really trying to do is help parents. We heard from Mike that they sit up at night and they read. And I look up at our pie chart, and when it comes to services research, there's very little that we can give parents.

But, what we can do is help them by providing citations to published research. And if we actually have that bank of information available for parents to pull and read to support their arguments for their IEP, to support whatever parents need to advocate for their child, I think it would be really beneficial.

I can't remember the years, if I'm getting this correct, but I think we have it for 2008, and I think when we change to nominating in 2009 is when that --

Dr. Daniels: Yes. We have a much longer version, however what we heard as feedback from the Committee was that it was overwhelming and not useful to have a list of 300 articles, which is why we moved to the nominating process which you all voted on.

And so, we no longer try to collect something comprehensive. And even at 300, that was culled down from the total number for us to put together a list of every autism publication that's ever been published and provide links, I think, would be quite an amazing accomplishment.

Dr. Insel: Ellen.

Ms. Blackwell: Christine, I think Susan made a really important point which is that the articles that didn't make -- the articles that didn't make it to the top -- sorry.

The articles that didn't make it to the top this year are listed in the Summary of Advances and there are some excellent articles for services that I would highly recommend folks look at.

Dr. Daniels: In some ways the

list of nominated articles, it kind of prioritizes the articles in some way because if you're looking at a list of a thousand articles, it's a little bit hard to tell what are maybe the higher quality articles, the ones to really look at.

And so, I think the Committee has done an excellent job in helping us identify what's important from your perspectives and point of view.

And so, I would encourage in the future for people to be generous with their nominations. We always, I think, allow ten for the year per person, and so that really could amount to quite a few.

Dr. Insel: Lyn.

Ms. Redwood: Susan, I had a question. We had also discussed several years ago when we started on this process of the strategic plan as to how we were going to be able to evaluate whether or not the research that we funded was effective: Did we get a bang for our buck?

And one of the things that came up was looking at publications from the research. So, is there a way, now that we have this plan for several years now, what we funded to have somebody drill in deeper to find out what publications came out of that particular research, because that will be a way for us to help analyze this plan moving forward to see what's happening.

And it would also be nice if, for each of these specific questions, the way you have it broken out -- I know you have the big pie chart for the whole plan, but if we had a same pie chart for each specific question, so we can quickly identify visually which of those opportunities that we thought were important have not been addressed yet, so we can consider either putting out a specific RFA to get that important research done, or some way to make sure that the plan that we've developed is actually being implemented by the researchers.

Dr. Daniels: In the document you're holding, actually, with Appendix A, we have that red light/green light system that was supposed to help identify which objectives are and are not being addressed.

So, I think we did it. We just didn't do it with a pie chart, but it's -- so, look at the red ones because those will tell you ones that have received no funding or don't have any projects.

Ms. Redwood: Last question. Now that we have that, when does the Strategic Planning Subcommittee meet?

Dr. Daniels: So, and that's something for this afternoon. I was going to bring that up as a business point that we should be having the Planning Subcommittee meet.

And in terms of looking at the impact of the research because, right now, the portfolio analysis talks about what did we fund. It doesn't talk about what the research results were.

I did ask the Committee in January whether you would like for us to collect information about publications in the next part -- analysis and you said you would like to do that.

So, that's our plan for when we put out our data call, we're going to ask every funder if they have the information about what articles have been published as a result of their funding, to have that information, then we'll have to work on how we'll work that into the new analysis.

But, I'd really like to talk to the Planning Subcommittee about that and what they feel will be the most useful pieces of information for us to analyze for them.

Dr. Insel: Lee.

Mr. Grossman: Yes. I'd like to continue what Christine was bringing up because she raises a very important point.

You know, one or two a.m. after somebody's gotten their child with autism to sleep and they go and they're looking for information, yes, there are a certain amount of parents that would find that the latest study on a knock-off mouse is very interesting, but the vast majority are looking at: How do I plan my IEP meetings? How do I apply for SSI? What are housing options? What are the best behavioral strategies, et cetera?

And I guess what I'm going to propose, since we're not busy enough, is that the services subcommittee look at making a recommendation to the Committee about how we can best organize that materials so that is available as one source.

There's plenty of websites out there that have this information, ours being one as well, that provide a pretty good balance of documentation, and I think it would be great if the IACC also had a link to how to resource -- or how to access these resources would be helpful.

Dr. Insel: So, if I can just distinguish those two things, I think there's an opportunity to identify where that information may reside.

That's quite different than us, the IACC website becoming the repository and the source for that kind of information, so I think we should clarify whether the Committee wants the IACC to become the website or the public source for information about services or about lots of other things that are going on which is -- will be a huge investment beyond what we've done here, which is really just trying to capture what's come out of the research plan.

Dr. Daniels: We also would want to hear what Jamie Kendall has to say today, because they have a very exciting new website called "Autism Now," and they're going to be speaking about that and letting people know what's available on that website.

I have this sneaking suspicion that that might cover a lot of what you're talking about.

Dr. Insel: So that's -- what we can -- why don't we put off the discussion till Jamie has a chance to do that presentation, which will be a little bit later in the day. That's a great idea.

Other comments?

Geri?

Dr. Dawson: Well, first of all, wow! a lot of work. This is a pretty amazing effort and I know it must have been a tremendous amount of work so, thank you, Susan, and the rest of you for doing that.

I'm wondering about, you know, thinking towards next year, and particularly the report to Congress, whether we might want to consider a more forward look around what we see as the critical themes or the strategic issues that need to be addressed, or that have been identified by the Committee as important for the Congress to be aware of.

So, I -- I mean, I think this is a great overview of all the activities, and I wonder whether it might be helpful to have some, you know, in a concise way, illustrating the major themes.

Some of the themes that we've touched on in our discussion earlier today around, you know, the services, around the upcoming needs of adults, some of the basic resources that are needed to promote scientific activities, some of the really new and exciting scientific areas that are on the horizon that need investments.

So, you know, just having that sense of forward-looking and where the areas, both from a scientific perspective, as well as from a service perspective that we need to be making our investments or need the most attention.

So, it's just a suggestion, maybe, for next year. And I know it's outside what's mandated through the Combating Autism Act, and that this is a response to that, but it just might be something that would be helpful for people to be able to get a pretty quick look at those issues.

Dr. Insel: Okay. Good.

We're going to move on to the next item on the agenda. We're fortunate to have Laura Kavanagh with us.

She is the Director of the Division of Research, Training and Education and the Maternal and Child Health Bureau at HRSA, and we wanted to hear from her about HRSA's investments related to the Combating Autism Act.

Welcome, Laura.

Ms. Kavanagh: Thank you so much.

Knowing -- being acutely aware that I am standing between you and your first break, I will try to be as brief as possible about our investments -- oops. Am I advancing my -- there we go.

Let me skip over the goals and the primary -- the three areas that we primarily invested funds through the Combating Autism Act, through the Health Resources and Services Administration, with through autism intervention research investments, training investments through our developmental behavioral pediatrics and as well as our Leadership Education in Neurodevelopmental Disabilities program, I'm going to focus primarily on the LEND program today, and our state implementation grants.

We currently fund 13 states to look at systems change and how to involve families in making that systems change occur.

So starting first with the Autism Intervention Research Program, we fund two large research networks. One we call AIR-P which focuses on physical and mental health interventions and one, AIR-B, which is behavioral interventions.

Each of these has multiple sites

that I'll talk about in just a moment. These networks, along with our intervention research grants currently support 27 research institutes across the United States.

They are focused not only on conducting the research, but also developing guidelines for interventions, validating tools and also they have a requirement for disseminating that information to help professionals and to the public.

And we also deliberately invested in research, training and demonstration together so that each of those areas can inform the other areas.

We're funding the clinical training programs and the research that we're conducting is informing the training that goes on in those settings. This is the AIR-B research network. UCLA is the hub. There are five sites total as part of the research network.

They are conducting the research

in natural environments. They are involving parents in many of their research designs as well and they are focusing on core deficits, primarily among underserved or underrepresented populations.

This is the AIR-P research network, a larger network for us. It utilizes the existing structure of the Autism Treatment Network to carry out the projects. Major focus on dissemination and focusing also on the ATN registry.

So, key topic areas that are being examined currently between the two networks include GI issues, diet and nutrition, sleep disturbances and medication choice. Those are mostly through the AIR-P network. And social skills connections, including joint engagement, a lot of activity within the school setting, peer relationships and friendships, family well-being and transitioning to adult life in the AIR-B network.

They also are doing a new study around interventions in rural health areas using distance technology.

So, as I mentioned before, they are examining different target populations. These are primary target populations for the Health Resources and Services Administration that administers the program, so focusing on low-income, underserved, non-English speaking and rural populations in particular, which has had some challenges in terms of implementation as well.

The AIR-B guidelines, we plan to be published. We've been connecting with the efforts that were underway at AHRQ as well. These also will be published in a peer reviewed journal. They are currently being reviewed by the technical expert panel.

Dissemination activities include several public websites. The first is for the AIR-B network, asdweb.org. The second is for the AIR-P network. They are also -- the AIR-B network has developed a phenowiki. There have been webinars and continuing education events as well.

The second tier of investments within HRSA includes a clinical training program. It includes many different disciplines called the Leadership Education and Neurodevelopmental Disabilities.

So, these were training programs that existed that received supplements to focus particularly around ASD, advancing knowledge, enhancing cultural competency. These are interdisciplinary education programs.

I'll show you the different disciplines that are included in these training programs. They also have requirements to provide continuing education and technical assistance, so it's not just the clinical based training. They have outreach requirements as well.

So, these are the disciplines

reached, and when we interviewed LEND programs after they received these funds, they -- many of them incorporated different disciplines as well.

You'll note that parents are both faculty members and trainees. In many of the LEND programs that's a requirement, including a variety of clinical disciplines, medicine, social work, nutrition, but also special education, health administration, public health and others.

We currently fund 39 complete LEND training programs across the country. In this past year we funded four planning grants. The states that appear in blue are those that received LEND training program funding, and you can now add -- Nevada, Alaska, Georgia and Arizona received planning grants in this past year.

These are the accomplishments and long-term goals. As I mentioned before, they focus not only on training, but also increasing awareness in building partnerships.

We've worked closely -- both the LEND program as well as the state implementation programs that I'll talk about shortly, are working closely with the CDC's “Learn the Signs. Act Early.” campaign, which you'll hear about later as well.

Just some data. The number of trainees focusing on evidence-based practice in ASD has increased. Also, the content of the training programs is changing to increased emphasis on ASD.

Continuing education, the number of CE events held and those reached, including primary care physicians, nurse practitioners, school nurses and others has increased dramatically due to Combating Autism Act funding.

And also, the number of screenings conducted clinically and diagnostic evaluations conducted has increased dramatically between 2009 and 2010.

So, in 2009 we supported 22 LEND grantees and by 2010 we're now supporting the 39 full -- fully-supported LEND grants, and then the four planning grants that are at a much smaller level.

The third leg of this stool is supporting state implementation grants. These were states that already had to have an autism plan in place. This was to help them implement the plans that they had discussed in their plan.

They are doing this through awareness building, reducing barriers through a variety of different mechanisms, training and also infrastructure building, and I'll give you a few examples of that.

So, in Illinois, for example, they're looking at in-person care coordination activities. Missouri, around financial planning sessions targeted to parents. These are just a few examples of family involvement in particular.

Utah is -- has a weekly course in English and Spanish around family education series around autism. And the State of Washington is looking at training for parent-to-parent coordinators.

So, through the state demonstration grants they are looking at reaching more people with general information about ASDs and accessing service, but also changing systems of care and improving coordination and collaboration.

We hope that this will result in building a foundation for accelerating systems change by breaking down barriers and looking at both research, the clinical training program as well as the implementation of evidence-based practices.

All of the current investments are available on the website. You see at the bottom of the last slide, and this is my contact information. I'm also happy to take any questions that you have.

Dr. Insel: Thank you. Very quick run-through.

Ari.

Mr. Ne'eman: I just wanted to ask a quick question. And first, thank you for that very comprehensive overview.

You mentioned at multiple occasions that LEND and, you know, AIR-P and AIR-B and the other grant programs that HRSA does, make a deliberate effort to include and do outreach to parents.

Ms. Kavanagh: Yes.

Mr. Ne'eman: I'm wondering if you can speak to to what degree you engage in similar outreach efforts and inclusion efforts with regards to self-advocates on the autism spectrum.

Ms. Kavanagh: I -- thank you for that question. We absolutely have similar outreach efforts, particularly in the LEND program to self-advocates. So, self-advocates are faculty members as well as being part of the -- active part of the training programs.

I'm most aware of those efforts, but certainly also within AIR-P and AIR-B in the research networks, self-advocates are part of both developing the research questions as well as the conduct of the research and outreach networks.

Mr. Ne'eman: Excellent. If you could send me more information on that --

Ms. Kavanagh: I'd be happy to.

Mr. Ne'eman: -- I'd be very grateful. Thank you.

Dr. Insel: Coleen.

Dr. Boyle: Thanks, Laura. That was a great overview of your program. Just a quick question.

On your last bar chart which actually shows your evidence of direct impact --

Ms. Kavanagh: Yes.

Dr. Boyle: -- a remarkable change in the number of screenings and diagnostic evaluations. I wonder if you're collecting information on something about time to, or how this is impacting time to an evaluation or that the delay --

Ms. Kavanagh: The age of evaluation, you mean?

Dr. Boyle: Age, yes. Something to get a better sense of that.

Ms. Kavanagh: We put together data collection efforts in order to inform the report to Congress. So, we do have some of that information.

Certainly on the diagnostic evaluation we have better data than we do on the screenings comprehensively, but I can get that information for you from -- it's collected in the NEERS System, which is also supported by ADD.

Dr. Insel: Other comments or questions?

Real quick, Laura. One thing I was wondering that, when Susan showed the data from NIH and particularly the Recovery Act, I mean, it's very impressive what's happened, but it's probably also important to note that that's all going away --

Ms. Kavanagh: Right.

Dr. Insel: -- in 2011.

What you're showing us is unrelated to that. This is really Combating Autism Act implementation. What is the projection for 2011, 2012? What do you see happening over the next couple of years?

Ms. Kavanagh: With the budget? Oh.

Dr. Insel: In terms of -- because you've got some great things that have been set up --

Ms. Kavanagh: Right.

Dr. Insel: -- fairly recently. Will they continue to be supported, or is this -- do you have concerns about the immediate and maybe even long-term future?

Ms. Kavanagh: Right. I don't --

I can't -- I don't know what's going to happen with the budget in the future. Our plans, we're moving forward with -- the President's budget had an increase in funds for the Combating Autism Act provisions that support HRSA, so that's 399BB of the Combating Autism Act.

I haven't seen the 2011 budget yet, but certainly if it does not sunset, our plan is that all three of these activities would continue.

So, there would be a research investment that would focus on intervention. There would be a training investment that would continue as well as a state implementation grant.

I mean, that model for us has been quite -- we think quite successful. Certainly, the researchers are having very different conversations now with parents and families, mostly at the state that -- we have joint grantee meetings, for example, where parents are asking the researchers, you know, what are the findings, how is this available to me today, very similar issues to the themes that emerged from the IACC meeting.

Our plans, if it does not sunset and, goodness knows what the future brings in terms of level of funding is to continue these sorts of activities.

Dr. Insel: Great. That was really what I was wanting to know.

Ms. Kavanagh: Good.

Dr. Insel: Great. All right. I think we have earned a break. This has been a really interesting beginning to the meeting.

Let's take ten minutes. Return by no later than 10:50, and we'll go on with the rest of the agenda.

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

Dr. Insel: The next item on the agenda involves an update on the State of the

States Report, and if I can have that committee come back to the table so we have a quorum, and then we can have Ellen Blackwell from CMS take us through a progress report on the State of the States effort in the first nine states in which we have launched this effort.

Ellen, I'm going to turn this over to you and your colleagues who are working on the report.

Ms. Blackwell: Okay. Thank you, Tom.

Well, we're very excited to be here today. CMS has two projects in progress with our -- and we're very grateful for the support, I might add, of our partners at the National Institute of Mental Health.

So, the first project is an update on the State of the States. This is a project that is actually looking at all 50 states, and we will hear about the data that's been collected so far from our contractor L&M, and

I'll be introducing Alyson Ward.

Alyson is right here and also her colleague, Steve Eiken who is with Thomson Reuters, and I can only say the nicest things about these two.

It is such a pleasure, as a project officer, to work with people who are so truly dedicated to helping people with autism.

So, Alyson and Steve, I'm going to turn it over to you and then in a moment I'll introduce our second contractor to talk about our nine-state project.

We expect the results of this project, the final results, to be in in early 2012.

So, Alyson, here you go.

Ms. Ward: I'm a bit shorter than Ellen. Can everyone hear me okay? Great.

Well, I just, first of all, want to thank you all very much for the opportunity to share with you where we are with this project, the State of the States Report, and I did want to acknowledge, not only my colleague from Thomson Reuters, Steve Eiken, here today, but we are also working very closely with Chas Moseley who is in the audience.

He's with the National Association of State Directors of Developmental Disability Services, and I just want to acknowledge the work we're doing in partnership in this effort.

And, for the purposes of today, we're going to give you a brief overview of the progress that Ellen mentioned, to date.

We are collecting -- our goal, or the purpose of the project is to collect state level information about available services and supports for persons with autism.

And essentially, our overall research goal which many of you are familiar with and have provided input on is to collect and compile all in one place qualitative data on existing programs and policies for the following topics subject to data availability.

And, as you see here, it listed we're collecting information, both using qualitative and quantitative research methodology on -- from corrections, developmental disability services, early intervention, education, insurance, Medicaid, mental health, public health and vocational rehabilitation.

And so again, today we're giving you an overview of our progress one year into the project. We'll be presenting some of our findings related to the quantitative data work.

We also have some open research questions that we'd like to share with you and get your input on as we continue to move forward in working on this project.

Early on in the project we convened a technical expert panel, advisory panel to provide input on our data collection instruments and how to proceed and progress with the project.

We've held discussions with autism organizations. Many of you are in the room today with whom we spoke over the phone around several months ago.

And finally, related to collecting this information at the state level, we plan on speaking with -- to cover the topics that we are collecting information about, state level representatives from various different agencies and offices.

And in order to do that, we are required by the Federal Government to submit a PRA, the Paper Reduction Act, an OMB package.

And with the work -- working very closely with Ellen within CMS, that package has been submitted and is now in its 60-day public comment period. It was released in the Federal Register March 25th.

And so, we're expecting to be able to convene and start our interviews in June, at the end of June, early July. And again, as

Ellen mentioned, for a report that will be ready early January 2012.

Here's listed just briefly here -- I wanted to share with you who our technical advisory panel members are currently. We've also received, as I mentioned, very invaluable input from autism organizations, and many of you who are in the room today.

I am actually now going to turn over this portion of the presentation to my colleague Steve Eiken from Thomson Reuters. He's going to share with you some of our data -- quantitative data findings today. Thank you.

Mr. Eiken: Thanks, Alyson. I'll adjust the mic briefly. The quantitative data, the first thing I want to mention is that we collected the data we have. In a lot of cases there are really valuable supports and valuable government-funded work that benefits people with autism that we can't really capture in a data format.

Actually, Ms. Kavanagh's presentation on what HRSA is doing is an excellent example of that. HRSA and the Administration on Developmental Disabilities, and other agencies and NIH, do wonderful work that is more on a population and public health basis, so we can't link it to -- okay, here's a person with autism, on the autism spectrum, here's the service they receive.

The other thing that we really couldn't capture very well was housing-related data. HUD is -- their data is mostly structured in terms of who's in the household, do the people in the household have seniors, people with disabilities or not.

It's not geared toward what kind of disability. I think, frankly, if I were in their shoes it would be too overwhelming to get into different types of disabilities.

So, the first thing I want to mention for collecting state data on what is available right now, we also focused on publicly-funded programs.

There's a lot of great private work going on, private research institutions, privately-funded services and supports through charitable foundations.

We really wanted to stick to the state to publicly-funded services at the state level partly because it's a -- it's something that we could do within -- within the scope of work, also because it's a huge factor in terms of what people with autism receive. What you can get depends, to a large extent, on where you live and some of the political decisions made in those states.

Our data captured that. To some degree, it also captures, frankly, how states collect data differently, and we'll talk about both of those.

So, we'll talk about the number of people -- now, for this presentation, I'm focusing more on the national level because of our limited time, data on number of people served, some notable findings and explanatory information about state variation and limits on data availability.

There's just a really basic numbers. The special education data, runs from ages three to 21. If you look at the narrower age range, like age six and older it's around 280,000, and all these numbers, for reasons I'll explain in a couple of slides, I would consider minimums.

Basically we know there's someone in the data that has an autism spectrum diagnosis. We don't know when we don't, and sometimes that's because of data, sometimes it's because people aren't identified in the community.

Medicare, I think most of you all know about that program. SSI and SSDI, I'll just explain briefly. Those are income support programs through the Social Security Administration that are based on people with, you know, proving that one has a disability that is significant enough to warrant income support.

The SSDI number is particularly striking to me. I did not expect that we would have that many people. I did not expect we'd find 30,000 people. Those are all adults, age 18 and older.

What's -- in addition to having a higher benefit than SSI, it's also significant because people with SSDI and at least in two years can also qualify for Medicare, and then we have the vocational rehab number.

The notable findings, and I think this will be familiar to a lot of you, the autism spectrum is less likely to be reported for Hispanic individuals, African American individuals and American Indians and Alaskan Natives.

This is consistent with what we had heard was in the research literature in terms of more surveillance studies.

The second bullet, more than half

the adults with ASD that are receiving Medicaid also receive Medicare, dual-eligible, is the common lingo that we're hearing in -- my focus is Medicaid, long-term care and I hear a lot about dual-eligibles.

What's really exciting is that there's a potential for states to really innovate in terms of how to integrate services across Medicare and Medicaid. That affects the autism spectrum.

And the last two bullets relate to prescription medications. Using the Medicaid data, 82 percent of people with an ASD diagnosis received at least one prescription drug. By comparison, people with intellectual disabilities, the number was 72 percent, so it's a little -- a little more medication usage.

Thirty-three percent of the most common type of prescription was an antipsychotic medication. We didn't get to the level of what particular drugs are people receiving because, frankly, it was too much data. We couldn't do it within our project scope.

So, we don't know whether these are the drugs that have been FDA-approved for people with autism or whether there's others. We don't know -- we don't know that, unfortunately.

State variation. What's really striking when you look at the state data tables which we have not released yet. I think the draft is going to be reviewed by our technical advisory panel -- tremendous variation across the states.

If you look at the state with the smallest frequency and largest it's at least fivefold, often tenfold. Some of that is -- now, the other -- the first thing I thought is, okay, is this more how states report things or is this more how autism is identified.

The second bullet suggests that is

part of it is whether it is agreed the way autism is identified. States with a high percentage of people with ASD in one program say Medicaid or vocational rehab tended to have a high percentage in another program.

We just use straight Pearson's r correlation coefficient. We didn't get too fancy. We just wanted to see if there's a basic relationship here.

So -- and vice versa. So, there's a few states that are always in the bottom ten and a few states that are always in the top ten.

Within each program, states with a low percentage of people with ASD were more likely to report a high percentage of people with ID. That doesn't explain all of the variance, but it's definitely a factor in terms of a lot of people have both ASD and intellectual disability, and sometimes the data only include one of those.

Sometimes it's because you have to

use a primary diagnosis and, by golly, you've got to pick one. Sometimes the data -- there are options for multiple diagnoses, but the data just have one of those.

And we can't -- because we're not doing the population surveillance, we're not actually going into the people's records, we can't tell the degree to which that's happened, but we know that those two things can happen.

Data availability limitations. On the numbers that are -- were a couple slides above, are likely to underrepresent people with ASD for several reasons. We already talked about co-occurring conditions.

Also, states have flexibility in terms of how they provide guidance to their school districts for IDEA reporting. Some states have a developmental disability category. Some do not.

The states with the developmental disability category had fewer people with ASD because the two can co-occur.

The Medicaid data source also does not include all services. Services through managed care organizations and services that are not paid through the state's main Medicaid claims system are more likely to not be in the Medicaid database that we use.

Now, L&M and Thomson Reuters and NASDDDS, we all work together to come up with a few open research questions. We'd like to hear from the committee and from the audience, in terms -- to inform our development of the final report which will include qualitative information.

Basically, we'd like your thoughts in terms of things we should look at when we talk to states. The questions are on this slide, what are the top three policy priorities for Federal and state agencies to improve services and supports.

The second bullet within the context of declining state revenues, what recommendations do you have for people receiving supports for the first time?

And the final bullet, what data in the State of the States Report is most useful, and we can't change a lot of what we can do now, but we can definitely make recommendations for the future if the committee or if others decide to replicate a State of the States Report, we could definitely make recommendations for how to make it a better report.

And I'd like to let the second -- the next presenter speak before we do a question-and-answer, but this email address is available at L&M, and please let us know your thoughts. If we don't have time to do that today, please let us know via email.

Thank you, everyone.

Ms. Blackwell: Okay. Thanks, Steve. We really appreciate that and I hope that everybody will take this to heart and definitely get in touch with -- with L&M and

Thomson Reuters.

Our next presenter is Donna Mauch and Donna is representing our second contractor. On the CMS website you can now find a copy of -- actually, it's the second piece of a project that we've been working with IMPAQ International on.

The first piece was an evidence -- an evidentiary review of the evidence base behind certain services for people with autism and the second piece of this project, we actually went out and looked at nine states and highlighted promising practices.

I'm going to let Donna talk about those and thanks to her and her colleagues at Abt International and also Julie Young, who is the lead at IMPAQ.

So, Donna, thank you and welcome.

Ms. Mauch: Thank you, Ellen.

I'm Donna Mauch from Abt Associates, and I'm delighted to be here today. I'd like to thank Ellen for her leadership and the CMS leadership in promoting this work, and I want to acknowledge the important contributions from leaders in state government agencies around the country who contributed time and information to making this report possible, to program directors who I know have more than enough to do every day, trying to meet the demand for their services and to the individuals with autism spectrum disorders and their families who really inspire those individuals every day to do the jobs they do, and our team to do what we've been doing as well.

I want to double-check if I am to hit this to move forward. Yes.

So, I want to talk briefly about the purpose of the study, the study's methods, and then give some highlights of the key findings before going into some more depth on the promising practice profiles, and then circle back around to some of the implementation considerations in adopting more broadly evidence-based and promising practices.

Okay. So, there were nine states selected for this study, and they were selected in consultation with CMS to reflect differences in size, geography and program maturity so they would be broadly representative of all the states.

And we built on the findings of the environmental scan that had been conducted earlier in this project with IMPAQ International in the lead on that work, and built the data collection around a structured key informant interview that was used with state directors as well as an interview guide used with programs that were effectively nominated by the state leadership as reflective of promising practices in their states.

We supplemented those interviews with peer-reviewed literature and gray literature and other reports that were available.

The standard that was used to identify evidence-based and promising practices is the standard promulgated by the National Professional Development Center for Autism Spectrum Disorders. That was also the basis for the data-gathering in the earlier environmental scan.

Dr. Insel: What is gray literature?

Ms. Mauch: Gray literature is literature that is not peer reviewed, published in scientific journals but might appear in a printed format or an electronic format as reports on topical areas, white papers, articles in the nonpeer-reviewed press, et cetera.

Dr. Insel: Okay. Thank you.

Ms. Mauch: Yes. Thank you. Sorry about that.

So, some of the key findings. I just want to highlight a few at the beginning here. There is a strong recognition across the states of the growing prevalence and the unique needs of individuals who have autism spectrum disorders.

It's an increasing focus in state agencies on issues of agency organization, program financing and service delivery, but a lot of fragmentation persists.

Effectively, these states have legacy bureaucratic structures that have been in place for scores of years and are now trying to grapple with a need to focus discreetly on the needs of this group of individuals, and there are conflicting eligibility rules and policies.

It's been very difficult to align Medicaid, Title V and education policy, for example, for children, alongside multiple state agencies who might have mandating an entitlement legislation that was written 20 years ago or 30 or 40 years ago.

So, there are a number of crossjurisdictional issues that have imposed, and states are trying to recognize this. Pennsylvania, as an example of a state that has actually established a Bureau of Autism Services within the Department of Public Welfare.

Just for young children, that Bureau of Autism Services has to coordinate and align the policy and program and financing functions of five different governmental entities, the Pennsylvania Office of Child Development and Early Learning, the Office of Mental Health and Substance Abuse Services, the Department of Education, the Office of Developmental Programs, and the Medicaid Program.

So, there are substantial challenges out there. Missouri has also established an Office of Autism Spectrum Disorders.

States recognize that there are significant gaps in services and gaps also, as has been discussed here already this morning, in the evidence base, and I want to cite a couple of findings from IMPAQ's environmental scan that was done for CMS.

The scan looked at the evidence base for practices for young children, for transition-aged youth and for adults. Of 31 interventions that were studied for young children, 48 percent of those in evidence-based practice standard, 42 percent an emerging standard, and only ten percent of the interventions for young children had no evidence.

But when we moved to looking at services for transition-aged youth, only seven percent met an evidence-based practice standard, and 73 percent of those practices in place in states had little or no evidence behind them.

When it came to adult services, and there were only nine interventions reviewed, 33 percent met an evidence standard and 56 percent had little or no evidence.

So, this is a challenge confronting all of us, even as you, in this Committee, work hard to identify and transfer knowledge to the field.

There is a huge problem in state budgets, as been mentioned before, not to mention Federal budgets, and despite the challenges in the state budget environment, I want to say that what we found is that innovation is on the rise and that people are working in spite of that to try to implement evidence-based practice or identify promising practices and support those.

However, the budget shortfalls are driving tactics to control costs, so states are increasingly placing caps on the number of individuals served by targeted services for persons with autism and autism spectrum disorder.

They are placing limits on spending. Sometimes it's a cap for programs.

Sometimes it's a total case cost. And the waiver and demonstration programs are typically not serving high numbers of individuals.

Other findings. And the states and providers also identify that shortages in staffing, both licensed professional staff as well as line staff and staff and providers who have the competencies to serve individuals with ASD, they see this as a greater impediment, frankly, than budget constraints, and they talk all the time about it being a significant barrier to widespread adoption of these practices, and they are taking steps to promulgate program standards and practice protocols and staff training -- and we'll talk more about some of those.

There's also a growing interest in self-directed services in five of the nine states that we studied have self-directed services or have set policies and self-directed services, and all the states are setting evidence-based practice policies.

Some of those are found in amendments to their mandating legislation. California's recent amendments to the Lanterman Act, for example, and -- or states have embedded in their waivers, like Arizona and Connecticut, referenced to the use of evidence-based practices in autism.

So we profiled evidence-based practices in nine states. These are states -- I talked before about the selection. We asked the states to nominate a practice that they consider to be evidence-based and promising.

Some states actually nominated more than one, but we were also trying to get practices that were representative of services along the life span, and services that would reflect some kind of systemic intervention.

So, on the next slide I'm resorting these practices. We have -- are identifying a practice in screening, diagnosis and assessment, several in early childhood intervention and education, and then some practices in youth services, transition management and young adult services, and then adult services, and finally a couple of system improvement and capacity-building initiatives.

So, let's talk briefly about these. Missouri is the best practice guidelines for screening, diagnosis and assessment.

Missouri has had a Blue Ribbon Commission, a very active panel that took as its task the development of autism guidelines, something known as the Missouri Autism Guidelines Initiative, and because they identified that there was a significant delay in the diagnosis statewide of ASD, the average age was between five and eight years.

I can't tell you why there is such a swing in the average age reported, but this is how Missouri reports it. They realize that there are critical delays in intervention and missed opportunities to really support kids in critical developmental windows, and losing -- the loss of potential gains in development were really critical.

So they prioritized the development of these guidelines and got a broad group of stakeholders and experts involved to formulate these.

The guidelines actually include validated instruments. The autism diagnostic interview-revised, for example, the Modified Checklist for Autism in Toddlers, Childhood Autism Rating Scale and the Autism Diagnosis Observation Scale, just to name several of those that are part of this protocol.

And they took a tactic of both disseminating broadly. As of 2010, more than 6,000 copies of this had been disseminated to a range of stakeholders and practitioners, but also preparing shorter summaries that were targeted to specific audiences, families, clinicians, educators and program staff, wanting to engage them in understanding the critical importance of early diagnosis and to get the word out there about the importance of doing that.

They also provided training statewide for practitioners and they went on to support those practitioners with consultation and technical assistance that was based at four Autism Centers for Excellence in the state.

They also, fortunately, measured the performance of this, and so the reports coming out of one county, St. Louis County, in this case, showed that for 55 M.D.'s identified in St. Louis County performing developmental screenings prior to the intervention, 30 percent of them were doing general developmental screening and ten percent were doing ASD-specific screening.

After the intervention, 90 percent reported doing general developmental screening, and 80 percent reported doing ASD-specific screening.

Indiana's First Steps Early Intervention Program -- now there are Early Intervention Programs everywhere. Indiana focused specialized early intervention program on persons with autism spectrum disorders, defined eligibility as requiring a diagnosis of delay or a medical condition with a high risk for delay and going on further, to assess as kids are admitted to the program for autism and autism spectrum disorders.

They had very clear service objectives. They had really health promotion objective to increase awareness about autism and autism spectrum disorders, try to intervene early, to prevent disability and to promote maximum developmental gains, and to make sure that the providers who were reimbursed, the providers to whom they were referring individuals and their families, were qualified.

So, there's been a lot of work done on the certification of providers and on establishing adequate rates for providers who meet certification standards.

They also describe a strong element of family partnership, that they see this is very important, not only to engaging families to work alongside them, but to bring new ideas to the table and support the further implementation of services.

They offer a very robust range of services and the service coordination and social work elements of the service are considered to be very critical as kids transition from early intervention to early education.

They try to promote the use of evidence-based services, and certainly services to young children are one of the areas where there are more of those, and they describe the fact that most of the services they support and fund, and most of the providers they choose to reimburse are credentialed providers of ABA services.

The second program we took a look at, and I understand that we have on the phone one of the co-founders of this program, the Southwest Autism Research and Research Center -- I'm sorry. Research and Resource Center.

They operate a full-inclusion, normative preschool for children who are both typically-developing and children who are delayed because of autism spectrum disorder.

They have a two-to-one ratio of typically-developing children to children with autism spectrum disorders. They first enroll children at 18 months of age and will keep a child in the program through five years of age.

There's a strong focus on the development of language, social and play skills, and reductions in problem behaviors. Again, they, like other early intervention programs, try to maximize developmental gains and make sure the kids are as ready as they can be for school.

It is a very data-driven program that begins with comprehensive assessments and the program plans and individual service plans and education plans are driven by those assessments.

There's a strong focus on cultural competence in the program. They have a number of children who come from families where English is a second language, particularly Spanish-speaking families.

They have staff who are fluent in Spanish as well as in two Asian languages, as I understand it, where there are clients who are representative.

They also work on trying to respond to the needs in the community for children who are economically disadvantaged. There's a strong focus on providing access to services by developing funds for scholarships and that kind of thing.

The program offers 20 hours of intensive programming at the school, and eight hours off-site in the homes of these children, training parents and working alongside parents with kids.

They do use evidence-based practices in their program, and I've just cited a couple of them here, pivotal response treatment for kids who are not as verbal.

They also use the picture exchange communication system and they measure progress in these kids daily, weekly and monthly, and they use those measures to refine the service plan and to more discreetly target their interventions.

They use, again, validated assessment instruments. There are a couple of them listed here, and their outcomes research is underway.

California, the Therapeutic PATHWAYS/Kendall Schools Program, that is up in the State Capital area. The eligibility there is kids starting at 12 months of age, diagnosed with autism spectrum disorders, and they do not serve kids who have serious medical or severe intellectual disabilities.

They also want to serve kids who have a parent at home who -- or parents at home who are actively able to provide support and involvement with the program.

They, like others, have goals I've listed here, acquisition of adaptive behaviors, language, social and educational skills and a strong focus on self-management skills.

Their services are led by board-certified clinical staff, all certified to provide ABA services. The have an individualized curriculum and treatment plan that is formulated by these clinicians and their staff, their line staff area all trained in these methods.

Again, driven by data, they modify programs, individual plans accordingly, and they provide both center-based services and home-based services. The novel -- well, there are many strengths in this program, but one of the novel things is they have a program called Kids Helping Kids where they train peers to provide assistance to kids with ASD and to help with building social skills, building verbal skills and modeling behaviors.

Wisconsin. They have an initiative that is a joint venture of the Departments of Public Instruction, Workforce Development and Health, to bridge the transitions from education to young adulthood, from youth to young adulthood, and from education to work.

And, recognizing that multiple state agencies with multiple responsibilities are a lot for families and young people to negotiate, and they take the burden upon themselves to align their policies and procedures.

They've issued a transition action guide for post-school planning. It's built after three years of experience, really, in having an interagency agreement where they work together.

They published these in 2010, and they manage the transition by identifying six domains or tasks that each of the agencies work together on, setting measurable employment goals, identifying the applicable vocational and health services that the individual will need going forward, and beginning to build the referral packages to those agencies and focusing a lot on the needs and the strengths of the young people they are referring.

They begin this two years before graduation. Now, there are some provisions in IDEA that talk about this kind of transition work, but this is a state that's really taken this very seriously and has expanded this beyond the education department.

And each year they update the joint transition plan and share it with all the parties. And the other state agencies, the adult-serving agencies, like vocational rehabilitation and other parts of the health services agencies are encouraged to come to these interagency planning events for two years prior to their formal responsibility for these individuals.

Connecticut recognized that there were significant problems and gaps in services for young adults and transition-aged youth, and that vocational achievement was a big goal, so they wanted to focus on a demonstration that addressed both the lack of services and the high rates of unemployment found among young adults with autism spectrum disorders.

They measured their efforts. The University of Connecticut did an evaluation from the start with the hope that the outcomes would inform their Medicaid waiver which they have actually now gotten.

The results for the first 52 clients showed significant improvements in the quality of life and community involvement. Seventy-seven percent of them, as we know, meet their goals.

Improvements in living -- community living skills, the employment rates increased by 50 percent for the young people enrolled with 75 percent meeting goals and a very important finding, that there was a reduction as measured by interviews with family members in family burden and increased satisfaction among family members.

The young people, themselves, perceive that their -- not only their quality of life was improved, but their emotional problems had improved as self-reported.

However, the scales to measure depression and anxiety and other conditions did not show significant improvement.

But the good news is, people felt better, even if the scales were not reflective of that, they reported feeling better.

In Pennsylvania there was a, you

know, not -- characteristic of all states, Pennsylvania's adult services to persons with autism was all over the place and largely embedded in the DD system, and the health system.

And they -- the Bureau of Autism Services wanted to have a more focused initiative on meeting the needs of these individuals and felt that there needed to be a lot more coordination of care and integration of care and that, you know, as they began to look at the costs and the investments that were being made, they were finding that they were all over the place, not unlike the comment that you made earlier before.

Some individuals with the same level of need getting very few services, others getting a lot of services, and there was really inadequate documentation of services.

So they supported the formation at Keystone Services, the formation -- Keystone

Human Services, I'm sorry -- the formation of a, really, a small special needs plan that is capitated.

It's designed to provide a very broad range. There are 50 covered treatment habilitation and rehabilitation and support services, a broad range of services that can be provided to people through a live, active staff, 16 hours a day with back-up of on-call staff 24 hours a day and seven days a week.

Keystone manages all the care. They build the specialty care networks. They have seen substantial improvements in members' clinical status, the rates of employment in the population, independence measured as people living in the community independently, beyond family homes.

Their improvements in self-care and self-determination and reductions in family caregiver stress.

One of the challenges has been, particularly in some of the rural counties, recruiting enough physicians to serve these individuals, so they have been actually borrowing some of the lessons from their Medicaid medical home demonstration to find innovative ways to recruit and pay a premium to the physicians to participate in training and serve people.

Maine's primary care clinician training program, a rural state, very few developmental, behavioral pediatricians and a large concern about delays in evaluation and assessment, which is critical for eligibility and a diagnosis.

Also, many physicians uncomfortable treating individuals so families traveling a long way. A lot of disruption for individuals, themselves, in getting access to care.

So they put together a set of guidelines and began training in screening, in doing more physical exams, in medication management, particularly for psychiatric drugs and in providing community and family support and collaborating with other practitioners and treating co-morbid conditions.

The data -- this has just recently been implemented. They are providing consultation and technical assistance for ongoing support and they are collecting data to see what the results are because they are not yet available.

Finally, New Mexico. This is a rural and frontier state with a lot of challenges in terms of both the high needs of the population and limited numbers of trained professionals to meet the demands for care.

They have actually centered their resources at New Mexico's Center for Development and Disability. That is at the University of New Mexico Medical School, in Albuquerque, and individuals there really built a practice that started as a small clinic for autism services 17 years ago, into a major University Center for Excellence in

Developmental Disabilities Education, Research and Services.

So they get federal funding as well as funding from the state education department and human services department.

And they provide a range of services, including directly to the state department in helping them formulate program plans, in helping them develop contracting mechanisms.

They provide most of the training that goes on in the state and consultation, a major information and referral service. They have a mobile team available to go to rural areas to do assessments and diagnostic work and they have been really focused on filling critical gaps.

They are now conducting applied research and reporting on their experience, and they are testing a number of models for their cultural competence, recognizing the high percentage of individuals in that state who are Spanish-speaking and come from a Hispanic culture.

And they've really been trying to grow professional service capacity. They actually have a 30-hour training course in autism spectrum disorders and are beginning to certify staff around the state.

So I think we're running tight on time, so I'm going to wrap up here and actually just move for a second to that slide.

States are struggling financially, but they are committed to innovation, and there are huge fragments in policy and program and financing and this blunts the focus on ASD and frankly burns resources that, in coordination across government entities, that could be using -- being used to provide care.

The shortages in staff are substantial and they do pose a major barrier. States are looking for guidance. They are looking for assistance.

They want to make investments in

effective services, and they -- every state I've spoken with wants national standards, they want best practice guidelines, and they want technical assistance.

They are begging for the kind of support that you are offering. There has been a lot of talk in the states about a national knowledge network and, of course, we heard some discussion here today about the formation of those and the importance of that, wanting more resource and information exchange and the guidance that you're providing.

So, I just can't encourage the work of this organization enough. I will say that I have some concern that they are more focused in the states on the production of enough staff to implement the few evidence-based practices that we know about and there is not as much understanding about some of the developments, particularly in brain research and how that might spawn, perhaps less staff-intensive interventions.

If staffing is going to continue to be a challenge, and we know how important it is because these interventions depend on very careful, very thoughtful, very consistent work by staff.

But, if there -- as there are some techniques emerging, I think it's critical that states can understand better how they might consider implementing some of the technology-driven learning programs and skill acquisition programs. Thank you very much.

Dr. Insel: Thank you very much to all three of you. We have a few minutes only for discussion. And I know, Steve, you had asked for input from the Committee for questions that they'd like to see involved in these surveys.

But, time is short, but I do think we should take five minutes or so to get comments or questions from the Committee. So, let's open this up. And hopefully, we still have Steve and Denise on the phone.

Alison.

Ms. Singer: So thank you for this presentation. I thought that was great detail on the nine most promising sites, but it was a lot of detail.

So, if you had to just characterize what are the most -- the top three characteristics of a best practice center, because they are all so different and a lot of what you focused on was how they were different and a lot of the summary that you presented were based on needs, but what are we doing that's working?

Ms. Mauch: Well, I think the characteristics: clear program objectives that are measured, carefully-trained staff and the use of evidence-based protocols and assessment instruments.

And the assessment instruments being so critical because if you can't begin with a clear understanding of what the individuals' needs are, you really can't hope to reach objectives on behalf of those individuals.

And so many programs really don't start -- out there, don't start with a clear foundation of knowing what needs are.

Dr. Insel: Other comments. We'll go around the table his way. Ari, then Lee, and then Lyn and Henry.

Mr. Ne'eman: So, Steve, your presentation raised many questions for me, but since we're short on time, I have already taken the opportunity to email most of them to you.

Mr. Eiken: Wonderful.

Mr. Ne'eman: But, one in particular that I just wanted to ask, you know, here, so we could all hear the answer is, I know in the past when we had spoken around this, one issue that came up was trying to ascertain the outcomes and service utilization for autistic adults who do not qualify for Medicaid waivers by virtue of not meeting an institutional level of care.

And, you know, particularly in light of the Shattuck study which came out recently which found that so many autistic adults transitioning out of high school don't have access to any service provision.

I'm curious, you know, what your current work and what your research is showing for that population, you know, where they're getting services, if they're getting services and what kinds of outcomes we're seeing for them.

Mr. Eiken: Well, unfortunately, especially with adult services, we didn't -- there's not a lot of data out there in terms of outcomes.

We're -- Medicaid is such an incredibly complicated program, we're lucky enough if we can get the inputs right. And that's not a criticism at all. It's just a reality of the tremendous challenge of such a complicated program.

You're right. There are a fair number of adult -- of people on the spectrum who do not qualify for the Medicaid long-term care services.

In what we identified, about one-third of the people -- and this is across the age band, did receive some sort of Medicaid long-term care. Usually, it was a Medicaid home and community-based services waiver. Sometimes it was an institutional setting.

In terms of what the outcomes were, we really couldn't get there. I couldn't even get to what services are people receiving in the waiver or what services are people receiving out of the waiver.

A particular challenge here is that states use different coding systems. I know that there was -- my goodness, I think was working for a health plan in the nineties when a law passed requiring the standard coding procedures, but it's not all the way in place yet, and that makes it really hard.

I mean, you can't -- some states have different coding procedures, and I won't get into too much detail, but we're just not -- we're not there in our data systems and it saddens me that we're not there.

Mr. Ne'eman: One quick follow-up question. Is there any information about use of Medicaid long-term services and support options, aside from the waiver, including the personal care option and the 1959 option?

Mr. Eiken: I'll tell you about 1959. I highly doubt -- if it's being used by people on the spectrum it's probably a small number.

Most of the states with that option have benefits that are not a good fit for ASD. They are more mental health benefits. In terms of state plan personal care, I know that California -- I know from state studies that California and Minnesota, both -- about ten percent of their personal care population has a developmental disability of some sort.

So, the autism spectrum is a subset. Most states target their personal care benefits, specifically for physical disability which really limits that service for the spectrum -- for people on the spectrum.

We weren't able to get much data about that in this project, but I can just tell you from other stuff I know.

Dr. Insel: We'll need to go on. Because of time, I want to make sure we get some other questions in.

Lee.

Mr. Grossman: Yes. Steve, I'm looking at your open research questions, "What are the top three public policy priorities that need to be addressed by federal and state agencies?"

We often hear -- and certainly, in all these discussions, that there's a lack of coordination. There's not a seamless system out there for care across the life span, and I would like to see that somehow being addressed, and if there's any states that are really working towards meaningful systems change.

Mr. Eiken: Go ahead.

Ms. Ward: Thank you, Steve and Chas and nine others from our team have worked very closely in the development of our data collection instruments, not only for the data work that Steve has completed, but that is a question that's part of our interview guide that we'll be asking of the various people we plan on speaking to, to add to and provide some context to the data Steve has already collected and some of the gaps that he's identified when we have the opportunity.

So, thank you for the question.

Dr. Insel: Lyn.

Ms. Redwood: Hi. I'll try to be quick. One question I had was whether or not the database is going to be made public so that other researchers could dig a little deeper.

I personally would like to know what the other 77 percent of drugs are that are being utilized in ASD spectrums. I think there may be some clues there regarding comorbidities.

I also think we should look at why ASD is less likely in Hispanic, African American, and Native Americans. I know the assumption is based on lack of services or diagnosis, but there may be other clues in there to exposure factors as to why that population is lower.

And thirdly, I would like to know, with the final summary that the states want more national standards, they want more national knowledge network and more guidance.

Who is going to provide that?

Mr. Eiken: So I'll address the start of that. The data -- the Medicaid database is a public database, but you need a data use agreement with CMS because it includes some data that can be private health information.

If you Google ResDAC, and you might need a couple more words. You might need the word "MAX," which is the nickname for the database, the Medicaid analytic extract.

I bet if you Google ResDAC MAX, you'll get there. If not, send us an email and I can get you to the website that -- the ResDAC is operated by the University of -- I want to say Minnesota.

I live there, so I should know, but I don't. It's an "M" state. And they are contracted with CMS to help coordinate access to this publicly-available research file.

Ms. Blackwell: And Lyn, I would add that when this project is complete all the appendices and all the data for both this project and already for the nine states project is on the CMS website and the HHS website.

Dr. Insel: Great. Henry, last comment.

Mr. Claypool: I just -- thanks. That kind of answered some of my questions I wanted to ask about your data source, and you're using MAX data for the Medicaid questions.

So, there -- Lyn, just a caution. It can still be a challenge in terms of really getting solid answers to questions with this data.

It's reported up to CMS and it's -- it's not that it's unreliable, it's just not very clean, sometimes and it -- there's an awful lot of work that CMS is currently doing to improve its data gathering from states so that we can answer some of these questions.

And the other piece is, when you're looking at that 30,000-plus number of people that are on SSDI, are you looking at their eligibility pathway, specifically, are they -- are they disabled adult children, are they getting their SSDI through their parents, death, retirement or disability?

Mr. Eiken: Here's the surprising thing. Ten thousand -- about ten thousand of those 30,000 had a work history. They had a sufficient work history to qualify for SSDI.

About two-thirds were disabled adult children, which means that their parent -- they had a parent that qualified for Medicare, either based on a disability or because the parent turned 65.

So, that's actually a mix.

Mr. Claypool: And just to think about -- it's a priority for the department right now to look at this population of dually-eligible folks, and I know that I've talked with NASDDDS and others, but I really think that there may be an opportunity here to focus on a population with developmental disabilities and their unique clinical and long-term support needs and try and evolve some models based on the research that you've gathered here from these states.

Mr. Eiken: Yes. I would agree with that.

Dr. Insel: Marjorie, last comment.

Dr. Solomon: Just two fast comments. One being, I sort of hear a frustration that there's a lot of services but no one knows what the best evidence-based practices are, and I think about it.

Perhaps our Services Subcommittee, in the coming year could undertake to surface a tractable question that might make it into the strategic plan and there could be research designed around it.

And the second frustration I heard was that there's not enough staff to implement these programs, and I'm wondering if the LEND network could do anything related to that or if some of the other national standards databases like National Professional -- the Sam Odom effort might be able to brought to bear in order to help training more people, and that might be something else services subcommittee could look at.

Dr. Insel: Great points.

Ellen, we're going to give you the last word by way of gratitude that you've pulled all this together, and this has been about a two-year effort, I know, maybe one year that the actual data-gathering has taken place, but I wanted to make sure you had a chance to say the final benediction on this.

Ms. Blackwell: Well, I hope everyone takes the opportunity to look both at Part 1 of the IMPAQ and Abt work which is the environmental scan that looks at the strength of the evidence that Danna mentioned.

And also, the report itself. I just had it. It's in everyone's packet. This is it. It's also up on our website. And then, thanks Steve and Alyson, in particular, for their really good work that they did in looking at this data which, as Steve indicated, is really difficult to manage and at the moment, not great, but it is what we have and we are working to improve it.

So I think in the next ten years or so we'll be able to look back and say, "Wow! Here's what we had then and here's what we have now, and we'll know a lot more.

But it is good to know something. So, I thank all of these folks for their really good work.

(Applause.)

Dr. Insel: Thank you. And we'll move on with the agenda.

We'd like to hear from Jamie Kendall, who is the Deputy Commissioner of the Administration on Developmental Disabilities and the Administration for Children and Families on the Autism NOW web portal, so this goes back to a little bit of what we talked about earlier in the morning.

Jamie.

Ms. Kendall: Thanks, Tom. Can

everyone hear me? Okay. Great.

Good morning, everybody. I'm really happy to be here on behalf of ADD and Sharon Lewis who is usually in attendance at these meetings. She's off in Kansas City today at an advocacy summit.

So, we're excited about our Autism NOW Project, and I am going to cover five areas today in my remarks. I'm going to talk about some background with the project and then move on to the website portal, which we have a snapshot up here for you all.

I will speak also about our steering committee and national advisory committees, our Autism NOW regional summits, and webinars.

So the mission of the National Autism Research and Information Center is to be an interactive, highly visible, and central point of resource and information for individuals with autism spectrum disorder and for their families and for our stakeholders.

A goal of our center is to provide resources and information in core areas all across the life span. These areas include early intervention, early detection, early education, transition from high school into early adulthood, community-based employment, advocacy for families and self-advocates, community inclusion, aging issues, implementation of health care reform and specifically long-term care services and supports, family and sibling support and networking in the state, local, and national arenas.

Our model of support for individuals with ASD and their families reflects evidence-based research and best practices, and it is our hope that we'll be able to populate this portal with a lot of great information.

Our center activities will be based on a logic model, and all of the activities are aligned and reflect the principles of the DD Act. These are inclusion, integration, independence, and self-determination.

I'm going to move on to talk next about the website-specific criteria so, in order to have information based and placed up on our website we have come up with some agreed-upon principles for inclusion of information.

These criteria include, first, that they must align with the DD Act. Information must be written in a way that focuses on our priorities of inclusion, integration and independence and self-determination.

These are the values of the DD Act, and we want to make sure that information posted on our website is consistent with that.

Secondly, the information should be welcoming and respectful. Third, it must be unbiased. We don't want information that uses persuasive speech or tone and, most importantly, information must be based on evidence, facts and research.

Staff at the Autism NOW site will do the first review of material. At that point, we will share it with our advocacy advisory committee, who then will review, hopefully, within five business days -- that's our goal -- and make final approval to post on the website.

Christine, you talked about a lot of information you'd like to see up. We hope to hear from all of you regarding information you'd like to see up on our website. You can actually email Tonia Ferguson who is our center director. Her email is tferguson@autismnow.org.

So you can see, the portal is set up along specific areas. First is at home, living in the home and community living. Here we will cover aging issues, early intervention, and support programs.

We want to have information across

the life span. We want to have information from families and we also hope to post good information on relationships.

The second area is on the job. Employment is a very important priority at ADD right now. Within the on-the-job category, we hope to have information on vocational rehabilitation, supported employment, transition planning for job opportunities, and other employment research and reports.

We also have a category for in the classroom. Here we will cover IDEA, a good portion of information we hope to have is on developing person-centered planning and also IEP's which came up earlier as well.

The next area will be in the community. Again, we hope to have information on promoting inclusion, independent living, creating inclusive spaces, recreation, travel, transportation, and safety.

In an effort to get information out and to give visitors on our website, we also have a presence on Facebook and Twitter, so we're hoping to capitalize on the social networking.

We do have a project steering committee, and the goal of the committee is to provide advice and counsel for management of the project. We held our first meeting actually this last Thursday and there will be a meeting once a month.

And the steering committee will provide input on the design and implementation of regional summits, which I'll talk about, and also web virtual summits which we hope to have online.

Committee members will include parents and family members, individuals with autism, program staff, volunteers, and also individual state and local chapters from The Arc who have autism programs.

In addition, they will be working with our national advisory committee. Max Barrows is the chairperson of that committee.

And the majority of the members of this committee either have autism spectrum or will be a family member of a person who has ASD in their family.

Okay. Now I'm going to talk about our regional summits. You can actually register for our first one now online. It will be May 14th and 15th here in the D.C. area.

Space is limited. We are limited to 200 participants for each one, so if you're interested, I encourage you to do that. We will also be having more. Indianapolis, Indiana in June, the 25th and 26th. Orlando, Florida in July, 9th and 10th.

We'll be out in L.A. at the end of July, the 30th and 31st. And lastly, in Austin, Texas on August 13th and 14th.

These will be two-day events for us, and the goal of these events is to promote relationships, capacity-building between families, people with autism, and key stakeholders in the regions.

We're hoping to have good information-sharing and resources and interactive discussions and town hall meetings. We also hope to have exhibits by local and regional experts in topics such as employment, safety, disclosure, military family issues, self-advocacy tools, aging supports, long-term care supports, transition planning, and family support.

If you cannot be there physically, we will also have real-time chat options. That's for people who prefer to do that or cannot come. And we will have closed-captioning.

Finally, the last thing I want to talk about today is we have webinars we'll posting from our website. We just started those last week in honor of Autism Awareness Month.

The first one was "What is Autism? Autism 101", and the Autism Society of America was our host. We also did a second one on Thursday, which was celebrating autism, community and self-advocacy, and we had ASAN as our host, along with Autism NOW, and we discussed the importance of the self-advocacy movement.

Tomorrow, we'll be having a webinar on early detection and screening, and that will be hosted with the Autism Society of America. And on Thursday we'll be doing a webinar celebrating the autism community with the Autism Network International.

So I'd like to encourage all of you to check out the website, register. I think we're still working out a couple of kinks and we're hoping to get it populated every day with more information.

So keep checking back. It's a work-in-progress and by this time next month I hope there's a lot -- a lot more there than there is now, but we're off to a good start.

Dr. Insel: Thank you, Jamie.

Let's take a few minutes for questions or comments.

Ellen.

Ms. Blackwell: Jamie, thank you so much. When I saw this website on the agenda last night, as I told you when I came in this morning, I played with it and it's a lot of fun and it looks really good.

And because your first event is in the PG County area, I think May -- I've forgotten the date.

Ms. Kendall: 14th.

Ms. Blackwell: May 14th. It's a weekend. I think it would be great if folks could attend. It looks really interesting. So, congratulations and thank you.

Ms. Kendall: Thank you, Ellen.

Dr. Insel: Other comments or questions?

Dr. Solomon: I was just looking at this section, and that's wonderful. That's amazingly great information to have out there.

I haven't seen anything so comprehensive. So thank you.

Ms. Kendall: Thank you.

Dr. Insel: You're getting good reviews, Jamie. This is good.

All right. Well, we're right at noon, and we have another item on the agenda that was scheduled before lunch, but I'm going to see whether we could go back to the original twelve-to-one lunch break, maybe even come back a little earlier than one.

And then we have public comment and then we'll hear from Dr. Strickland and Ms. Southern after lunch, rather than before, if that's okay. Hopefully. And we'll -- that way we'll be able to get back on schedule.

Hopefully there -- some people who were scheduled to do public comments who are not going to be able to attend, so we'll be able to save some time in that one o'clock timeframe, I think.

So, we'll break now. Let's be

back, I'm going to say before one o'clock so we can start exactly at one o'clock. If you get delayed in getting lunch, bring it back. You can eat here, but we do want to get back on -- right on schedule. Thanks.

(Whereupon, the committee recessed for lunch at 12:01 p.m. and resumed at 1:01 p.m.)

AFTERNOON SESSION

1:01 p.m.

Dr. Insel: We are ready to get started. I wanted to make sure everybody gets to the table.

I have also been encouraged to make sure that you lean forward into the microphones so everyone can hear when you speak. As others have pointed out, this is kind of an odd configuration for the room since we have many people who have joined the meeting who are behind us. It feels a little bit like we are meeting in a fishbowl that way. It would be much better if we could turn all this around, but, apparently, there is no way to do that.

So, let's do this. I think we will change the order a little bit. We wanted to make sure that we have adequate time for public comment, and, then, we will come back to hear about JobTIPS after that.

We had scheduled 40 minutes for

public comment, but there are several people who have let us know that they are not going to be able to attend.

Each of the public comment participants have been given five minutes. As you recall, what we will do generally is have discussion about the public comment at the end of the day. So, we won't be responding to the comments after each person's oral presentation.

But, with that as a preamble, let's go ahead and we will hear initially from Laurie Reyes.

You can either sit at the table or use the podium, whatever you find most comfortable.

Hi. Hi, Josie. Welcome.

And we have a couple of other people. So, Laura Kavanagh is now sitting in for HRSA. Josie Briggs, welcome from the Office of the Director, representing Francis Collins. And Henry Claypool I think has had to leave us, as has Jamie Kendall, but they may be back in just a few minutes. We will hopefully see them in a few minutes, as well as Ellen Blackwell.

Welcome.

Ms. Reyes: Thank you for having me here. I really appreciate it. Thank you. I am very excited to be here.

It's funny, I did have three minutes and 47 seconds, but now I have a little bit more time, right? Like a minute more?

Dr. Insel: Right. You can slow down.

Ms. Reyes: Okay. Thank you. Thank you.

Normally, I just speak from the cuff, but since a lot of what I say, I want to get out everything. So, I am going to read from my iPad. So, we will see how well my iPad does on a presentation.

I am a police officer with

Montgomery County Department of Police. I am Laurie Reyes in Montgomery County.

And I need to start by saying thank you to all of the amazing caregivers and teachers of individuals with autism that never cease to inspire and amaze me with their strength. They are the ones who actually got me here today.

I am grateful to have the opportunity to speak to everybody.

First and foremost, I am here to let the autism community know that I am just one of so many police officers and first responders that care about the well-being of your loved ones with autism.

I have listened in to several IACC Safety Subcommittee discussions and felt the panel could benefit from the firsthand experience of law enforcement.

I have had the amazing opportunity to coordinate the Project Lifesaver Program in Montgomery County for the past six years. The

Project Lifesaver Program places trackable bracelets on individuals at risk to themselves if they wander.

Everybody familiar with Project Lifesaver? I am sure in this room they are.

Officers adopt, what I call adopt, a participant and meet them on a regular basis. There is actually an officer in the back of the room who has adopted one of the clients, and she interacts with this child on a regular basis.

This interaction helps develop an atmosphere of understanding and education between caregivers, the client, and the police. This program is just one way to help prevent wandering tragedies. It is in operation in over 900 agencies throughout the United States.

I wanted to discuss the idea of preventing incidents of wandering through a layered approach today. That is just my wording. But, basically, it says that there needs to be more than just tracking devices, but that there is all kinds of different things that could be put in place.

So, I am obviously a proponent of utilizing available tracking technology to assist law enforcement in locating the critically-missing person. All of those with autism who wander and are a threat to themselves if not located immediately should have access to tracking devices.

I have found through experience that tracking devices can be an excellent tool, but not the only tool. Educating doctors, caregivers, first responders, and the community on ways to prevent wandering tragedies is paramount.

I understand the controversies surrounding the idea of medically coding an autistic individual who wanders. Some are worried that if the child or adult with autism is labeled as a wanderer, they will be at risk of mistreatment from caregivers trying to prevent them from wandering. There is always a risk of mistreatment from caregivers, regardless of coding.

Coding should be coupled with education. As soon as the medical label, a code of wandering is established, parents would immediately be educated on prevention as well as provided access to whatever tools and resources were necessary to prevent an incident of wandering from becoming a tragedy.

Medical labeling of wandering leads to a heightened awareness and creates a dialogue surrounding the dangers of our most severely-impacted loved ones with autism. I feel that medical coding of wandering is just the first layer of protection, and this is my layered approach.

Beginning from the time of the initial diagnosis of autism, medical personnel should educate caregivers on the potential risk of wandering. Caregivers should be provided with resources of wandering prevention.

In the event of a search, regardless of whether a tracking device is operational or being used at all, first responders should be trained to quickly respond to a call involving a critically-missing autistic person. They should be trained to ask the right questions to caregivers and quickly go to bodies of water and other potential dangers.

If the panicked caregiver under stress forgets to provide important information related to their child, the emergency call-taker will know to ask questions related to the dangers specific of autism.

If the officers responding are not familiar with dealing with individuals with autism, the parents should already be educated to have a script prepared to relay important information.

The caregiver should know to be

calm, yet forceful, and become their child's advocate at the time of the incident. Parents should know what information needs to be relayed to responding officers immediately. Parents should be informed to tell their neighbors about risks in the neighborhood if their child should wander, pools, traffic, and any other dangers.

The community, including the police, should understand that wandering incidents can happen to the best of caregivers. Some caregivers just don't know where to turn for advice and guidance. They are making up the rules as they go along and may not be making sound decisions, to no fault of their own.

Many autistic children may never wander, but for the ones that do parents need to have resources available to prevent a tragedy.

Thank you.

Dr. Insel: Thank you very much

for joining us. And as I said, we will loop back to your comments later in the meeting and have a chance for further discussion.

Ms. Reyes: Thank you.

Dr. Insel: I would like to invite John Erb.

(No response.)

In that case, we will go on to Mark Blaxill.

Mr. Blaxill: Good afternoon, everyone.

My name is Mark Blaxill, and Lyn Redwood has encouraged me to make some specific asks. So, I am going to read my statement, but I will embellish just slightly with a couple of specific things for you all to consider for later.

I am the father of a 15-year-old daughter diagnosed with autism, Director of SafeMinds, and Editor-at-Large for The Age of Autism, the online web newspaper of the autism epidemic. I am also a co-author of The Age of

Autism: Mercury, Medicine, and a Manmade Epidemic.

Since our book was published last September, I have had really an extraordinary privilege of traveling across the country at book events to meet with dozens of groups and thousands of families that are affected by autism.

I was deeply impressed by all the affected individuals, mothers, fathers, and family members that we met on our tour. But, above all else, I was impressed by how so many families have the same story to tell and by how many of us are asking for the same thing, and asking you for the same thing.

We are asking for bold leadership that, unfortunately, we have not yet seen. I will be direct. Most directly, in the midst of the greatest childhood epidemic of all of our lives we are trapped in an historic failure of the scientific process.

Many of you may remember Thomas

Kuhn's book, and Kuhn taught us how communities of normal scientists can prevent progress and trap important fields of inquiry in a scientific orthodoxy.

We have seen this pattern play itself out in autism, first, in the now-rejected idea that parents, and especially mothers, caused autism because they hated, indeed, they even wanted to murder their children. More recently, we have been trapped in an equally failed search for inherited autism genes.

In the meantime, we are investing next to nothing in environmental causation. This, as anyone could tell you walking the streets in the autism community, is a fundamentally irrational approach. Yet, the orthodox researchers who benefit from this irrationality have defended their territory while they invoke science in the name of their own interests.

Just to reflect on your mission

here, not a single dollar spent in the process has prevented a single case of autism. Worse than that, we are spending millions of dollars now to promote the denial of the reality of the autism epidemic.

So, one ask, one specific ask I would make in Lyn's spirit is to begin making rational decisions about allocation of funds. Focus your funding and investments, our public investments in research on environmental causation, and please stop spending money promoting theories of social causes of autism and epidemic denial.

Further, in an environment of increasing budget scarcity, this is more than just a scientific failure; it is an economic one as well. We are wasting taxpayer dollars and approaching the governance process of the autism epidemic with a lack of urgency that seeps into all aspects of autism science.

At NIH, you are a near monopsonistic buyer, and you have a unique power in setting scientific agendas. In that role, in that unique position that you play, the IACC should be serving the consumers of autism science. Instead, you appear to many of us to serve the medical industry, aiding and abetting the fiction that the controversies over autism research pit, quote, "parents versus science." That couldn't be further from the truth. In reality, the controversy is one between critical consumers of autism science and the orthodox producers whose work has so far failed us.

In the debate between the autism community and the medical industry, your responsibilities here should be clear. And one ask I would make in that respect, a specific one, is that you need to take the concerns, the frequently-expressed concerns over vaccine injury seriously and not reject them as just the fringe concerns of some whacked-out bunch of crazies. And vaccine injury, vaccinated versus unvaccinated science deserves serious attention and funding, which it does not receive today.

These are not abstract problems. One of the things we write about in our book is the evidence that is very clear. Before 1930, the rate of autism in the world was effectively zero. Before 1990, autism in the United States was exceedingly rare, as low as 1 in 10,000. Today, we are facing roughly 1 percent of children born in the 1990s.

It is should be breathtakingly clear to us that autism is manmade. And that fact makes the autism epidemic not merely a public health crisis, but also a crisis of public ethics and morality as well.

Hundreds of thousands of children now growing to adulthood are victims of preventable injuries, a form of violence, a form of invisible violence. Because it is invisible, it is a form of violence that requires witnesses. Unfortunately, the nature of the injuries involved require witnesses that have a scientific, medical, or technical background and training. But, in large part, this witness pool also has career and economic interests in the medical industry, one of the main suspects of the environmental causation problem.

Tragically, but perhaps not surprisingly, we are seeing, also, not just a scientific failure or an economic failure. We are seeing a moral failure of enormous proportions as potential witnesses are sanctioned, censored, intimidated while the entrenched power of the orthodoxy successfully sustains its prerogatives. This is not right. More to the point, it is not good. And it is long past time for a change.

And so, my final ask is a broader ask. More than any other single group of individuals, you members of the IACC are in a position to lead a change. That requires many things of you.

It requires you to show up and pay

attention. It requires you to think independently and rationally. It requires you to take personal risk. It requires you to challenge close friends and colleagues who are part of the orthodoxy that perpetuates the problem. Above all, it requires moral courage.

The only thing it does not require is that you wade through complex machinations of epidemic denial because the problem really is that simple. It is staring you in the face.

As parents, we are staring you in the face, and we are asking you for change. Because autism is what it is, we will continue to stand in front of you until we are gone or until you have done the right thing, whichever comes first.

Thank you very much.

Dr. Insel: Thank you.

We have a couple of other written comments that have been submitted that were going to be oral comments, actually, some of which sound very much like what you just heard from Mark. And because the people were not able to make it, I would just refer you to what you have been handed out. So, you have their comments as part of the package that you received.

In addition, there are others who have made oral comments or have submitted written comments that I want to make sure everyone on the Committee has read.

We have a couple of other comments for people who were able to make it today. Jim Moody and Lori McIlwain are on the agenda here.

Ms. McIlwain: Thank you. Thanks for this opportunity once again to speak to you.

I know the first sentence says four children have died. That number has changed. In recent weeks, five children with autism have died following a wandering-related incident.

As summer approaches, we anticipate more of these deaths. Parents listening in are invited to log onto awaare.org. That is "awaare" with two "A's" in the middle, "dot org" for wandering prevention information.

One year ago and again this past October, the National Autism Association stood before this Committee to address autism fatalities, in particular, those with wandering-related incidents and elopement.

During both meetings, we requested your assistance in obtaining potentially lifesaving resources, including a medical diagnostic code for wandering similar to that already established in the Alzheimer's community. We received no opposition at either meeting regarding this resource and no cause for concern.

We wish to thank IACC members who took urgent action on the wandering issue and unanimously voted to form a Safety Subcommittee. What you accomplished in a few short months will, no doubt, work to save lives. And that is coming from me, who has been working on this for four years. Thank you, especially to Dr. Rice.

I am speaking to you today as a Committee, but also individuals and advocates and org leaders who have access to resources. It is our strong belief that every member in this room has our community's best interest at heart.

The sudden opposition received by other IACC members in relation to the wandering code and other lifesaving resources was eye-opening for us. It has led our organization to reevaluate how progress can be made for our children and adults, and how unintended consequences of autism's broad labeling may play a significant role in limiting future resources for our sickest kids and most vulnerable individuals.

A shared diagnosis that embodies multiple meanings to multiple subgroups within our community is an ongoing challenge. And we fear the population we represent stands to lose the most. How do we make it so that all individuals on the spectrum gain access to what is needed without label crossover jeopardizing the medical needs of those most profoundly affected?

The autism we represent at NAA is a very specific kind. Each time IACC holds a meeting, our autism is unable to physically be here and have any sort of tangible presence.

Our autism does not have a microphone, seat at the table, or the opportunity to raise its hand. Our autism is the one that does not speak or respond, play or socialize.

Our autism wanders off and drowns, gets left in a hot van, is restrained until suffocated, disfigured after bolting into traffic, dead after two days in the cold.

Much of our autism is the regressive kind that has increased in numbers, and we still do not have a firm answer on whether those numbers have increased as a result of a true rise. In 2009, it said it could not be ruled out, a true rise could not be ruled out. We need a definitive answer on that.

It is this autism at greatest risk of being exploited, raped, abused, lost, neglected, and killed. It is the one most unwanted by schools, underserved by federal and state funding and disability organizations, and misunderstood by society and members of its own community. And parents like me often hear the words, if that's your autism, you must be doing something wrong.

If our autism were cancer, it would be stage four. If our autism were a blood sugar disorder, it would be insulin-dependent. On Maslow's hierarchy, our autism would be at those bottom two levels.

It is difficult to focus on psychological needs when physiological and safety needs for our children and our adults remain unmet. Our autism is desperately ill and in dire need of medical treatments. Our autism is seizures, head banging, insomnia, crippling bowel disease, debilitating fear, overwhelming sensory dysfunction, pica, and self-injury.

It defines human beings, young and old, who are severely impacted and the families who live in constant prevention and survival mode. We need a crisis-level response specific to their needs.

I have attached a photo of Brian Blakey. Brian is 31 years old, and he wandered from his day program in Arizona, where he proceeded into traffic and was struck by a vehicle. Brian's biggest challenge used to be autism, but now it is a traumatic brain injury.

So, how do we recognize that those

with unmet needs may never have the chance to be independent if they are further injured or killed? How do we help them specifically? How do we recognize that, if we are negligent to individuals like Brian, they are going to get injured; they are never going to have a chance for a lifespan, for independence, for self-determination?

At each IACC meeting, we hope to begin seeing and hearing from the children and adults most profoundly affected by autism. Public statements alone cannot illustrate their true challenges. They deserve constant visual presence among IACC members, so that their struggles remain an ongoing part of the decision making process. The suggestion came up that maybe we could show videos during public comments of these children.

Beyond a stronger presence, our autism needs right now resources. It cannot afford watered-down research and broad solutions that have no application. It also cannot afford for us to filter and edit our words when seeking specific solutions.

And with that, we raise the difficult question, should there be better identification, qualification, classification, or someone called categorization, of this disorder, so that our most severely-affected individuals may receive specific medical attention and resources they need without risk of crossing over into other subgroups of the spectrum who do not want or need those resources?

It is Autism Awareness Month. Let us be aware of those unable to be in this room today and their specific needs.

It is also National Child Abuse Prevention Month. Abuse of our children with autism is a key reason why NAA requested that an IACC Safety Subcommittee be formed. And in closing, we ask Safety Subcommittee members for their help and guidance in obtaining the following:

Data collection to gain understanding of autism abuse, restraint, and seclusion in schools. And that would be data collection coming from the parents, not the schools.

Mandatory electronic monitoring in all special Ed. classrooms.

Federally-backed and widely-distributed educational materials for autism caregivers on how to prevent and respond to abuse, restraint, and seclusion in schools. I can't find any information on any federal disability websites as it pertains to restraint and seclusion. I don't know how parents are supposed to get this information. And that is for the lucky ones who have internet access. So, the ones who have no access at all to the internet have nothing.

Request to HHS and the Department of Education for accessible, ongoing, positive support training and education for special ed staff across the country.

Child protective services and social services jurisdiction over schools. Currently, state agencies assigned to protect children and investigate child abuse or neglect are unable to protect these children in schools or investigate alleged abuse by school staff.

In-classroom placement of signage and messaging materials directed at special Ed. staff that serves to prompt, encourage, and remind staff to use positive behavioral supports instead of practices that pose serious health risk to our children. And we provided examples of a more positive approach to take with that. We feel it is something that can be very easily done. Even if laws pass, it would take two years at least to get those in place. Having in-classroom messaging pretty much serves the same purpose for teachers who need that messaging right there.

And we also need support of federal legislative efforts, particularly bill

1381 just introduced, that work to eliminate dangerous restraints and seclusion in schools. We will be back, rest assured, to address bullying at the next IACC and other autism-specific issues.

And we extend our sincerest appreciation for your ongoing support.

Dr. Insel: Thank you.

The last public comment is from Lindsey Nebeker.

We want to try to stay within the five-minute boundary, if we can, because there are so many other things we are trying to accomplish today.

Ms. Nebeker: Well, before I begin, what I will be speaking up here is an abridged version of the written copy that you have. So, my recommendation would be for you to hold off reviewing the written statement until after I finish speaking.

Members of the Committee, I would like to thank you for providing the opportunity for me to share my thoughts with you today.

My name is Lindsey Nebeker, and I am personally representing myself as an individual with autism.

Let us open an additional conversation into the topic of safety. As I have shared in my past comments to the Committee, I have a younger brother, James, who also has autism. Due to the severity of James' condition, his needs for services have been far greater.

Eleven years ago, at the age of 16, James was placed into a group home under the care of full-time staff, due to my parents' aging and limitations regarding their strength to care for him. As of now, in his current place James appears in good physical health, and my family trusts that he is being treated well by his caretakers.

So, what would lead me to still be concerned? When my parents die, I will become my brother's legal guardian. I will be holding the responsibility of ensuring his care, his safety, and his well-being.

James' home is nearly 2,000 miles out West. This makes it extremely difficult for me to be able to monitor what goes on in his home or how his days are spent, and it goes beyond his tendencies to wander because safety does not just refer to protecting the adult while outside the home. Safety also refers to how an adult is treated inside the home.

The New York Times recently published an article on a year-long investigation into more than 2,000 state-run homes in New York. During the investigation, The Times retrieved a long list of accounts of sexual abuse, physical abuse, discrimination, and other dehumanizing behavior, around 13,000 allegations in 2009 alone.

Times that by 50 for each of the 50 states, and you have a possibility of

650,000 incidents of abuse to adults with developmental disabilities, including autism, across the United States in 2009, and a mere 5 percent of these incidents gets reported.

It would not be surprising to hear if a high percentage of these incidents involved individuals who do not speak or have difficulty in communicating.

As one of the supervisors confesses in an interview with The Times, quote, "It's a hard road without a confession by the defendant."

So, how can research help with this issue? Two ways. First, research can help determine what training is most effective and what can solidify stricter requirements of the employees who work in state-run and private-run residential programs. A list of specific areas of focus is provided in the written copy of my statement.

And second, research can help the individuals with limited or no language skills communicate more effectively. So, in the event they do run into a violation of their personal safety, he or she will know how to communicate it to loved ones, law enforcement, or other authority.

As of now, James, who is in his late twenties, is still unable to speak or use a communication device, is not able to tell my parents nor myself what has occurred during his day, how his staff treats him, or if his rights are violated.

I would like to close with a thought. If there is one thing that unites us as a community, it is this: providing the best for our individuals with autism and ensuring their happiness.

There is no reason, given the right accommodations and support, that every individual can participate in being a citizen, the thing that defines us as people who have a role in society, and as an individual with autism, I can testify to that.

What connects my brother, myself, and all of us in this room is that we are humans. And as humans, we have the capability to recognize when we are of worth and when we feel belonged. The least we can ask is our basic human right to be treated with dignity and respect.

But it is nearly impossible for a person to know their self-worth when that person is not surrounded by an environment of others who can teach that person their rights to dignity, respect, and self-worth, to ensure the thousands of adults in residential placement of fulfilling quality of life.

So, I encourage you, as we continue to have a conversation on many important issues, regardless of the issue, that you continue to remember your influence and your roles as members of the Committee, and the potential you can initiate towards providing those who will become adults and those who are already adults one step closer to achieving what could possibly be the most important basic human right, the right to have a voice, a voice which holds the key to full inclusion in the human race.

Thank you.

Dr. Insel: Thank you, and thanks to all those who provided oral testimony.

We also, as I mentioned, have the written version of each of these statements, as well as those from people who didn't make it today. So, I would encourage you to look through all of that. We will have an opportunity at 4:30 to circle back, so that we can comment on what we have heard and what we have read.

I want to go back in the agenda in a little bit to catch one of the presentations that we missed before, which was from Dorothy Strickland and Louise Southern about the new JobTIPS website. And so, if I can have Dr. Strickland come to the podium, and we will have a chance to tell you about this as well.

This is just one other of the many things that have emerged as part of Autism Awareness Month that we thought would be good for you to hear about here.

Dr. Strickland: Hi. Can you hear me?

Do2learn is a website that we have had up about 10 years, which takes sort of the treatment techniques that the people here and people in the community have worked to develop and puts it out freely for individuals to use to help them with the people they work with who have autism.

JobTIPS is really just an extension of that that we have been able to put together through funding from the stimulus grant.

In autism, JobTIPS' approach is a skill that this Committee and most of our million users have pointed out is needed, which is transition services as a child goes into adulthood.

What JobTIPS is a web-based, freely-available. We have no advertising on it. It helps individuals evaluate, find, and keep a job. It is really a toolbox for not only individuals and their caregivers, but for professionals.

There is a resource toolbox that is coming up soon that will contain information that support agencies can particularly use, such as the legal responsibilities of employers.

Its design is that, if you are a professional, you will be able to get information that might be helpful for the people that you are supporting. If you are an individual in an area where you don't have services, you should be able to go in, access the material. And in fact, for those who may be at home now, you should be able to go to Do2learn.com, click on the JobTIPS, and you should be able to go to the website live.

It has hundreds of pages of guides

on how to get and keep a job. It has modeling videos. It has checklists, schedules, remote devices, print guides. It is actually designed to take the techniques that our professionals have claimed are the most effective in helping individuals transition and putting it out in a clear, easy-to-use, no-nonsense way.

It targets complex social skills such as the why something would happen. We have been supported by NIH for about 10 years. And during that time, in our studies we always try to explain the theory of mind behind it, because we have determined that generalization occurs more often if you understand why you are doing something.

There are actually four parts of JobTIPS. The first part that Louise is going to talk about in just a moment is what is available right now. It is basically the core information that an individual and a caregiver would need in order to understand the skills that would be necessary to evaluate, find, and keep a job.

The second part, which will be out later in the summer, is a toolbox which is for support agencies. And again, it will be at the site, freely available. If you go to the site, you will see when it opens up, that you will be able to get to it.

The third part is a virtual reality practice space, which is designed to let individuals read the material on the website and, then, go into a safe place with a therapist or a professional and practice the particular skills that they are trying to learn.

And the fourth part, which will be available next year, is a controlled study. In the controlled study, as we do in all our studies, we test not only will they learn from using the material on the site, but will they generalize it. So, it will be actual job interviews with professional interviewers to see if people get better from using these tools.

And the truth is Louise Southern is the one who is the heart and soul of it. So, she is going to present the details of the site now.

Ms. Southern: There is a wonderful team of people, educators, psychologists, and technological gurus who helped to develop this site. So, I definitely do not take all the credit for this.

My objective in this brief talk is just to highlight for you the core sections of the JobTIPS website that are currently live, and also to underscore our implementation of key strategies and principles that we view as vital to the effective instruction of individuals with autism.

So, there are four core sections to the JobTIPS website as of now. Those are determining interests, finding a job, getting a job, and keeping a job.

Our "determining interests" section, the objective of this section is really to assist our users in identifying their strengths and interests as they relate to vocation, and, then, helping our users align those strengths with specific vocational domains that they might further explore.

The "determining interests" section contains several informal assessments of social and communication skills. The results of those assessments can be used to assist our users in identifying what levels of social demand might best fit with their levels of social competence.

We also offer an informal interest quiz. The results of this interest quiz might yield out to a list of 50 jobs that the user could further explore in our job description section of the website.

Our "what's your scene" section links back to the informal social skills assessments that the user would encounter at the beginning of the website. The purpose of the "what's your scene" section is to encourage our users to consider how their levels of social competence might align with the level of social demand that is inherent within particular jobs.

We conceptualize most jobs as being either in-the-scene, behind-the-scene, or out-of-the-scene jobs. For instance, what I mean by that is that an in-the-scene job would be one that requires frequent and direct interaction with customers and coworkers across the day. So, that is sort of our conceptualization of "what's your scene."

Also, in the "determining interests" section of the website, we include a section called environmental demands. And what we do in that section is define for our users specific environmental demands that they might encounter when they are at work.

The environmental demands that we define are such things as the physical conditions of the environment, such as noise level and lighting level. We also define work pace requirements, work attire requirements, and, also, structure and predictability levels that exist within various jobs.

In addition to defining these environmental demands for our users, we also provide them with an array of coping strategies and workplace accommodations that they might arrange in order to mitigate some of these environmental demands, and, thus, perform more successfully and happily in their jobs.

The next core section of the JobTIPS website that is live right now is finding a job. In our "finding a job" section, we walk our users through the steps and social nuances of such job-finding activities as networking, attending job fairs, and conducting door-to-door searches. We also guide our users through the often very confusing online search domains, as well as newspaper resources for finding a job.

This is an example of several printables from our "finding a job" section of the site, just to give you a sense of what those might look like. However, as of right now, we have well over 300 free and downloadable printables accessible across the JobTIPS website. These printables come in an array of forms. There are visual checklists, cue cards, scripts, worksheets, graphic organizers, and key points summary.

Obviously, our objective in providing so many free and downloadable printables is to promote practice opportunities for our users with autism and, also, of course, to promote retention of the key concepts.

This is a page from one of our job fair subsections. This page exemplifies our use of task analysis and visual supports, which is a strategy that we employ across the website.

Basically, on this page, I don't know if you can really read it, but we are essentially walking our user through what they would do and what they would say as they approach a job fair booth, for those individuals with autism who are brave enough to go to a job fair.

The third core section of the JobTIPS website is called "getting a job." In "getting a job" we offer an array of usable templates and examples of resumes, cover letters, and job applications. We also walk our users through who they might ask to serve as references for them, and, also, how and when specifically they would ask someone to serve as a reference for them. And in doing so, we are walking them through the social nuances of this as well.

A very large subsection of the website, of this section, is devoted to interviews, everything that should happen before, most importantly, during, and also after the interview.

And we also guide our users in the decision of disclosing that they have a disability. We help them weigh out our content, helps them weigh out the pros and cons of disclosure. And, also, if they do decide to disclose, how do they disclose and when do they disclose? Do they disclose during the application process, during the interview process, once they have been hired, or when problems occur?

Throughout our website, you will find what are called "why" boxes embedded within the content. There is a "why" box extending to the right of the screen right now.

Essentially, what we are striving to do is not only tell our users what they should do in a given context, but, also, we want to provide the rationale behind that targeted response or social nuance. And again, these "why" boxes are embedded across the site. And, of course, our goal is to promote the perspective-taking skills that one would need in order to better understand and predict behavior.

Also, in our "getting a job" section, we deconstruct the pre-employment screening assessments that many large corporations such as Target, Wal-Mart, McDonald's, et cetera, now utilize to screen applicants.

Given how difficult these pre-employment screening assessments can be for one to navigate to interpret, we also offer two full-on practice assessments that we developed at JobTIPS, which are closely aligned to many of the corporations that we developed. Of course, the content is all our own.

And we also, in that process of them taking those practice assessments, we offer them comprehensive answer keys explaining what are the most desirable responses that these corporations are looking for and why are these the most desirable responses.

As of now, we have approximately 150 videos in the JobTIPS website. And given that this is, of course, a web-based tool, we thought it was very important to incorporate video modeling into our site. I say there is 150 because that is certainly anticipated to grow to well over 200, when it is all said and done.

Every single video on the JobTIPS website is captioned. Most of the videos are presented in side-by-side sets, so that the user not only gets to view the targeted appropriate response, but also the inappropriate response in the same context.

And at the conclusion of each video, there is a visual icon to signal that the response was either appropriate or was less appropriate. The appropriate response is signaled with a green checkmark, and the less appropriate response is signaled with a red "X." And again, these are live on the site right now, approximately 150 thus far.

Another strategy that we employ across the site is scripting. We offer an array of scripts in a variety of formats, visual formals, and also on a variety of topics. These are scripts from the "getting a job" section of the site, but we cover such topics as how you would approach a manager to ask for an application to how you would disclose that you have a disability in an interview, to how would you make a social initiation with a coworker, to how you would ask a supervisor for assistance when you are on the job. The vast majority of these scripts are printable, and there is well over 100 of them on the site thus far.

The "keeping a job" section is the last section that is live on the site right now. It is definitely the most comprehensive section of the site, as it seeks to address the myriad of challenges that individuals with autism often face in maintaining employment. We explicitly address such issues as grooming and dressing, accepting feedback from supervisors, tolerating changes to routines and procedures, and managing down time and breaks at work.

We offer an array of time management and organizational strategies that our users might arrange or have someone else help them arrange those. These strategies range from left-to-right work systems, picture schedules, up through monthly, daily, and weekly calendars, and an array of other organizational systems that might be necessary to promote more independent and accurate performance on the job, as well as to reduce anxiety of the employee with autism.

We certainly view the arrangement of visual supports and structure as one of the keys to success of independent work for many individuals with autism.

The vast majority of our content overall, but particularly within the "keeping a job" section of the site, is devoted to the social demands that one would encounter. We target such topics as small talk and conversations, what it means to be a team player, how you distinguish between private versus public behaviors, what are the rules regarding personal space, how do you interface appropriately with customers, and an array of other issues that I am about to touch on.

This is just a snapshot from our "small talk and conversations" section of the site. One of the things we target again and again are perspective-taking skills in order to help our users identify what the conversational partner might be thinking and feeling in a given context. And we use an array of different visual representations to try to teach this.

We also use concrete and explicit visual representations of the social norms that govern, or should govern, behavior. This is an example. This is a snapshot of our personal space page.

And in response to the fact that so many individuals with autism often struggle to cope with the social and environmental and performance demands on the job, we devote a very large section to coping strategies. In this section, we assist the user in identifying what are their personal triggers, their stress triggers; what are some effective coping strategies that they might practice and implement; and, also, what visual coping plans might they arrange that they can then rehearse and also implement when things might escalate.

And finally, as we are all very well aware, the issues of workplace bullying and harassment have certainly taken center stage in many vocational and certainly educational and cyberspace contexts. And so, we at JobTIPS thought it was important to respond comprehensively to this issue.

One subsection within the large bullying section is called "developing response plans." Of course, in this section what we are trying to do is arm our users with practical and safe plans that they can practice and, then, implement in the face of workplace bullying and harassment.

I hope that this quick overview has given you a sense of the breadth and depth of the JobTIPS website. Our goals were really twofold. It was to develop a comprehensive vehicle of self-instruction for individuals with autism and, secondly, as a former special educator, also, we hope it will serve as a curriculum that educators, job coaches, and clinicians can implement as they seek to support individuals with autism.

Thank you so much for the opportunity.

Dr. Insel: Thank you very much.

(Applause.)

We have just a couple of minutes

because we are so far behind schedule, but I wanted to make sure that the Committee had a chance to respond, either with questions or comments.

Ari?

Mr. Ne'eman: Yes, first, I wanted to thank you for putting together a very comprehensive resource.

I had actually seen some of this earlier and took the opportunity to send it to some folks within our organization, all of which are autistic adults who are either seeking employment or are in employment. And there was a lot of positive feedback. It seems like this is a very comprehensive resource.

One area in which I know some folks did have some concerns is the social assessment that you put up. My understanding is you have folks take a test with a proxy, and where the proxy's answers differs from the self-advocate's answers, the assumption is that the proxy's answers are the correct one. I think that is not necessarily the case for every job-related setting.

Ms. Southern: Certainly.

Mr. Ne'eman: So, I wonder if we could see -- I don't know to what degree you are already working with the self-advocate community, but I wanted to take the opportunity to encourage you, and we would be glad to help facilitate that, to meet with some self-advocates who are potential users of this to explore that in more detail.

Ms. Southern: Yes. Thank you for your comments, and I definitely see what you are saying.

We have had a number of individuals with autism who are self-advocates, as you are describing, begin reviewing our site, because we are seeking exactly that kind of feedback. What are we missing? What are we not thinking about?

Because the site is going to

continue to grow, and that is the wonderful thing about a website. It can also continue to be revised to respond to various needs and interests.

So, I definitely hear what you are saying and would be happy and would want to talk with you further about that, get some more advisement from you, because your voice and the voice of many others like you is what we want most for sure. Thank you.

Dr. Strickland: Let me just add one thing. Since we went live April the 1st, we have about 2,000 new users a day, and we are continually getting feedback. We actually encourage all of our users to email us. If they want to speak with us, we are always glad to do that because the site itself is dedicated to providing the resources as the users indicate they need them.

So, absolutely, we want all users who are listening to contact us and let us know what they think is missing and what they like about the site.

Dr. Insel: Great.

Lee?

Mr. Grossman: Yes. I didn't know this existed. So, thank you. That was excellent. I appreciate this.

Actually, I am going to see a program later this month that employs similar techniques, but in an actual job training site. I will be referring them to this because I am very impressed.

And with that, since I didn't know, I am wondering, what are your goals and what are your plans for getting this out?

Dr. Strickland: Well, NIH actually did a press release, and we did one with them. We have several million users for Do2learn.com, and it is actually through the home page.

So, we don't have a lot of funds for marketing and advertising, but the blogs and the users actually get the word out pretty fast. So, if you type "job tips", now we are like No. 3 on Google, where we didn't exist before April the 1st, when we went live.

So, we could use all the help we can get in getting it out, but usually the people who get it out are the users. They are usually pretty good at getting this out. We get about 11 million hits a month.

Dr. Insel: And I think the Secretary in her release for Autism Awareness Month also mentioned this program.

I have one quick question, and, then, we will need to move on. This was supported through the Recovery Act.

Dr. Strickland: Yes, it was. It was supported through a two-year stimulus grant, one of the first ones rewarded.

Dr. Insel: What happens then? So, those funds are not --

Dr. Strickland: Okay. The beauty of what we do is, if you give us money to put it out, I can keep it out, because it costs money to put these resources together. But to keep a server going that streams the video, to keep the Do2learn server, I make enough from the other things on the site. We don't take outside ads. It is actually self-sufficient. So, if we get money to develop something, it is there forever.

Dr. Insel: Thank you. Okay. Thanks for very much to both of you for coming and telling us about this.

Hopefully, the IACC can be part of the vehicle, also, for disseminating interest. You can let us know how many more millions of hits you are getting on the site.

We are going to go back now to where we were on the agenda, to hear about a couple of other items from Autism Awareness Month updates.

The first one is something you asked for at a previous meeting, which was an update on the Autism Centers of Excellence. We have Dr. Lisa Gilotty here to introduce the topic, and then we are going to hear from a couple of the principal investigators from two of the Centers.

Lisa?

Dr. Gilotty: Thank you.

So, I am just going to do two to three minutes, very quickly giving an overview of the Autism Centers of Excellence Program. Then, I will move right into the introductions.

So, the ACE program is a trans-NIH collaboration. So, there are five Institutes involved in the funding and in the management of the program.

It was formed out of a consolidation of the two prior Centers programs, the Collaborative Programs of Excellence in Autism, which began in 1997, and the Studies to Advance Autism Research and Treatment, which began in 2002, with some additional Centers funded in 2003.

The ACE program has Centers and

Networks. Centers are multidisciplinary. They are comprised of multiple projects that are interdependent and interrelated. Networks focus on one specific topic of research, but have multiple sites collecting data to respond to the hypotheses that are within the topic of interest.

The ACE program has several specific requirements. First and foremost is data sharing with NDAR. The second is there are several common phenotypic measures that are required of all the sites, and the investigators are required to meet annually.

This is just a geographic representation of where the sites are located. So, you can see kind of the spread. The Centers are designated by circles, and the Networks are designated by squares.

You note, say, for example, the University of California at Los Angeles has a circle within a square because they have one Center and one Network at that site.

This is just a slightly different breakdown. So, there are six Centers. You can see the principal investigators and their sites. And, then, underneath, the overall goal or topic of the Center itself, and you can see the varied foci of them.

And, then, this is a breakdown. There are five Networks. Again, the principal investigators -- the site, the home institution, parent institution of the principal investigator, and, then, again, the topics, the primary research question for the Networks.

Now I should point out that the Networks have multiple sites. There just wasn't enough space to list everything in a nice, neat fashion. So, this is just the parent institution for the PI, but there are multiple sites for each of the Networks. And you will be hearing, as Dr. Insel said, from two ACE Network PIs in just a few moments.

The future of the ACE program,

NIH, specifically NICHD, recently released a Notice of Intent regarding the upcoming RFAs for Centers and Networks. These are the notice numbers here. There's 11-003 and 11-004. These are not the RFAs themselves. Again, this is the Notice of Intent. These are guide notices of the intent to publish. So, you can go to the NIH Guide and look those up.

I just put a couple of things in here, just that were in the Notice of Intent. The projects, we indicated in the Notices that the projects responding to the subsequent RFAs must be strongly related to gap areas identified in the 2011 IACC Strategic Plan. And, also, specifically for ACE Centers, we are requiring them, they must include at least one project related to interventions and/or services research.

And so, I think if I move forward this, all right, so I am going to go ahead and introduce the next speaker. Dr. Joseph Piven received his medical degree from the University of Maryland in 1981 and completed training in general and childhood adolescent psychiatry at the Johns Hopkins Hospital in Baltimore.

He joined the faculty of the Department of Psychiatry at the University of Iowa from 1990 through 1999. Dr. Piven is currently the Sarah Graham Kenan Professor of Psychiatry, Pediatrics, and Psychology at the University of North Carolina at Chapel Hill, and Director of the Carolina Institute for Developmental Disabilities, a comprehensive institute for services, research, and training relevant to neurodevelopmental disorders.

He directs an NIH-funded post-doctoral research training program in neurodevelopmental disorders at UNC and is Director of an NIH-funded Autism Center of Excellence Network Study of brain development in infants at risk for autism. His research is focused on the pathogenesis of autism and related disorders and includes studies on the molecular genetics of autism, the neuropsychological basis of autism, and the broad autism phenotype, and magnetic resonance imaging of early brain development.

Dr. Piven?

Dr. Piven: Thank you. Thank you, Lisa. And thanks very much to the Committee for inviting me. It is really a pleasure to be here, and, in particular, to represent this group of seven sites that are part of the Network, our Network that Lisa was referring to.

So, our Network is an ACE-funded Network, and the title of it is a Longitudinal MRI Study of Infants at Risk for Autism. The idea of our study is to study infants, infant siblings of older autistic children over time. They enter the study at six months, and we see them at 6, 12, and 24 months, with behavioral assessments and neuroimaging assessments of the brain.

So, this is the rationale for our study. It is actually pretty straightforward and simple. It is based on two things.

The first is that the onset of brain overgrowth occurs in the latter part of the first year of life in at least a significant portion of children with autism.

The second is that, also, in at least a significant portion of children with autism, the onset of autistic behavior seems to occur around that same time.

So, I want to talk about each of these just briefly, just to give you a little bit of background. This is, hopefully, aimed at the non-scientists in the group, and, hopefully, it will be simple enough to understand.

So, this is a compilation of many of the studies that have been done over the last few years, brain imaging studies of autism. One of the things that it shows is that all of them, at least on the slide that I put together, and really most of them in the last few years that are studying brain volume, show that the brain volume in autism is increased. Now, to find any one thing where there is so much agreement on in autism is actually very, very unusual. So, this is really a pretty striking finding in and of itself.

Now, if you look closely at the literature, the findings that seem to be most robust are those in the youngest children. And the youngest age at which we have shown that there is this brain volume enlargement in autism is by two years of age.

Now we have a study that we have completed that is about to hit the literature, it is in press, that followed a fairly large number of 2-year-olds with autism, 50, forward for two years. You can see those in red. This is a comparison group in blue.

And what this study shows is that the difference between the two in brain volume is maintained -- these are pretty much parallel lines -- over this interval. And what it really strongly suggests is that this difference came about prior to age two.

Now we have only to this point really been able to think about this indirectly. As I will tell you in a few minutes, we are now trying to examine this more directly with prospective studies.

But, indirectly, we have known for a long time that head circumference in people with autism seems to be increased. So, about 20 percent of the people with autism have head circumference in the 98th percentile. So, that is really what we would expect only 2 percent of the population to have.

So, we and others have done a number of head circumference studies. This is a retrospective study looking at medical records of a very large number of people with autism that are systematically assessed with the standard assessments of the day, and a large group of local community controls.

When we examined their head circumference on average at about four points in time, what we see is the autism group in red. At around 12 months of age, they seem to start getting larger. This is a significant difference.

What was striking to us when we saw it was that they really didn't start until about 12 months of age. The differences weren't present between birth and about 12 months. It really suggested in a sort of, again, indirect way that what was happening was happening just prior to this separation.

And specifically, the brain was getting enlarged and pushing out the skull. So, we have this difference that we really think points to the onset of brain enlargement in the latter part of the first year.

So, just to kind of summarize this point, we have direct evidence for an increased rate of brain growth in autism occurring before age two. From head circumference studies, we have this indirect evidence that suggests that overgrowth occurs in the latter part of the first year of life.

So, let me go on to the second rational for our study about the onset of autistic behavior. First, I want to introduce this new paradigm in autism research that really is the basis for our design. Most of you have probably heard this reference to the baby sibs or infant sibs studies of autism.

And they are really based on the idea that autism is a strongly genetic disorder. We know that from twin, family, and molecular studies.

And specifically, that once you have had a child with autism, the risk of having a subsequent child with autism is higher than that of the general population. So, it is as high as 10 to 20 percent, depending on the studies. As you can see, that is larger than what we would find in the general population.

So, we take advantage of this high genetic risk sample because it is a much more efficient strategy than studying the general population, and we would expect that somewhere around 10 or 20 percent of those children that are enrolled in the study before their diagnosis are going to go to have a diagnosis of an autism spectrum disorder.

So, this is the first study that was published using this paradigm by Lonnie Zwaigenbaum in what has been referred to as the Canadian Infant Sibs Study. Lonnie Zwaigenbaum is a member of our Network.

In this study, this group looked at 74 infant siblings who had an older sibling with autism, and 10 of them were seen early on at 6, 12, and 18 months and, then, later at 36 months and 48 months. They received a diagnosis of autism.

This group developed their own instrument to assess these children, something called the Autism Observation Scale for Infants. It is largely, especially at six months, it is largely based on a lot of social behaviors.

This is kind of a cartoon version of their finding. Both of these lines are children that went on to have, that are infant siblings of older children with autism.

The red line are the kids that went on to have a diagnosis at three years of age of autism, and the green line are those infant sibs that didn't have a diagnosis of autism, at least at 36 months of age.

The thing that I think was very striking in the field was this separation, that by 12 months of age in this high-risk group, we could find a very clear difference on the AOSI between the kids that went on to have autism and the ones that didn't. That is a very important and exciting new, or it was at the time in 2005, new finding.

What was less clear, and I think

received a little less attention, was the fact that these lines intersected around six months of age. And the question to me, when I first saw this, was, well, I couldn't quite remember what my kids looked like at six months of age, and I wondered, well, maybe kids at six months of age just don't do a lot of stuff. Maybe this was just an artifact of our measurement tools.

So, I wish I had been able to bring videos. I normally at this point of the talk show you videos, a video of a 6-month-old and, very clearly, as most of you probably know, 6-month-olds are very social beings, but, then, show you a videotape of a little boy who has an older sister with autism who at six months looks very social, has back-and-forth social reciprocity and a lot of affect. But when he is videotaped at 12 months, he really has none of that, and it is really a very striking change. And he went on to have a diagnosis later on of autism. Those kinds of videos are, obviously, much more striking.

But I think what it points to is that this data point here, what it really tells us is that these children do, in fact, have a lot of behavior, a lot of social behavior that can be measured. At least as far as the defining features of autism, they don't really look different than the comparison group or typical kids. And there is a change that takes place between six and twelve months, at least in this study.

So, this is just a little bit more meat on the Canadian infant sibs study. It tells us that these children did have some differences that were observed at six months of age. They had some visual tracking problems, some problems with anticipatory responses, some motor control problems, but they didn't have any, at least as far as social -- now these children are too early to begin talking -- of what I am referring to as the defining features of autism. So, these social deficits.

Now I want to point out that I am deliberately oversimplifying this story. This is sort of the first-generation story. I don't know if we are at the second or the third generation, but a few other papers are starting to come out and others still are about to come out.

It is very clear that there are kids that start here and they may drift down here, and they may end up looking a little bit more autistic later. Some start and look more autistic even by 18 months and drift down to this column.

But, for my purposes, I think this really makes the point that I want to make. That is that there is a major change as far as the onset of autistic behavior that occurs either during this interval or a larger interval, but it starts sometime around here when we see these children.

Of course, you have to always keep

in mind that these are early days in these studies. So, we have nothing that we can say about every single child.

But in these studies, they all seem to be pointing towards a period of time early on where these children seem to be looking, functioning in the relatively typical range, and, then, they have a change.

And I think that, also, as I referred to this as a new paradigm, this is really a very new direction and a new finding in the autism world. When I started my research career, I think what we all thought was that autism just really started from the get-go and that we really didn't have the ability to observe it until later on.

Now I think what this is telling us is that is not the case, that there is a period of post-natal development that seems to be relatively intact, although there are some markers, but that in the early post-natal period there is a change that takes place.

The onset of these symptoms occurs in the early post-natal period.

And there are, as I referred to, other studies that are starting to come out. This is, I guess, a second-generation study on a larger sample of 25 children in this category, infant sibs that went on to have a diagnosis of autism by Sally Ozonoff and her group.

They looked at a variety of different measures of social behavior. As you can see, these kids are all overlapping very early on, and, then, they start to separate in their social abilities. So, this is really a step forward or a replication, but really a very similar kind of findings that points to this early post-natal change.

So, when we juxtapose these two lines, independent lines of study, what we find is this sort of striking evidence that there is something happening in behavior at the latter part of the first year of life, an onset of autistic symptoms, and with brain overgrowth as well. And it really suggests that the onset of autistic behaviors is at least temporally related to the onset of brain enlargement during this time, although we don't have a single cohort of kids that we followed through and studied them for both brain and behavior.

So, that is really the interest and the focus of our study. It is to really narrow down on this interval and to map the relationship between brain development and behavioral development or trajectories during this time.

The real hope is that this will give us insights into pathogenesis or the causes and neurobiological mechanisms that are happening here by making these observations, and they will also begin to give us some insights into early prediction and, hopefully, intervention.

So, I want to just dwell for a

moment on one methodologic point, and, then, I will go on to talk a little bit more about the study. That is the idea of studying development.

So, until the late 1990s, when we studied the development of the brain, it was really, I think, best shown by this slide of a cross-sectional study of brain volume or gray matter volume over the ages of sort of birth to whenever, 30.

This is what we call a cross-sectional study where we have individuals that are measured at a single point in time. They are obviously across these different age groups.

Now that is in contrast to what we refer to as a longitudinal study where these individuals are measured and then measured again. And sometimes they are measured at three points in time.

So, you can see that illustrated here by what really is a landmark study about brain development that was published by Jay

Giedd's group at NIMH in the late 1990s.

What this first study up here found was that gray matter volume seemed to hit its maximum around four years of age; whereas, with a longitudinal study, the maximum was found to be closer to 12 and in some cases later in other parts of the brain.

The point here is that there are great differences between this cross-sectional study and this longitudinal design. When you have subjects that you are studying that really are different, in other words, you can't assume that this person here at age five that has a diagnosis perhaps of autism is the same as the person at age 25 except that they are older. When you have what we call heterogeneity or different causes and different trajectories, or not to in any way be sort of dismissive, but so-called apples and oranges, and when you have what we call non-linear development, in other words, development doesn't proceed along this straight, this dashed line, but more along this curved line, in order to find the right answer, what you really have to do is a longitudinal study. So, rather than measure change across different individuals at different ages, you have to measure change in the same individual over time.

Now this is a little bit of a plug, but I think it is really an important one. That is that these aren't easy studies to do. They take a lot of time, and they are very expensive, because you have to follow all of these kids, or whatever it is that you are studying, forward over time.

And so, that is the study that I want to tell you about, the study that we are doing currently. In order to collect a large enough sample, we really had to fit into this Network design. It was really perfectly suited for what we were intending to do.

And we have four data collection sites, one at my site at North Carolina, one under Bob Schultz's direction at Children's Hospital of Philadelphia, one at the Washington University of St. Louis, under the direction of Kelly Botteron, and one at the University of Washington, under the direction of Steve Dager and Annette Estes.

We have several other sites. Our data collection site is up in Montreal. Lonnie Zwaigenbaum, who is instrumental in helping us with doing proper assessments and reliability, is at the University of Alberta in Edmonton. Our computer scientists are headquartered in Utah. As you can see, it is a pretty big cast of characters.

So, what are we doing? We are trying to find, as best we can, 400 so-called high-risk or children that have older siblings with autism by six months of age to have them enter our study. We are adding in another group that sort of passively show up at our door maybe a few weeks after their six-month point. And so, we enroll them at 12 months of age, for a total group of 500 high-risk infants. And we are collecting a comparison group of 150 low-risk controls or kids that don't have siblings or relatives with autism.

We are following them all forward. So, all 650 infants, hopefully, we are trying to follow forward with brain imaging assessments and behavior assessments at 6, 12, and 24 months of age.

Now all those kids aren't going to develop autism. We are anticipating that we will have, roughly, 60 to 75 that have autism spectrum disorder. There will be another group that sort of have almost autism spectrum disorder. So, they will have some cognitive deficits or behavior deficits, but be sub-threshold for a diagnosis of an autism spectrum disorder. There will be a significant portion, of course, of these high-risk kids that won't have any evidence of cognitive or behavioral problems. Then, we have a control group.

Since starting this study, we have actually added another group through funding from NIH, infants that have fragile X syndrome. Now fragile X is a genetic condition due to an abnormality at a single gene, the fragile X gene. A significant portion of those children have autism or a diagnosis of autism spectrum disorder.

So, what have we done so far? This is really the result that I want to show you because it is actually a little premature for me to show you much in the way of results.

But probably our best accomplishment is that we have done so far 780 scans. We have enrolled 266 high-risk subjects in the study. We have 217, a smaller number, that have gotten imaging. They haven't all been able to get through our imaging, but we have a larger number that have behavior assessments.

We have some entering here at 12 months. So, we have 225 that have been assessed at 12 months, 126 at 24 months. We have a bunch of our controls and a number that have made it through our study. So, we can begin doing some analyses at this point.

And the other thing I want to point out is that not only is this a complicated study to do as far as finding these children and assessing them, but it is not a trivial thing to have all these sites take the same kind of picture of the brain. So, we have put an enormous amount of effort into doing this, and have actually been very successful.

So, this is really kind of a backbone of our study because what we want to do is have this enormous task of doing 2,000 scans across four different sites at three different ages, and to get agreement or to do it the same way is very complicated.

So, what I want to talk about in the last little bit of time is really what is the potential impact from this kind of research.

So, to begin with, as I have really alluded to early on in this talk, we are focused on this interval time from 6 to 12 or 6 to 24 months. What we really want to do is look at the relationship between brain and behavior. We want to see, in the same sample of children, those children that go from not looking as if they have any symptoms of autism to those that have autism and see what actually changes in the brain. And we really can't do it any other way than we have designed here. I think that, in and of itself, is an extremely important question.

Now we are going to measure the brain or we are measuring the brain in a lot of different ways. I have talked a lot about this idea of brain overgrowth. In many ways, I think that was really just the ticket in the door, but that is not really the only thing certainly that we are looking at.

We want to look at tissue. So,

this is a depiction of white matter and gray matter tissues. We want to look at substructures like the amygdala. We want to look at neural circuits that we can now see with something called diffusion tensor imaging and the maturation of those circuits.

We have very good data that shows that those circuits are different at six months of age and, then, even three weeks later they are different. Those are very measurable differences about how these circuits mature.

We started about midway into our study measuring networks in the brain using, also, a new approach called resting BOLD or functional imaging.

And we are looking at various levels of behavior. So, we are looking to see what is going on at the onset of the diagnosis of autism, so in a very global way. We are looking at social deficits and sort of disaggregating the syndrome of autism into its component parts. We are drilling down at some of the underpinnings by looking at social cognition, looking at how infants look at faces, so through eye tracking. And we are looking at underlying those kinds of things, like attending to parts of the face. We are actually looking at attention as well.

And we are looking at this over time. The idea is that these changes over time or studying these changes over time will allow us to make inferences about mechanisms.

We are also able to ask the question of, are these changes specific to autism? Are they specific to autism or are they associated with what we call the genetic liability for autism?

So, we know that head circumference or head size is not only enlarged in children with autism, but from this study by Janet Lainhart, that in parents and even in other siblings we see increases in head size.

And so, with our study, we will be able to look at the children that develop autism, those that develop these milder symptoms, and those with typical development, to really ask the question, which brain changes are specific to the presence of autistic disorder and which ones are associated with genetic liability?

This study will give us, hopefully, an ability to make predictions from early brain findings. We know from other studies in other disorders, Parkinson's and Alzheimer's and Huntington's, that major brain changes occur well before the appearance of behavioral symptoms. So, we are hoping that we can do the same in this study as well.

I think I will skip over that.

And, then, finally, we are interested in studying pathogenesis or how can this information tell us about the underlying causes and mechanisms. So, particular kinds of abnormalities -- I am getting a little sign here that I need to move quickly. So, I am going to go quickly through this.

Particular kinds of abnormalities like our recent observation that, rather than cortical thickness, we see increased surface area as being responsible for the increase in gray matter volume. That points us to particular underlying neurobiologic mechanisms to think about, and, then, particular genes to think about.

We are very fortunate to get terrific funding from Autism Speaks, to collaborate with the EARLI Network, another Network that is in this ACE mechanism, run by Craig Newschaffer, to collect DNA on all these individuals and parents, and to look at the molecular genetics underpinnings of these brain abnormalities and behavior abnormalities.

The idea that we are not looking at single points in time here, we are looking at really a relatively new idea of what autism is. It is a trajectory of changes over time rather than looking at a single point of time, to give us new ideas about what genes we might look for.

And finally, I mentioned this comparison to fragile X that also will give us insights into a subset of individuals that have a different genetic basis for their autistic symptoms.

So, just to close, we are looking at early behavior. We are looking at behavioral trajectories over time. We are looking at trajectories of brain development, and we are looking at these genetic signatures to try to tell us about new ideas about what autism looks like, the phenotypes; to give us insight into underlying mechanisms, causes. And, hopefully, that will inform us about early detection, prevention, and treatment.

So, we think that this study and this design really points us to the idea that major understanding of autism will require going beyond single points in time, single brain structures, single genes, to predict trajectories of development, particularly around the time of onset of the disorder, to elucidate underlying pathogenic mechanisms and to develop rational approaches to treatment and prevention.

So, just a word about some important acknowledgments: this really, truly is a wonderful public/private partnership. I have mentioned Autism Speaks, and that is a collaboration. Our funding from NIH has been really critical. We also have support from the Simons Foundation, LENA Foundation.

We have a tremendous cast of characters here. I won't go through all of them, but you can imagine. This is a terrific group.

And, then, this is an extremely demanding study for families. So, we are very grateful to all the families that have contributed to this study.

Thank you.

(Applause.)

Dr. Gilotty: Thank you very much, Dr. Piven.

I think, in the interest of time, we will just move forward to the next talk and I will introduce the next speaker.

Dr. Sally Rogers received her Ph.D. from Ohio State University with a specialization in mental retardation and developmental disabilities. She is a developmental psychologist and a Professor of Psychiatry at the M.I.N.D. Institute, University of California, Davis.

She is the principal investigator of several autism research projects, including an NIH-funded Autism Center of Excellence Network project involving a multi-site controlled trial of an infant/toddler treatment for autism.

She is also the Director of an NIH-funded T32 post-doctoral training grant for interdisciplinary autism research.

Her current research is focused in two areas, developing effective interventions for infants and toddlers with autism that families and professionals can deliver, and earliest identification of autism in infancy.

The intervention models that she developed with Geri Dawson and other colleagues, the Denver Model, and the Early Start Denver Model is internationally known, and the treatment manual and instrumentation for this approach has recently been published by Guilford Press.

Dr. Rogers?

Dr. Rogers: Thank you. Thank you very much for the invitation to present to the group today. I am delighted to be here.

And it was very good timing to have my work follow Joe's because the line from -- the reason we are trying to understand autism and the onset is so that we can do something about it.

So, I will be sharing with you today the work that we are doing on developing effective interventions for young children with autism, as soon as I figure out how to operate everything.

Okay. I want to acknowledge the colleagues that I have. Geri Dawson and Laurie Vismara and I have been working for 10 years now to develop the particular model that we are working on today.

I have had funding for the treatment work that I am doing from many of the Institutes at NIH, from NIDCD, from NICHD, from NIMH. Our work is currently funded by NIMH and NICHD through the ACE funding. We also have ARRA funding, which I will be talking about. And we have had additional funding from the U.S. Office of Special Education. We are part of the NPDC and the work from the Office of Special Ed Programs as well, and several foundations, including Autism Speaks, the Marcia and John Goldman

Foundation, the Coleman Foundation, and the M.I.N.D. Institute.

I do have a conflict of interest involving the materials that are published from this particular treatment and an honoraria for talks.

So, today I want to talk with you about three studies that I have been engaged in. The first is the eight multi-site study involving a randomized controlled trial of 1-year-olds. The second will be the ARRA-funded infant treatment study that we are just beginning to develop for 6 to 12-month-olds. And finally, I am going to be sharing with you some of Dr. Laurie Vismara's work on use of distance technology to provide interventions for families who are too far away to access typical interventions.

I want to start by talking about the model that we are operating from when we are talking about early intervention research. This is a way I think that many of my colleagues think about autism, in that it is a biological disorder with strong both genetic and environmental components, and these are part of what children come into the world with, that they affect the way brains are growing and developing, and those differences in brain structure lead to differences in brain function. These brain differences affect development, and these effects of abnormalities of the biology of autism are reflected in the symptoms that we see.

I think for many people the idea of intervention is that you do something here to affect the symptoms that are here, that maybe we can use different approaches to increase speech or decrease repetitive behavior, and that we can operate at the final expression of autism, as it is demonstrated in behaviors of autism.

But when we are thinking about autism in infants and toddlers, we are really using a model from developmental psychology which looks at a human infant as a constant, kind of the behavior repertoire is a constant product of both the biology of that infant and the experiences that infant is having every day and every hour.

And we feel that a transactional model is appropriate for infants with autism as well. In a transactional model, the biological differences that infants are coming into the world with are affecting each level back and forth, but they are also being affected by the experiences the infant is having moment to moment and day by day.

And social environment experiences don't just affect symptom levels, but they affect even at the level of genetic expression. They affect the structural development of infant brain growth. They affect the function of those brain structures and neural networks. And those are affecting development on a day-by-day basis.

We understand that the symptoms

that come into the world with a child with autism also affects the social environment and can change the impact that the family is having by changing the way the baby is interacting with families.

So, we really understand that intervening with infants with autism is a way of affecting all of autism, the biology of autism, the brain development of autism, the developmental profiles, and the symptom production, and that this is an ongoing process of constant transactions.

So, our ACE study, the purpose of this is threefold. First, to conduct a multi-site, intent-to-treat, randomized, controlled trial of the Early Start Denver Model, which I will describe to you in a minute, compared to standard community treatment for 1-year-olds with autism.

Our second goal is to evaluate the efficacy of the intervention on cognition, language, and social development, and on the symptoms of autism.

Our third aim is to evaluate family characteristics and the responses of families, both in terms of additional stresses and additional benefits, from participating in this particular intervention.

And finally, we want to be able to look at influences from the child's biology, the child's development, and the social milieu around the child, and how that affects their outcomes and their responses to the treatment.

This is a multi-site study. It is going in three sites. The first is our site at the University of California at Davis, at the M.I.N.D. Institute, where I am the Director.

Each of these projects involves three separate teams, a team of evaluators who are blind to the assignment of the children, a large team of interventionists who are providing the intervention, and, then, a team of data quality people who are gathering data and coordinating with our Data Center.

So, this is the team at the University of California at Davis. Here is the team at the University of Washington, headed by Annette Estes, who is the PI at that site. And our third team is at the University of Michigan, headed by Cathy Lord, who is the PI at that site.

Our Data Coordinating Center is at the University of Washington. Annette Fitzpatrick is the PI of that site.

So, the purpose of this ACE Network addresses very well Question No. 4 in the IACC strategic aims for 2011. It specifically addresses two of the short-term objectives, Objective D, which involves carrying out multi-site, randomized, controlled trials of early intervention, and short-term Objective F, which involves specific interventions for developing infants and treating symptoms early in the life of a child with autism.

The interventions that we are working on all come from the Early Start Denver Model, which is an intervention that I began working on in Denver -- that is where its name comes from -- 30 years ago, 1981, thanks to grants from the Office of Special Education Research.

The Denver Model, I collaborated with Geri Dawson when she was carrying out her STAART Center. She and I and the team at the University of Washington evolved this into an intervention for infants. The STAART Center was the first to take this model into the area of toddlerhood.

So, the core elements of the Early Start Denver Model involve, first of all, a specific curriculum and a specific way of teaching infants. That way of teaching or working with infants involves using a developmental framework for thinking about how skills develop and how infants and adults interact in ways that facilitate sharing of emotion, the development of communication, and the awareness of other minds. We are talking about a relationship-based intervention with the idea that human infants learn and develop inside particular kinds of interactive, bidirectional relationships with significant others.

We assume that this is also true for infants with autism. And in fact, studies by our colleagues, Marian Sigman, Michael Siller, and others, have demonstrated the importance of reciprocal and responsive qualities of adults to enable children with autism to learn communication.

The ESDM, or Early Start Denver Model, focuses on the core aspects of autism as it is demonstrated in the earliest phenotype, difficulties with social orientation and attention, problems with imitation of other people, lack of joint attention behavior, difficulties developing language, and unusual, repetitive play patterns that do not evolve into pretend play.

The particular approach that we use takes these developmental and relationship constructs, carries them out in typical play kinds of interactions with young children with ASD. But underneath the play, you will see the principles of learning which come from the science of learning or applied behavior analysis.

Underneath this very natural-looking play, you will see careful controls that the adults have over what is the stimulus for the child to be playing or speaking or engaging with an adult, making eye contact, and what is the reinforcer inside the child's own goals and preferences. So that, you can deconstruct the play to see very clear antecedent behavior, consequence kinds of teaching, although the consequences are child chosen. They are intrinsic to the activities, and the main aspects that you see are high positive affect and very active, communicating children. I will show you in videos later.

The ESDM is a fully manualized intervention that uses ongoing data that is gathered in therapies to make decisions and a response-to-intervention approach which allows the therapist to systematically change procedures if children aren't learning quickly.

And the model is based on interdisciplinary and multidisciplinary in teams, including occupational therapists, speech and language therapists, psychology, special education, and physicians.

The ESDM was first tested by Geri Dawson in this very important paper published a year ago from her STAART Center in which she randomized 48 children under the age of two and a half years to either Early Start Denver Model or standard community intervention. We delivered two years of intervention at 20 hours a week, putting young therapists in the homes with children and, also, interacting with parents and teaching them the strategies, two hours, four hours every month for the entire two years.

We followed these children and assessed them at the initial enrollment and at one year after enrollment and two years after enrollment at the end of the treatment. We also carefully tracked how much intervention children were receiving over this time period.

Much to our surprise, we found that the children who were in the community group received virtually as much intervention as did the children we were receiving. The children in the community group averaged 18 hours of intervention a week over the two years of the study. The children in the ESDM averaged 22 hours a week over the period of the study.

And the outcome measures were conducted by people who were naive to the assignment group.

One of the most important findings

from this study is a significant gain in IQ and an advantage of the children receiving ESDM over the community benefit, in which the children with ESDM in a two-year period showed an almost 20-point gain in IQ, beginning at about an IQ of 62, and after two years performing at an IQ level of 78, where the comparison children gained only about six points in IQ, even getting 18 hours a week on the average of intervention over this entire period.

I think this is important because sometimes people think it is just the hours that result in treatment gain, but it is hours and approach. You can't just throw hours at children and expect that these kinds of gains will happen. This is a very clear demonstration of it.

A very important finding that Geri has recently demonstrated is that pre-treatment IQ does not moderate the effect of treatment. You will read in other studies that pre-treatment IQ is going to predict outcomes, but in the ESDM study we found that that was simply not true, that the children in the lower IQ group, starting in the mean IQ of about 52, gained 14 points over two years, which is a 27-point addition to where they were starting; whereas, the higher IQ group, starting at a mean IQ of 68, gained about 22 points, which was an increase of 32 percent. So, this is quite similar and demonstrates that children in the lower IQ groups are making as much progress from this developmental speech- and language-based intervention as were the children with higher IQs.

We found that this pre-treatment IQ did not moderate the effect of language development. We are talking about speech development. Ninety percent of the children in this study gained useful, fluid, functional sentences and phrases by the time they are four years old. I think that was one of the goals of an earlier IACC Strategic Plan, was that 90 percent of the children with autism would have speech. In this study they had it, and they had it within two years of intervention. Here we see the gains that children in both the lower and the higher IQ groups are making in language development.

We did find that pre-treatment severity of autism symptoms moderated the IQ gain, and that children who had less severe autism symptoms over time showed more IQ gain over time.

However, that does not mean that the children with more severe symptoms did not respond. In fact, they did respond. Here are the children with the most severe symptoms, and those getting ESDM showed double the IQ gain, or more than double, than did the community group; whereas, the children with less severe autism symptoms receiving ESDM showed four times the amount of IQ gain as did the children receiving standard community treatment.

So, that is the background for the ACE study that I am carrying now, which involves 100 1-year-olds with autism spectrum disorder stratified as we did in the earlier study. These 100 1-year-olds are being gathered across the three sites that I told you about, Seattle, Ann Arbor, and Sacramento. They are randomized to either community treatment or ESDM.

We begin with three months of parent training in which the children are getting one hour a week of contact with a therapist while the parent learns the ESDM techniques. And, then, after that 12 weeks, we reassess the children and, then, follow it with 24 months of intensive one-to-one ESDM in their homes, as Geri carried out in the initial STAART study.

So, the children who are in ESDM are getting this 20 hours a week of one-on-one at home from paraprofessional, highly-trained therapists, supervised by professionals, and the parents are getting four hours a month of parent training.

Thus far in this study, we have delivered 31,325 hours of home treatment, and that does not include the amount of time we spend driving around to all these children's homes. In Michigan, it averages an hour for every visit. So, these studies involve work and money.

But we have done quite well in enrolling the children. At this point, we have enrolled -- we kept enrolling 100 and, then, one child or another kept dropping out. So, we finally said, all right, 97 is our target number. We have 97 children now who are enrolled in the intensive part of the intervention; 24 have completed it. But this is from 228 children who have been screened in 166 assessments. So, finding this sample involves a great deal of qualification work.

We have 56 children who are

through their one-year time point. And so, this study is moving along quite well.

The groups are well-balanced. The mean age in both groups is 21 months of age at the time we meet them. Their mean IQ is 63. They are, as you would expect, predominantly boys.

Interestingly, two-thirds to three-quarters of the group are Caucasian, which means a quarter to a third of the group are of diverse backgrounds, which is very positive for us. We were seeking that.

The only area in which the children differ is in the parental self-reports of mental health symptoms. Interestingly, the community group's parents report higher levels of distressing mental health symptoms on the SCL-90 than does the comparison group.

Well, most of our data are in the Data Coordinating Center, but there are some data that I can share with you today. And what I can share with you is our first analyses looking at the response of the families to the parent coaching part of the intervention.

I am showing you here the responses, the week-by-week responses, of the parents of the intervention who are in those first 12 weeks of parent coaching. So, each week they come in and here is week two, four, six, eight, ten, twelve.

And they begin each session by warming their children up through a little bit of play. During that play period, we take data from that, and we are looking at the parent's use of techniques which we end up teaching them, the techniques that are the basis for the Early Start Denver Model way of working with children.

So, what you see here is that at the very beginning the parents range from a score of about two to four, with a mean score of three, which is a very typical way of interacting. Parents of children with autism are just as sensitive and responsive as any other set of parents, and this demonstrates a very normal range of parenting skills that are present in the children, with parents here at this end being a little more directed, parents at this end being a little more responsive, but everybody involved with this children.

Our goal is for the parents to get to about an average of a four. A four is what we expect of our very well-trained therapists, which shows a very responsive dyadic way of interacting in which there are lots of learning opportunities which are very carefully delivered. The children are joyous. There is a ton of communication opportunities, and parents are focusing on imitation and joint attention.

Well, what you see in this data, and we demonstrated this before in a single subject design, but we are delighted to see it with this whole group of parents, is that by week eight, right here, the parents converge on a score of four. What this means is that in eight hours the parents have learned to do this intervention at the level of a trained therapist. And from that point on, they continue to make progress. This is the smooth curve for that.

So, that you can see that by the end of the study there is continuing gain across all 12 weeks. So, it is worth it to do this intervention for 12 weeks.

But by week six to eight, parents are extremely skilled. And so, they are now creating as many learning opportunities that are as well-done as a therapist would. This demonstrates that, even though this intervention, you will read some people think because there are 12 points and it requires a lot of kind of response to the child, that this is a complex intervention. But it may be a complex intervention, but this wide range of parents who are not selected in any way learn it quickly, and they carry it out well, and they generalize it. In our previous studies, they maintain it for months and months after their intervention is done.

Dr. Insel: Sally, we have got about five minutes left, and I know you have a lot of slides.

Dr. Rogers: Oh, okay.

Dr. Insel: So, I want to make sure we get through this.

Dr. Rogers: Five minutes? I thought I had 10.

All right. Well, let me move along quickly, then, to show one of the things that we have been tracking is how much intervention the children are actually getting. And much to our surprise, in the first 12 weeks after diagnosis, the children in the community group are averaging four hours a week of intervention, and some children are getting 10 to 15 hours a week within the first 12 weeks of diagnosis.

The children in our sample, the Early Start Denver Model, are only getting about two and a half hours a week. That is on purpose. We are delivering an hour a week, and that is part of the agreement, is that families do not add intensive intervention because they are going to be getting it.

But this is more than double the amount of intervention that is going on in the community group. If you look at the distribution of these hours, these are the children in California. These are the children in Washington. These are the children in Michigan.

There is a huge disparity of access to public services for 1-year-olds who have just gotten a diagnosis and have been referred to services, with children in California averaging eight hours a week within a few weeks of diagnosis and children in Michigan averaging an hour a week. So, this points out the kind of disparity of access to services that we talked about earlier.

This is meaningful because we looked at the relationship between the number of hours these 1-year-olds are getting within the first 12 weeks of diagnosis and the change in their IQ and language scores within those 12 weeks. And we found for the children in the community group there is an extremely significant and strong response of IQ changes to the number of hours they are getting, just within 12 weeks, and there is also a very strong response in terms of their autism symptoms. So, their autism symptoms are going down, and their IQs are going up within 12 weeks. It is predicted by the number of hours they are getting. That is even true in our treatment group.

This means that hours really matter. And it matters very quickly. These are IQ changes from children who are only getting two to three or four hours a week of treatment, which is one of the first times we have been able to demonstrate that hours matter.

Now these are the changes in children over the first 12 weeks. What you see is that both groups are showing significant gains in verbal IQ, significant reductions in repetitive behavior, and significant gains in imitation skills in these 12 weeks. It is highly significant, and we have no site differences based on this.

We don't have significant group differences in these two groups. To me, what this is demonstrating is that an intervention which we are delivering, teaching the parents to do it for an hour a week, is demonstrating as much effect as interventions for children who are getting four or five hours a week, even within just a few short periods.

All right, let me move to two other points quickly. This has to do with disparity. My colleague, Laurie Vismara, has been very concerned about the lack of access most families I think in this country have to high-quality early intervention. She is currently carrying out the second of her studies looking at the effect of technology on early intervention, parents' ability to access early intervention services.

So, we have been looking at the success of carrying out Early Start Denver Model completely through internet connections in real-time with families all over the country and even in Canada.

This is the first 10 children that Laurie saw. They live from California to North Carolina, to Texas, to Quebec. And these children are all under three years old at the time that they begin. They range from quite severe to milder.

We have demonstrated parents learn the techniques just as quickly and just as well through the internet, as the data I just showed you in the clinics, in the universities, with the therapists right there, parents making the same kinds of gains, reaching therapist-level skills within six to eight weeks and performing as well and as quickly as families who are in the clinic.

And children are showing the same kinds of language learning progress that we have seen before in the clinic, where this group of children goes from an average of three words spoken in their hour session over the internet to 30 words spoken in their hour session, and parents report from 40 words ever spoken to 147 words used in the last week over 15 weeks of internet intervention for 12 weeks and then follow up.

The final study I want to just point out to you is funded by our funding. This is a study, NICHD is supporting this, and this is our first effort to address the problems that Joe is talking about, about what happens when we are identifying infants in the first year of life who do demonstrate symptoms of autism.

So, this is a pilot study in which we are trying to develop effective interventions for 6- to 12-month-olds for infants who are showing evidence of unusual repetitive behaviors, lack of vocal development, lack of social interest and face-to-face engagement, unusual visual fixations, and very poor quality and infrequent dyadic engagements. We are using the same 12-week model based on ESDM.

I want to show you data from the first child that we saw. This little guy came to us at six months of age. His mother was extremely concerned about his silence, his lack of eye contact, his lack of smiles.

We saw him three times on the AOSI. These are very clinically-elevated scores at seven months, at eight months, and at nine months.

We began the intervention here. This is three months later. His AOSI scores are in the normal range. We have seen him at

15 months, 18 months, and 24 months. His scores continue to be completely normal. This is his ADOS. He is a delightful little boy.

Here are his developmental scores. The line across the middle shows the typical developmental levels.

Sorry, I have lost my pointer.

The first point on the elevating line shows his development quotient at seven months of age, which was at 80. The star shows when his treatment is developed, and that line demonstrates his increasing IQ scores from 15 to 18, to 20, to 24 months of age, at which point, currently, he is above average in both speech and social development, cognitive development in every way. He is doing absolutely beautifully.

So, I don't have time to show you videos -- I wish I did -- of the intervention and what children look like in this intervention, but I want you to imagine children who are lively, smiling, social, very talkative and easily --

Dr. Insel: Sally, I am looking around the room, and I think there are a lot of people who might want to see the video.

Dr. Rogers: Who would like to see the video? Okay. All right, I will show you a video of the first child that we saw. Okay, it is going to take me just one second.

All right. This is a little guy. This is our first child. This is his first session.

(Whereupon, a video is shown.)

Please do not record these videos, for those of you who are recording.

He is 24 months of age. He has no speech. He is the third child in his family, very experienced parents whose other children are thriving.

This is my colleague, Laurie Vismara, down at the left.

We cannot figure out how to make him happy. He is wound up. He is inconsolable. We give him what he wants. He just cries.

I said during this interview with the father, "How often does this happen? Once a month, once a day?" Dad says once an hour. Literally, this child cries from the moment he opens his eyes until the moment he goes to sleep, and it has been like that since he was born.

You see us trying to give him the toys he seems to be wanting. He has no gestures, no way of showing his mother what he wants. He's hitting at her, throwing things down. He is an extremely difficult child who will not interact with other children and has no skills.

All right. Let me show you one year later.

This is in a therapy session 12 months later. He is in his bedroom.

(Whereupon, a video is shown.)

Okay. So, this little boy, I hope

what you see is his warmth, his smile. He offered that hug. He felt the emotions. He comforted the adult. He reassured him, "You're okay. It's okay." This little boy is smiling. His tantrums are gone. At this point, as you see, he is speaking in multi-word utterances.

Now we are a year past this, and he finished in our program a couple of months ago. All of his scores are in the normal range. He has no symptoms of autism. He is in a typical preschool where his teacher wonders why we spent so much time working with him. His parents feel like he is doing just as well as his brother and sister.

And he is not an atypical child in our Center. Of the first eight children who have left our Center, he is representative of the first eight children. Six of the eight children who have so far finished our program are functioning like this boy.

So, this is the kind of quality

that we are talking about in an intervention which is focused on affective development, on use of language as a social communicative tool, and on the development of play and social relations.

I am delighted to be able to be able to share the work with you. Our hope is that we will be able to develop interventions for infants and be able to use the power of development and the power of the social world to give infants the kinds of enriched communicative learning that may be able to alleviate the effects of autism and help children develop as fully as they are capable of.

Thank you very much.

(Applause.)

Dr. Insel: Well, we are way over schedule, but I know that there are people around the table who certainly will have questions or comments.

So, for both Joe Piven and for

Sally Rogers, let's take five minutes for questions that you want to raise. Anything?

Lyn?

Ms. Redwood: I have a lot of questions. But, one, were there any other treatments? Were there controls for other treatments happening at the same time with the families?

Dr. Rogers: These children were not getting any other treatment other than maybe an hour of OT. That was part of the agreement when families came in, is that they were not getting other interventions.

They were getting 20 hours a week in their homes plus the work the parents were doing, and many of the children were enrolled in preschool as well. So, there wasn't time for very many other interventions.

Ms. Redwood: Well, I didn't know like about biomedical treatments or diets, or things along those lines.

Dr. Rogers: There's no

restriction for the families who want to use those things. I don't think very many of our families were, although in California lots and lots of families are. It was completely up to the parents.

I have gathered data on that, but I haven't analyzed it yet. So, I'm sorry, I can't share that with you.

Ms. Redwood: Is there a big difference between the model that you are using, the Denver approach, versus a discrete trial training or the Lovaas Method? I am just trying to get a handle --

Dr. Rogers: Yes, it is an extremely different approach. The emphasis on this kind of an approach is on child initiative, children making choices, children being very spontaneous communicators. The adults are not giving, as you see, the adults are not giving directions. They are not leading. They are not deciding what to do. Children are pulling from materials that they want and they are initiating play, and adults are helping them learn how to do that.

Language is taught through gesture, not through discrete trial language. Children learn the concepts for the feelings that they are having and the actions that they are doing. So, it is an extremely different teaching approach.

Ms. Redwood: Sally, it looks wonderful. So, my next question is, how many more studies do we need before this can become sort of the standard of care for early intervention?

Dr. Rogers: Well, as you know, one study never makes a fact. Two studies make a fact. And Geri did the first study, and, hopefully, if our findings from our ACE multi-site study are in the ballpark of Geri's study, then we will have two independent, randomized trials of this particular method.

It is already in the public. We have published the manuals. People can get access to all of our materials at no cost. So, it is available. We would like to make sure the science is behind it as well.

Dr. Insel: Just a clarification, the results that you talked about at the end, the six of eight kids or so that were doing so well --

Dr. Rogers: Yes.

Dr. Insel: -- what study was that? What was the intervention?

Dr. Rogers: What I am talking about is these are the first children coming out of our ACE multi-site study.

Dr. Insel: Okay.

Dr. Rogers: I don't have the outcome data. I can only say that clinically the children that we have treated, this is the first child from the ACE study.

Dr. Insel: Good.

Ari? And, then, Alison.

Mr. Ne'eman: Yes, two questions. The first is, what IQ test did you utilize to measure IQ both before and after the intervention?

Dr. Rogers: We are using the Mullen. We are using the Mullen scales of early learning all the way across these studies. That is the standard. That is the core IQ measure for preschoolers with autism across all of the Network studies, both the ACE and before that the CPA and the STAART. So, there is a long tradition in these NIMH Center studies for using that tool.

Mr. Ne'eman: I was just curious just in the context of some of the research I have seen which indicates that IQ tests, you know, that are more verbal in nature may not adequately measure the intelligence of autistic children.

Dr. Rogers: Well, these are developmental tests. And so, they are not particularly verbal in nature. There are both some language scales on them, but there are also three different non-verbal scales. And we measure all of that. The scores are highly correlated between verbal and non-verbal.

I am showing you a full-scale IQ on these. But if I pulled out either the verbal or the non-verbal, you would see the same relationships.

Mr. Ne'eman: And, then, my other question was you mentioned as one of the outcomes that the child -- I don't know if that was in the context of the study or just that individual child -- was in a general education classroom. But, you know, as you are familiar, special education is a service and not a place. So, that is not necessarily connected to whether or not the child has a disability.

Do you have any data as to whether or not these children are receiving special education services afterwards?

Dr. Rogers: I do have data on that. What I said was that this child was in a typical preschool. He is in a private preschool that his family chooses to send their other children to as well. So, he is there without any services or any particular supports and doing well.

I am gathering data on the educational placements of each of the children that graduate. And when we’re finished with this study, we will be able to look at whether there are differences in placements. But, remember, they are only three and four when they are coming out. They are starting at one. So, they are still preschoolers at the end of this intervention.

Mr. Ne'eman: No, I understand. My question was less oriented around placement and more around service provision, just because, you know, questions of placement are somewhat socially-determined.

Dr. Insel: Alison?

Ms. Singer: What was the standardized community treatment that the kids in the control group received?

Dr. Rogers: Well, it wasn't standardized community treatment. It was just community treatment. And they are getting what the parents are choosing from what is available for them in their communities.

So, some of the children are getting, not many, but some of them are getting 30 or 40 hours a week of discrete trial teaching that they are purchasing. All of the families are getting zero-to-three services inside their communities. Children, as they turn three, are getting public preschools. They are getting speech and language therapy.

So, they are getting what -- you know, we do the diagnoses. We refer all the families in all of the sites to their public services. And from that point on, the families are getting what they can find in their communities and what they choose, and in some situations what they can afford.

Dr. Insel: Coleen?

Dr. Boyle: Actually, a question for Joe. I am just curious, in the work that you have done and the underlying hypotheses, both in terms of the onset of autistic behavior in very young children and the brain growth issue, that has all been done in high-risk children or high-risk families. Is that generalizable to other children with autism? Or are the observations more focusing on children or families, children that have more of a genetic component to autism?

Dr. Piven: Well, the behavioral studies are in high-risk groups. So, those are using the baby sibs paradigm.

Dr. Boyle: And the brain growth as well?

Dr. Piven: The brain growth is in sort of a clinically-ascertained sample. So, those are kids that come to us with early evidence of a diagnosis, or come to other investigators, that we diagnose with autism. So, they don't necessarily have a high risk.

And, then, the head circumference studies are just retrospective of those that already have a diagnosis.

Dr. Insel: Gail?

Dr. Houle: Yes, I had a question for Sally. You’re getting the kids and you have them diagnosed by 12 months of age. So, where are your referrals coming from? That is my question, and, then, I will have a comment after that.

Dr. Rogers: They are 1-year-olds. So, they are anywhere from 12 to 23 months at the time that we get them. They are all coming from community referrals.

And actually, we were quite concerned about diagnosis that young. We were using the ADOS-T and clinical expertise. But one of our concerns was about the inability to be comfortable with those diagnoses.

So, that is part of why we started with that 12-week parent training. We did the 12 weeks and, then, we reassessed each child.

And surprising, very surprisingly, is one of the points I wanted to share with you. Of the 117 1-year-olds that we initially saw, 115 of those children maintained their diagnosis of autism not only for three months, but for a year later. So, we were actually surprised at our ability to diagnose autism and to have that be a stable diagnosis from community-referred children, people who are worried about these children, families who are seeking services.

So, I think it is good news for the autism intervention world in that the tools that we are using in a large group of children at three different sites were very good at identifying autism in children at an average of 21 months, but we had children as young as 13 months in this study. And virtually every child, 99 percent of the children maintained their diagnoses up through their second year of --

Dr. Houle: So, might they have

been screened already by a pediatrician and, then, referred to you?

Dr. Rogers: Well, we screened them. When they would call us, we would first --

Dr. Houle: They would call you?

Dr. Rogers: We would do telephone screenings before we saw them. And we did two different telephone screens. And, then, if the children on the telephone screens continued to meet autism criteria, then we brought them in.

Dr. Houle: I am very interested in the distance learning, distance intervention technology part of it because, as you said, in Michigan there is a great disparity of services. You also said it is like an hour to reach the site.

Dr. Rogers: Yes. Yes.

Dr. Houle: So, you know, it would make sense that they would be unable to deliver as many hours of services as you can in Los Angeles or somewhere like that, where you don't have that huge amount of travel distance time.

So, we are going to be looking at ways to use technology in that. So, I would like to talk to you a little more in the future about pursuing that area.

Dr. Rogers: Sure. I would be happy to do that. That is Laurie Vismara's work, and she is currently doing a randomized controlled trial of that --

Dr. Houle: Great.

Dr. Rogers: -- internet-delivered intervention.

Dr. Insel: One of the major issues in the Strategic Plan, the Research Strategic Plan, was early intervention, early detection. And I think this has given us a pretty good glimpse into where the field is going. So, this is very encouraging.

Any other comments or questions?

(No response.)

If not, thank you to both of you and to Lisa Gilotty for bringing this topic forward.

I think we will take a five-minute break at this point.

And if it is okay with you, Coleen, we will do the CDC presentation afterwards. We have some buffer built into the agenda, so that we had a chance to catch up a bit.

We will plan to reconvene in five, let's say seven minutes, to split the break. So, we can catch up a little bit. Okay?

(Whereupon, there the committee members took a brief break starting at 3:20 p.m. and reconvening at 3:27 p.m.)

Dr. Boyle: So, I was just going to do a few minutes of introduction. I know many of you have heard about CDC's program and autism, but I was just going to briefly update everyone on our surveillance, our research, and our health communication/education activities.

Our surveillance and tracking program, the ADDM, the early detection program, the 2008 data, we are working on developing that new report. We hope to have it published later this year.

We are also expanding as we get better in our ability to collect information on autism, we are expanding the program to put more of an emphasis on using the data really and bolstering the utility of the data, and trying to have impact, really empower the data to have impact on programs and policies.

And as part of that initiative, we held a workshop that Dr. Cathy Rice will tell you about more in a few minutes. That workshop was really focusing on getting a better understanding of the gains and the trends in autism over time.

The second focus of our work, as you all know, has been on epidemiologic research. We actually had invited one of the co-PIs of our site in Maryland, Dani Fallin, but she actually had a baby last night at 6:00 p.m. So, she won't be with us today.

(Laughter.)

But we will be delighted in bringing you up-to-date on that project sometime in the future. But I do want to give a quick update on it.

Most of our work in the epidemiologic research area focuses on a study we call the SEED study, the Study to Explore Early Development. And that study is winding up really the second phase of it, where by the end of 2011 we will have enrolled 650 children with ASD and a similar number of children in two comparison groups.

We are starting a third cycle for that study. The goals of the third cycle will be to double the numbers of children enrolled as well as to refine the study protocol.

The presentation that Dani was going to present is in your handouts. So, you can take a look at that.

And actually, that was an effort that was funded through ARRA funds. It was focusing on using the biosamples that are being collected through SEED and trying to look at some of our intriguing genetic, environmental/gene interaction studies.

And, then, the third component of our program is our health communications and health education activities. I know you have all heard about our “Learn the Signs. Act Early.” program, started a number of years ago by Katherine Lyon-Daniels and actually Jose Cordero.

We are going to show you where we are with that program. It has emerged from being a health communication and health campaign to really being much more of a program that has more of a state focus, and partnering very much with HRSA on that engagement.

So, I am going to turn now to Dr.

Cathy Rice. I think all of you know Cathy. She has been one of our leaders in our surveillance and epidemiologic tracking program, the ADDM program. She is going to bring you up-to-date on some of our new challenges there.

Cathy?

Dr. Rice: Okay. Thank you, everybody.

I hope you all got some caffeine for the afternoon.

I want to talk a little bit about a workshop that we had in February on evaluating change in ASD prevalence. The primary focus of the workshop was the very important issue that identified prevalence of ASD has increased significantly in a short amount of time across multiple studies in multiple countries, but, particularly, also, among the U.S.-based Autism and Developmental Disabilities Monitoring Network, CDC's ADDM Network, where our current prevalence estimates come from an average of 1 in 110 children affected.

So, I would like to also thank Autism Speaks for co-sponsoring this workshop and the planning committee that was involved in this.

In the room, we have several participants and Chairs of some of the panels we had. So, if there is time for discussion, they may have additional information to include.

So, the purpose of the workshop was to bring together epidemiologic prevalence, in particular, prevalence in surveillance expertise. So, there are multiple forms of epidemiologic studies and tools.

Prevalence studies, typically, are sort of one-shot-in-time studies looking at how common a condition is in the population, where surveillance studies typically look at sort of serial estimates of prevalence in the same population.

So, we wanted to bring together expertise who had worked in that area among autism, but also in other conditions; for instance, people who have worked in cancer or asthma or schizophrenia, conditions that have changed over time, have multiple causes, and looking at methods that they have used to help inform our work.

Then, we had four panels that met together to help us identify priorities in terms of focusing primarily on U.S.-based data, trying to be as concrete as possible in terms of what can we do now with existing data, what else can be done to build on the existing data systems that we do have in the U.S., and what else is needed in terms of data collection analyses, additional things that could help inform prevalence.

This is just a very broad summary of prevalence studies that have been done across multiple countries over time. You will see certainly increases in terms of identified prevalence now.

Whoops, the formatting is off a little bit.

But the one in 2000 reflecting primarily autistic disorder, but when you get in post-1990s and sort of these averages from across multiple studies, we see significant increases over time, which is very concerning.

We have also seen this in our U.S.-based ADDM Network data. This is multiple surveillance years that we have starting in 1996 up to 2006. As Dr. Boyle mentioned, we will be adding an additional data point later this year, and we are in the field collecting another data point as well.

But we have published some information examining trends from this time point to this time point, showing a 57 percent increase in autism spectrum disorders over a short period of time.

So, where are we in understanding

the reasons behind these increases? Sort of generalizing a bit, the most important thing is we know that the impact on individuals, families, and communities is significant. You have this large increase over time. You have more families trying to sort out what is happening, more individuals trying to understand what is going on with them, and more communities trying to deal with, as we have heard many examples today of a lot of the resources that are being developed, but many unmet needs as well.

But when we look at the reasons, what is happening in terms of autism prevalence, the debate has really been kind of polarized to some degree, as this is all identification or this is all risk. Tell me one way or the other which it is.

And, in reality, we are not going to find such a simple answer. So, how do we move forward to say we know that some of the increase is due to identification factors?

Now is all of the increase due to that? Most likely not. However, how do we get more specific in looking at the multiple overlapping factors that could be at play here?

Now, when you read the prevalence studies, most prevalence studies look at what you can measure in that particular area. We have done the same in ADDM, where we have been able to say, well, we have been able to locate more records over time; we have better documented information; kids are getting identified earlier. So, those are some of the identification factors that help us know that some of that increase is due to identification factors.

But, typically, studies end with "but a true increase in symptoms can't be ruled out." And the challenge with going further in that is it is hard to prove. It is an issue that is really hard to prove when we don't really have as detailed and specific information about the multiple causes that could be at play with autism.

So, it is a challenge because, when we are prevalence in surveillance studies, we are looking at the population level. We are looking typically at describing changes over time in groups. We can look at increased risk, but it doesn't really tell us for individuals what is the etiology, what is the cause. So, we need to work complementarily with other types of epi studies and basic science.

A good example is the most common finding in autism studies throughout the years has been about four to five boys for every girl. So, we are consistently finding that, but we don't know why that is. Prevalence studies are never going to tell us why that is.

So, is it a genetic issue? Is it a hormonal issue? So, we need to feed back and forth with basic science.

But, looking at a population level, we can get more specific in terms of what are some of these identification and risk factors that may be at play in the general population.

So, what we wanted to do in this workshop -- and I think the formatting is off a little bit here -- is to be more specific in terms of identification factors. And we pulled out and defined intrinsic identification factors, so those that are related to internal methodology or measurement issues. So, variations in methodologies that are used. Are we looking at service-based data? Are we doing surveys? Are we doing an in-depth screening? Improved ascertainment over time, how is that impacting prevalence?

Also, there are very important extrinsic identification factors, the things that you often hear as influencing prevalence: changes in diagnostic criteria, improved early identification, improved access to services, those types of things.

But we also have the important concern about changes in underlying risk. Is there something happening etiologically that is changing, that is impacting the risk of individuals actually expressing autism? Which also begs the important question, is there a modifiable risk factor? Can we identify what is changing in the environment, so that, then, we can intervene and help those individuals not develop the disability that we are talking about, and maybe particularly the encouraging news in terms of understanding what may put somebody at risk, to start early identification, as we have heard very promising results from Dr. Rogers?

So, there have been some efforts to be more specific. This is just a summary of some of the recent studies that have tried to look at some of the identification, some of the potential risk factors, but there are many out there.

As part of the workshop, we have a grid that we have laid out of just some of the many both identification and risk factors that could be looked at, which I am more than happy to share with the Committee if people are interested in that.

But we could go on listing many, many other potential risk factors. So, what we want to say is, well, how can we begin to get data in the population to look at how that has changed over time in relationship to how prevalence has changed over time? But, then, how do we model when many of these factors are overlapping?

So, this is just a quick look at the four panels that we had, chaired by Alison Singer, Lisa Croen, Geri Dawson, and Maureen Durkin.

The first focused on the utility of prevalence data, what kind of data are helpful, are useful. How could they be used, and how are they being used? U.S. service-based data, so a lot of people have looked at the California Department of Developmental Services data or the Department of Education data in terms of autism eligibility; the ADDM Network data that I mentioned earlier. And, then, what else do we need in the bigger picture to focus on U.S.-based trends?

So, I just want to give you a flavor of some of the discussions. There is a full report in preparation. Certainly, we will share that with the IACC when it is available.

But one of the questions that we posed to panel four is, can we actually answer the why of prevalence changes? And, then, what do we do to move that forward?

And so, there was a lot of debate among panel members. There wasn't a resounding agreement of, yes, we can answer this; we can have a neat pie chart and tell you exactly how much is due to these identification factors and actually how much is due to this amount of risk.

But, in the end, there certainly was a willingness, some interest for sure, and focus on the fact that we need to move forward to try to evaluate that. But some individuals said that, really, this is the wrong question; of course, there is an increase because we have seen an increase in the number of cases.

Others said, well, prevalence data by themselves are really important for services in helping families, so let's focus on the use of these data for that purpose.

Others said, well, until we know more about underlying risk factors that we can measure changing in the population, we are going to be limited in terms of looking at associations with measures of prevalence.

Again, most agreed that there are multiple factors involved, and there was definitely clear agreement that autism is a very important public health issue and that the prevalence data has really made that clear.

So, going back to that main question about we need multiple approaches, if we are going to better evaluate, whether we will be able to come up with a neat pie chart or not is still in question, but certainly an effort towards better quantifying and qualifying what makes up the realm of reasons for increases in prevalence is really important.

However, people acknowledge that there are several insurmountable, maybe not insurmountable, but one mentioned was insurmountable measurement error; also, the need for data on risk factors in the population.

One thing we have had challenges of saying, well, if we are going to look over this time period, how have some of these risk factors -- so, I will take a simple one, parental age, that has been looked at. And one of the reasons that that has been looked at so far is because you can actually get data on that. So, some of the other risk factors, it may be challenging to get. When people have wanted to look at things like hazardous air pollutants, for instance, do you actually have a measure that you can correlate with the individuals that you are looking for or that you are looking at? So, we definitely not only need the prevalence data, but we also need the risk data to match up with it.

Another challenge is the broadness of the phenotype. Prevalence data are only as good as your identification methods. And so, the focus in terms of having more clear-cut ways of identifying autism that can be consistently used across studies was another point that was made.

Some of the key recommendations that were made in terms of immediate priorities:

One was to enhance the utility of the current data for the community. For instance, with the ADDM Network, we collect a variety of data that don't make it to our initial prevalence reports. And there was a big emphasis on help us better understand, I think as we have heard today, the range of functioning within autism. When we are talking about 1 in 110 children, what does that mean in terms of functioning level? What does that mean in terms of the characteristics of those individuals?

Using these data to understand disparities, for instance, in terms of informing identification efforts.

There was also a recommendation to expand the analyses based on the data we have. So, looking at the factors influencing differences among subgroups and across places. For instance, in the ADDM Network, we saw very similar overall trends in terms of increases among boys and girls, but when you looked at girls across sites, we saw some sites actually decrease in prevalence, others go up quite a bit. So, what's happening among those sites and the individual variation that may be happening across sites, even when you can summarize an overall trend?

Also, we need to use complex modeling and multi-factorial analyses and looking at trends in ASD population by specific characteristics beyond IQ, for instance, but also looking at co-morbidities and how those are shifting in the population.

Certainly, a call to examine other behaviorally-defined conditions. And one of the things that was surprising, as much as we have been challenged to collect really quality data in autism, other areas are really looking to us for a model these days in terms of how do we collect information on some of these behaviorally-defined conditions. So, having that comparison data is also somewhat of a challenge, but we need to look at how those are changing as well.

There was also an emphasis,

particularly now more than ever we hear this across the day, is continuing to collaborate with families, individuals on the spectrum, researchers, service providers, to get input from multiple area in terms of what is important to look at and how do we move forward, and seeking partnerships and collaboration within the autism community and outside the autism community.

So, some of the next priorities beyond, so more in terms of the two- to five-year range, is to provide additional funding opportunities for trend analyses using existing datasets, linking datasets across multiple health, service, and research databases.

And many of these things are actually in the current update of the IACC plan. So, it was actually really encouraging to see that the current Strategic Plan is ahead of the game in terms of some of these recommendations.

Leveraging data systems that are being developed to see if proactively we can get data collection in as part of these new resources, including information on service use and needs; also, the importance of validation for different methods and expanded validation for the record of the method.

So, for instance, the ADDM Network has done a validation study showing that, although we have very good specificity, our sensitivity is relatively low, indicating that our estimates of about 1 in 110 children are actually still an underestimate.

We also need to follow up existing cohorts and evaluate prevalence across multiple age groups, including adults.

So, in terms of the bigger picture of what else is needed, people were calling for expanded coverage of prevalence projects, not only for estimating service needs, but, also, for increasing the numbers to do comparability and subpopulation evaluations.

Supplementing quantitative data with more qualitative information in terms of functioning, and other types of collection. Can we at some point combine a surveillance system with some of these very nicely-done studies that look in-depth at terms of biology and behavior?

We also need to look -- one of the challenges we have in terms of prevalence can shift wildly, depending on where we draw that line between an autism spectrum disorder and having some of the features or characteristics of autism. So, if we had a way to monitor some of the traits in terms that are associated with autism at a larger level in the population, it may help us see how our definitions may or may not be affecting what our prevalence is.

Also, clearly, the need for longitudinal studies, addressing that need would enhance what we know about autism over time.

So, where do we go from here? The ADDM Network, as I mentioned, is busy at work on the next prevalence report and collecting data for the next surveillance year. So, we are continuing to build the trend dataset, and using different analytic techniques from this dataset to look at some of the various identification and risk factors that we can actually measure using these data.

We will certainly share the report with the IACC, and we will use it at CDC to inform our planning efforts, and hope that other agencies and researchers and folks out there who are doing this type of work will also utilize this to move forward in terms of understanding ASD trends.

So, where we are now is putting this together, but I think one thing that I would love for the Committee to talk about and discuss, particularly in these budget times, how do we move this agenda forward when most of us are happy to maintain what we have, and there is not a great deal of additional funding on the horizon? Are there ideas for collaborations that we can have that can strengthen?

A good example is we have this, in terms of the ADDM Network, this infrastructure here, and we are always happy to pass on funding opportunities to our grantees. For instance, one of our sites, South Carolina, has had funding from Autism Speaks to do a follow-up cohort. So, they looked at kids when they were eight years of age and, then, again when they were 15 years of age. And there will be a publication coming out about that in the future.

So, there are opportunities like that that we can think to collaborate on or other ways that we can collaborate to move this agenda forward.

So, thank you for your attention, and we will see if there are any questions or comments.

Dr. Insel: Maybe we should move on to the next presentation, and, then, we will take questions for both, if that is okay, Coleen.

Dr. Boyle: That would be fine.

Thank you very much, Cathy. That was wonderful.

And a related topic -- it definitely helps feed into the work that we do on our ADDM Network -- is the work with our health communication/education focus. I want to introduce Becky Wolf, who is a health communications specialist in the Division of Birth Defects and Developmental Disabilities at CDC.

I do want to mention that my colleague to the left, Alison Singer, was very engaged when we first started the “Learn the Signs. Act Early.” campaign. I think one of the reasons why there was so much success in that area was really the sort of private/public partnership that developed in terms of really the launching of that event.

So, Becky?

Ms. Wolf: Okay. Thanks, Coleen, and thanks for the opportunity to be here to talk about the “Learn the Signs. Act Early” program.

As Coleen said, we have a new approach, new tools. So, I know you all have heard about “Learn the Signs” before, but I think this is perfect timing to hear about it anew. So, thank you.

The purpose of the “Learn the Signs” program, just as a reminder, is to improve early identification of autism and other developmental disabilities, so children and their families can get the services and the support that they need early.

There are three components to the “Learn the Signs” program. The biggest, and the one I will talk about first, is the health education campaign. Second is the Act Early Initiative, and third are research studies and evaluation projects that support both of those.

And by the way, that is an image of one of our new materials which is hot off the press.

So, for the first component, the health education campaign, we aim to change perceptions about the importance of identifying developmental concerns early. We give parents and healthcare professionals and childcare professionals the tools, which are free, by the way, they need to help track children's development and developmental milestones.

We promote awareness of the importance of early identification, the importance of monitoring developmental milestones, and the importance of acting early if there is a concern.

And, then, last year, after much discussion and a lot of strategic planning, we shifted our approach from what was really a broad marketing campaign to a more strategic partnership-based approach. So, we are specifically targeting underserved populations by working with other federal, state, and local programs that serve young children and their parents, and we are building relationships with programs that have an interest or mandate in child development, but may not necessarily have the tools or the resources to address tracking developmental milestones or encouraging early action.

So, we think that we have already begun to significantly increase our reach with our target populations and without any increase in funding. We did not get any ARRA funds. So, we are doing it with the same budget that we have had.

And I will talk about the tools, the new tools and new approach in a second. But, first, I want to say just a couple of words about our campaign impact.

We did launch in 2004. So, it has

been in the field for a while, and we have data that show that pediatricians aware of the campaign are more likely to have resources to educate parents about monitoring their child's development. They are more likely to have resources for referral and treatment. They are more likely to discuss cognitive development with parents. And pediatricians are less likely to advocate a wait-and-see approach.

And in the last seven years since the campaign was launched, we think we have helped make a difference in how child development is now viewed, that height, weight, first words, and first steps are no longer sufficient when we are talking about childhood development, and how a child plays, learns, speaks, and acts are all equally important, with the traditional measures.

And, then, one more word I want to say about impact is that none of us think or believe that printed materials will result in behavior change by themselves, that it takes more than that. We know that building awareness is still important, and we are still going to be doing that. But awareness alone isn't enough. We want to make a real difference in the early identification. And so, our new implementation strategies take that into account, and I will talk about that in a second.

So, we have free customizable materials for any federal, state, or local program. We have new materials. You see an image of one there that we developed with Wisconsin. Actually, it was their suggestion. And I have one that was only printed on a DeskJet printer. So, that is what we have got so far, but I will be happy to share it with anyone who wants to see it afterwards.

All our materials are being updated. And based on our two new ones that we have developed, they are all research-based and parent-friendly. They all build on the gold standard milestone list from the American Academy of Pediatrics and Bright Futures and Caring for Your Baby and Child.

And they provide monitoring tools that parents and early educators can use, and they explicitly encourage parents to check off the milestones that their child has reached and take the checklist with them to their child's healthcare provider and have a conversation about their child's development.

Everything is available in English and Spanish. Some of our materials are available in other languages as well, and we are expanding that list.

So, we think that they are useful for any program that serves parents of young children and has an interest in child development. And you can review all the materials we have at the website you see here, www.cdc.gov/actearly. And you can email us at actearly@cdc.gov.   And we will be happy to work with you or anyone else in your agency or organization to customize the materials with your own logo and contact information. And we can do that for you, actually, and send you a print-ready file. So, we would love to do that, actually.

So, then, talking about strategic approach, like I said, we are working with federal, state, and local partners who are beginning to integrate our materials into their programs. Here's the list of some of those that we have already got budding partnerships with: WIC clinics, and Head Start, and Just in Time Parenting, and ACF Childcare Block Grant, and we have others besides.

But this is where we hope to not only increase awareness, but also to build the partnerships that could lead to the interpersonal contacts that can help us move further than awareness and to getting into actual impact and behavior change, and why these partnerships are so important to us.

So, the next component of the "Learn the Signs" program is the Act Early Initiative, which we have been working with HRSA and AUCD very closely to improve collaboration among what we all know are very complex systems at the state and local level for early childhood, very complex funding streams, and a variety of programs.

So, we convened Act Early Regional Summits in all the HHS Regions that brought together public health and medical and education, social service, and advocacy representatives. In some cases, it was the first time that all of those folks got together around one table.

And they developed, those state teams developed plans for improving early identification, awareness, and screening in their own state.

We continue to support their efforts, their high-priority efforts and their state plans through AUCD and AMCHP.

We talked to all of the state team leaders or almost all of them after the Regional Summits were done to find out what were their opinions about the effectiveness of these Regional Summits. And most state team leaders felt like they were important for strengthening the partnerships they had and equally important for bringing new folks in that they needed to be talking to and hadn't in the past, and that they were on the path towards improving early identification.

Most teams continue to meet and work on some of these post-Summit activities you see up here: education and training, awareness, and policy change.

And this screenshot is an image of Wisconsin's new single point-of-entry portal for parents. As you see, it is “Learn the Signs. Act Early.” Wisconsin.

So, here are just a few examples of what some other states are doing to improve awareness and, also, making use of our “Learn the Signs” materials with their own customized versions.

So, Delaware is distributing them widely to pregnant women through home visiting programs and to new mothers in their birthing hospitals.

Connecticut has provided customized “Learn the Signs” materials to every childcare center in their state.

New York is working on widely distributing through a variety of programs, and their list keeps increasing.

And there are other examples as well.

So, here are a couple of comments that we heard during our interviews from state Act Early team leaders. They felt that the process was helpful. It gave them a purpose. It brought them together. It gave them a clear idea of what they can and should accomplish. So, the Summits, we think, helped put everybody on the same page.

And, then, our last component is our research studies and evaluation projects to support the other two. We are working to advance our understanding of the information needs of our key campaign audiences.

We did our original formative research back in 2003-2004. As we all know, a lot of water has passed under the bridge since then, and we need to redo that. So, we are; we are funding that now.

We also have research projects we are funding through AUCD about how to reach special populations. Some examples are low-literacy groups, families in the welfare system, Hispanic families in Little Havana in Miami; and, also, how to improve collaboration across the complex state systems.

And we are also funding evaluation projects to better learn what are the best implementation strategies. So, we have an interagency agreement with HRSA.

We are funding four states that

receive the Combating Autism Act Initiative funding. Those are Alaska, Missouri, Utah, and Washington.

And we are focusing really on feasibility and effectiveness of campaign implementation strategies. They are all taking quite different approaches.

Missouri is working very closely with WIC clinics in St. Louis city. Alaska is focusing on native populations. Utah and Washington are both focusing on Hispanic populations, as well as some others.

So, those are all my slides. I did want to make mention of the autism case training curriculum that we have done in conjunction with HRSA and the developmental peds training programs. And we are very excited about this. It is to educate future pediatricians on identifying, diagnosing, and managing ASDs through case studies, and it will be ready later this month, which is very exciting.

I think that the Services Subcommittee will be hearing about the case training curriculum at an upcoming meeting.

So, I guess it is time for questions. I would also like to say you can look at our materials on our website and contact us by email. We would love to hear from you.

Dr. Insel: Terrific. Cathy and Becky, thanks for this quick rundown.

Let's take a couple of minutes for questions or comments.

Dr. Lawler: I have a question for Cathy. Have you had discussions with NDAR in terms of sort of federating the ADDM or the SEED data? Because, I mean, that could be one way that could really help leverage use of those datasets and facilitate comparisons with more clinic-based populations that we have mostly in NDAR now.

Dr. Rice: We have had discussions with them in the past, not in the very recent times, but certainly we would be glad to have those discussions again. We are also working on a public use dataset which would help with the transition to NDAR, I think.

Dr. Insel: Ellen?

Ms. Blackwell: I have a question for Becky. Are you working with the Medicaid State EPSDT Coordinators?

Ms. Wolf: A number of the state teams are doing that, yes.

Ms. Blackwell: Okay. Because I think that is something we would be really interested in exploring.

Ms. Wolf: Yes. Right. Yes. I think almost all the state teams included them. I don't have the number.

Ms. Blackwell: Good. Great.

Dr. Insel: Lyn?

Ms. Redwood: Cathy, I was just wondering, when you look at like the National Cancer Institute and the way that they do their surveillance studies, is there any way we could have some type of mandatory reporting when a child is diagnosed and have certain criteria be met, and, then, have a national database from each state? I mean, it just seems like that would be sort of the simple way to be able to track what is going on.

I know there is mandatory reporting for infectious diseases, and it is very easy for CDC to determine the incidence of H1N1 in every single state. So, I am just curious if we could utilize a system like that.

Dr. Rice: Yes, so some states have started mandatory reporting of autism. A challenge with that, when there are these reportable conditions, is the teeth behind it in terms of what is the enforcement of that.

So, for the states that have implemented that at this point, we haven't really seen that they have been able to collect the amount of data anywhere near what we think is the actual diagnoses that are happening over time. But I think that is something that over time, as identification is getting more and more consistent, that that may be something that is helpful.

Another challenge with that is it is very different than, say, with H1N1, where you have a clear onset, symptoms, and acute sort of process that is happening versus over time. But I would love it if we could get to the point where all kids with autism are getting screened when they should be screened, and we are to the point where we can integrate it in a way that we can track kids and they are following up on those screenings, and we have those diagnoses.

So, I think it is a good idea, but I don't know that it is going to serve the purpose that we would want it to serve at this point.

Ms. Redwood: Do you know how the National Cancer Institute does it? Because they have state by state, county, types of cancer, long-term survival rates. How do they do it?

Dr. Rice: Dr. Boyle, you may be able to answer that a little bit more --

Dr. Boyle: So, there's two systems that influence cancer reporting. NCI actually has their SEER Network. I don't know if -- there's 11 states. Then, the CDC actually has a cancer registry program as well. That is based on reporting either to the state, if it is CDC, or to the research institute, if it is NCI.

It is not necessarily mandatory reporting. I mean, they have folks that would go in and review hospital discharge records, pathology laboratories. It is fairly intensive reportings.

Dr. Insel: But since you already had this ADDM Network, what prevents us from keeping this as an ongoing surveillance system? And, then you would know every year what the increase is or decrease is in any given part of the Network. Because right now we are dealing with data that is chunked every four to five years.

So, we were just talking about 2006 data. Now we are in the middle of 2011. That is five years of lost information that we don't have. Is there a way to do this that is more real-time?

Dr. Rice: Well, I think the issue is what we have done is combining those methodologies, is really helpful at this point.

So, some of the states we work with do have a reportable condition. So, for example, Colorado and Utah both have autism as a reportable condition.

But what that does is help the project, then, have the authority, working with the State Health Department, to go in and actively identify those kids that have been diagnosed, but those kids that have been missed, too, that have the symptom profile.

So, you could have that system, but it really depends on what kind of data you are looking for.

Because of the variation in the age of diagnosis, we could say, yes, how many kids are being diagnosed, if people will report it. But we are going to say, well, how many are being diagnosed in quite an age range. I mean, we have such an age range with the average age of diagnosis still being four and a half to five and a half years of age.

So, I mean, I think it sounds good in the ideal world, but in the actual world, unless you have consistent screening, identification and follow up at a consistent time point, it is really hard to use that to get that type of incidence data, which I know that is the goal, but that is quite a challenge when we have the variation in identification in autism.

Dr. Insel: Well, what prevents you from doing this even in a single site?

So, it is having one place that will be the national incubator to follow trends, knowing that it may not be representative of the whole country.

I mean, I just can't think of an infectious disease where we are talking about 2006 rates in 2011. We are always pretty much up-to-date.

I know how much Tom Frieden cares about having current data on virtually all disorders. It seems like that is really happened in many areas, but somehow it hasn't happened here. And I am not sure what prevents us from doing it, even if it isn't comprehensive, just to have some place where you can track and know almost in real time what is happening in the community.

Even though there may be questions about how to validate and questions about the sampling method, at least if you are consistent, you could see shifts in the numbers. And, then, you can worry -- so, you have the reliability -- you can worry about the validity by doing a subsequent in-depth study.

Dr. Rice: So, we have funded a few projects to try to evaluate that with earlier surveillance using a screening methodology. For instance, we are working with Amy Wetherby in Florida State to take a 10-county area in northern Florida where we are screening different cohorts over time with that follow up.

So, that has definitely been a goal, but it has to be at this point that sort of incubator model, and to see what information do we get with it and how practical is it for surveillance. And so, that is what we are currently evaluating.

So, I think in the long-range that would certainly be a goal, and we are evaluating how feasible and practical that is for an ongoing surveillance system.

Now it still is very different,

though, when we were talking about an infectious disease versus a chronic condition. So, if you look at the data for things like cancer, we can even look at the data for mental health conditions; we don't have real-time data for any of those types of things, even things like asthma, heart conditions, anything that is more chronic that doesn't have an acute onset that is tracked in a very specific way in terms of hospital reporting. A lot of those data systems, unfortunately, are much older than we would want them to be.

So, I think it is a challenge that we always have to keep improving, and we are actually now on a cycle to report data at a three-year interval, and are constantly working to improve that. But we also have to be realistic about what's the model for other data systems as well. We are not talking about an infectious condition right here.

Dr. Insel: Okay. I think, again, we are way past our time on the agenda, but I wanted to make sure that you had a chance to hear about each piece of what is going on in terms of the updates.

We are going to move on to hear -- and thanks to both Becky and Cathy and Coleen for bringing this together.

Geri, do you want to give us a quick update on the Translational Medicine Workshop?

Dr. Dawson: All right. So, this is a very brief report on a meeting that was cosponsored by Pfizer and Autism Speaks that was held in January in Santa Monica on translational medicine research.

Tom was very actively involved as part of the planning committee, as were several people from Autism Speaks, and Rob Ring from Pfizer, and a number of people from the academic community.

Let's see if I can get it pulled up here. Okay.

So, the purpose of this meeting

was to identify strategies to accelerate the development of novel diagnostics and drugs that can assist in early detection and ameliorate the core and associated symptoms of autism, improve responses to behavioral interventions, and, ultimately, enhance quality of life for people with autism spectrum disorders and their families.

So, as you may be aware, there is a very challenging pathway from first describing autism as a disability and, then, conducting the biological research. That is varied in terms of being a very multidisciplinary approach that allows us to finally begin to understand some of the biochemical pathways that are affected in autism, and, then, to use that biologic information to come up with hypotheses about target pathways that might be responsive to some kind of a medical intervention.

Even after developing a target, there is a very complex and very time-intensive process of assay development and, then, screening of compounds to see what can get in the brain, what might have toxicity, et cetera. And, then, after that is done, testing them in an animal model.

So, this middle phase of the drug discovery pathway is often called the Valley of Death because that is where many exciting new leads don't actually make it to the phase of a clinical trial. And then, of course, when we get into clinical trials, there's several phases of that before FDA approval. So, this is a very long process. So, the question was, how can we accelerate this process in terms of both discovery of potential medicines and developing them?

So, the objectives of the meeting, then, were to begin to develop a dialogue and promote collaboration and cross-fertilization among the academic community, industry, the NIH, nonprofit organizations, and the families and people affected by autism.

As you may know, there are a number of companies who are now entering into the autism drug development arena. So, this includes Pfizer, Roche, Novartis, and some other smaller companies such as Seaside Therapeutics.

What we wanted to do was to continue to encourage and facilitate their entry into the autism field and to spend time together identifying possible drug targets and strategies for validating those targets, and, also, to identify gaps and opportunities for the future research and just strategies for accelerating progress.

So, what I am going to do now is just briefly show you the agenda, so you can get a sense of what the meeting was about. We began by asking people who were thought leaders and who had experience in the area of drug discovery, so Ed Scolnick, David Bredt, Rob Ring, Paul Chapman, who could give us their perspectives, some from NIH such as Tom and others from industry, about what we know now and what they saw as some of the strategies for moving forward.

And, then, the next session focused on what we have learned thus far from the single gene disorders that are associated with autism. Because, as you may know, this is the area in which most progress is being made because the genetic basis is simpler, and the animal models have been developed.

We actually are learning quite a bit about the underlying pathways that are involved, and the animal model studies have been quite promising in showing that certain kinds of drug interventions could help to restore and rescue some of the impairments that you see with these neurodevelopmental disorders.

So, we had a number of very stimulating presentations on the work that is going on in that area and what its implication is for developing drugs for idiopathic autism.

And, then, in the next session we focused on what genetics is telling us about some of the pathways that could be involved. And so, we had some talks that focused on common variants, such as the serotonin pathway or the Cntnap2 gene, as well as some of the rare mutations such as neurexin, neuroligin.

And the idea there was to not only try to identify what were some of the more promising pathways that may be disrupted in autism, but also how the genetics is pointing towards common pathways across different forms of autism that may actually have different genetic etiologies.

The next session was kind of a potpourri of conditions that we know are affected in autism that we think are important to consider when we begin moving towards medical interventions. So, these include gastrointestinal problems, immune abnormalities, metabolic abnormalities, seizures, and disruption in hormonal systems or, in particular, the oxytocin pathway.

So, we had just a really interesting discussion of mitochondrial dysfunction. Pat Levitt talked about his work on the MET gene and its relationship to GI problems in autism. And we had some very interesting presentations on the beginning use of oxytocin as a medication that may be helpful for addressing social impairments in autism.

The next session was more on target validation and looking at the really wide range of animal model systems that can be used, everything from Drosophila to primate models, to induced pluripotent stem cells, to mouse models of a variety of kinds that Jackie Crawley presented that could be used to validate some of the medications in an animal model or to be used for screening. Particularly, I think, the potential of the induced pluripotent stem cells as a mechanism for screening potential drugs is promising.

So, then, these are just finally some themes that emerged in terms of looking towards the future, what are needed. Certainly, I think we are still at the really early stages in terms of developing promising drug targets. And even after they are developed, as we pointed out earlier, there is going to be quite a long process and many kinds of resources that will be needed to get them to the point of a clinical trial.

We need better validated animal models, better high throughput drug screening platforms, which, by the way, NIH is now investing in as part of their new Translational Research Center.

We have a great need for large clinical registries and tissue banks that have detailed phenotypic data and biosamples of a wide range. So, not only DNA, but brain tissue, induced pluripotent stem cells, again, I think are going to be important.

Clinical trial networks, so that

when we have drugs that are promising, we can test them rapidly. We also, because there is a tremendous variability and heterogeneity in autism, we need biomarkers that can help us understand who will respond to what kinds of drugs.

We need better clinical trial end points and, also, it is going to be important that we move from a traditional clinical trial design to more innovative designs. So, there is an interest in looking at combination therapies because we know that in autism it is rarely the case that we have one treatment by itself, and, also, strategies for being able to either stratify or subtype individuals, as well as being able to measure very quickly what kind of response somebody is having to an intervention, and, then, perhaps randomizing them to a second intervention. So, these so-called smart or adaptive designs are going to be important as well.

So, lots of work ahead, but I do

feel like that we are at a very interesting and important point in the history of science of autism, where for the first time I think there is promise that we may be able to develop medications that could address some of either the core symptoms or the associated medical conditions, and could improve quality of life for people with autism.

Dr. Insel: Thanks, Geri.

Any questions or comments?

(No response.)

Okay. Let's go on to the business meeting. We do have business we have to do today. I think it starts with getting approval of the minutes.

Okay. Do you want to mention this? I am going to turn this over to Susan, then.

Dr. Daniels: First, I just wanted to highlight that NIMH is going to be hosting a special seminar on advances in treatment research with speakers Sue Swedo and Becky

Landa. This is going to be webcast live for the public. It will be available on NIH videocast, and we will put it up on our non-IACC meetings website, so people can access that. But we wanted to make sure that people knew that they were welcome to listen to this new information about advances in treatments.

So, on to IACC business, the first item of business is the approval of the minutes. Everyone received a copy of the draft minutes from January 18th in their packets.

Does anyone have any comments on the minutes as written?

(No response.)

Not seeing any, do we have a motion to approve?

Ms. Resnik: So moved.

Dr. Daniels: Second?

Ms. Blackwell: Second.

Dr. Daniels: All in favor?

(Chorus of ayes.)

Any opposed?

(No response.)

Any abstaining?

(No response.)

The motion carries, and the minutes are approved and will be posted to the IACC website within the next few days.

So, I wanted to quickly run through some recent and upcoming IACC activities. In your packets, you also have a copy of the letter to the Secretary on wandering and elopement that was sent in February. You have received now a response from the Secretary, which was discussed a little bit this morning. And that is also in your packets, and it is up on the IACC website as a part of the meeting materials for this meeting and, then, will be moved to a more permanent location after the meeting is over.

But I don't know if anyone needed to, wanted to discuss anything regarding that letter.

(No response.)

If not, then I will move on to the next item, which is that we are going to be doing an IACC booth at IMFAR this year, May 12th-14th, 2011. And it will be the same process as we had last year.

Any of you that would like to attend and work at the booth, we will be able to get you there and provide you with accommodations for IMFAR. What we won't be providing is the registration for the meeting, but we can get you over to IMFAR, and we would love to have you join us.

So, I will send out an email to all of you, so that you can send me a reply, if you would like to participate in that.

The 2009 Portfolio Analysis, we already discussed this morning, but I just wanted to let you know that we are anticipating web release this month. It will be a phased release. So, we will do the report first and, then the data tables in two other chunks because I don't want to hold back the report longer than necessary, because the tables take longer to format for the web. So, we will do the report first and then the tables will come out later. And we will send out emails to everyone, so they know when they are up.

For the 2010 portfolio analysis, we are moving along quickly into starting the data collection for that to begin this spring. One question I had for the IACC is whether you would like to include any additional funders in addition to the funders that have already been included in the previous analysis. We could include up to two more private funders, if you had any that you wanted to suggest.

In our analysis, one that I happened to notice, as we were looking through some of the grants, was that the Nancy Lurie Marks Foundation seemed to be a co-funder of a number of grants that were involved. And so, I don't know if that is a funder that you would like to have us approach.

Today we heard a number of other foundations that I am not as familiar with: the LENA Foundation, the Marcia and John Goldman Foundation, and the Coleman Foundation. But I don't know if the IACC has any strong opinions about these foundations and whether you would like for us to reach out to them.

Ms. Redwood: Shouldn't we look at how much they are funding? And if it is a good chunk of change, then reach out to them, and base our outreach, if we can only do two, to the two that seem to be funding the most?

Dr. Daniels: We can try to do that. We can try to find out more information about which ones are maybe the largest, the next largest funders, and try to see --

Dr. Insel: Part of what we were asking is whether you know of one that we left out. I actually think that Nancy Lurie Marks is a fairly large effort, and it is increasing in a very profound way this next year. So, we want to get them into the pool.

But is there anyone else that you know of that is at that scale?

Ellen?

Ms. Blackwell: I am wondering if we, Jamie, you might know, or Lee -- we didn't look at cross-disability organizations that might be funding autism-specific research. Is that something that we would want to include?

Dr. Insel: For instance?

Ms. Blackwell: Lee, you could probably give more examples. Easter Seals or The Arc.

Mr. Grossman: Easter Seals, The Arc. There's others.

Mr. Ne'eman: SAMHSA.

Dr. Daniels: SAMHSA had been asked before, and they said that they didn't have any research.

Mr. Ne'eman: Oh, okay.

Mr. Grossman: One other biomedical is the Hussman Foundation.

Dr. Insel: That is very helpful. So, we can check. That's two S's? Okay. Great.

So, if there is anyone else like that, just let us know and we will do a quick survey before we get into the 2010 analysis. Okay.

Dr. Daniels: Correct, and we will be collecting some information about publications this time, and we will meet with the Planning Subcommittee to see what you would like to do with that information.

I also wanted to just quickly remind you that we will be doing the mid-year selection of the 2011 IACC Summary of Advances this July. So, that will be coming up.

And we will be meeting with the Planning Committee before that, hopefully. And so, you can let me know if you feel that there is a need to change anything in that process.

And, then, we will begin to make preparations for the 2012 IACC Strategic Plan, assuming that we will be reauthorized. We don't want to get behind on our schedule. So, we will act as if we think that we be doing a Strategic Plan and be preparing for that. So, more information should be coming up.

In terms of upcoming meetings, we have a joint meeting of the IACC Services Subcommittee and Subcommittee on Safety on the topic of seclusion and restraint. We have, just as of last week, reserved May 19th, 2011. We have the Bethesda North Marriott reserved for that, and it will be from 10:00 a.m. to 4:00 p.m., is what we have on the schedule, unless it turns out that the Committee feels that there isn't enough to talk about during that period. We could make it shorter. But more information will be coming about that, and we will try to send out some materials.

The Services Subcommittee has

worked on planning a townhall meeting. They would like to do that in conjunction with the Autism Society meeting, July 6th through 9th, in Orlando, Florida.

We are planning for the townhall to be either the Thursday or Friday of that meeting, but have not completely confirmed all of that with Autism Society yet. And some more information should be coming for that.

The next IACC full Committee meeting is July 19th, 2011. And, then, as I mentioned, there will be possible meetings of all of the Subcommittees over the next few months before the July meeting.

So, that is all I have, unless anyone has any questions.

Dr. Insel: Lyn?

Ms. Redwood: Yes, I have a question about having the townhall meeting at the Autism Society meeting. Didn't we do that previously? Isn't that where one of the townhall meetings was held?

Dr. Daniels: Yes, it was two years ago.

Ms. Redwood: I am just wondering if we should branch out into other areas, since the population is so diverse. There is a certain group that tend to go to that particular meeting, and there's other groups that go to other meetings.

So, I am just thinking that, if we really want to hear from a broader swath of the community, we should go to different locations.

Dr. Daniels: At the January meeting, the full Committee delegated planning of this to the Services Subcommittee, and they took a vote and decided they would like to do it with Autism Society, unless this full Committee wants to go back to considering this and think about other possibilities for this year's townhall.

Dr. Insel: So, just to clarify, this townhall meeting is just on services, is that right, Lee?

Dr. Daniels: Services, and you said that you wanted to include some safety issues in with the services meeting. At one point, you had said that. I don't know if that is still what your plan is.

Mr. Grossman: The emphasis is on services, and that is what it will be. That is what it was going to be advertised as such, but, no, it is always, as we know from these townhall meetings, once the audience gets involved, they are going to present and discuss what it is that they want to talk about.

Ms. Blackwell: Lyn, I think the other venue we talked about was perhaps doing it in Washington and that that might include more participation from other IACC members. So, this is still in flux, I would have to say right now.

As Susan said, we haven't heard back from the ASA. So, there may be opportunities to do this in another way.

Ms. Redwood: There's other large conferences similar to that ASA conference, too, that you could approach, like Autism One or the Autism Research Foundation. So, there's other opportunities, too.

Dr. Daniels: Does the Committee have particular suggestions? Or do you want to kind of undelegate it to the Services Subcommittee and bring it back to the full Committee to talk about this more?

Ari?

Mr. Ne'eman: I personally think that we should stand by the Services Subcommittee's decision, you know, both by virtue of the fact that we want to be able to get this done in a timely fashion before the possible expiration of the Committee, but, also, by virtue of the fact that I think the situation is substantially different today than it was two years ago.

Frankly, although there are other

autism conferences, ASA's is probably the largest where we can expect a meaningful cross-section of the different stakeholders in the autism community, both in terms of perspective and self-advocates, parents, researchers, providers, and so on.

So, you know, my personal inclination, both for reasons of process and because I agree with the decision, is that we should probably stick with what the Services Subcommittee has recommended.

Dr. Insel: Could I ask that, since there is an upcoming meeting May 19th of the Subcommittee, that at least that group could revisit this and think about whether it is worth having more than a single meeting, and maybe, as Lyn says, try to get input from another part of the community?

Dr. Daniels: The other event that we are planning is not a safety, a services workshop that will take place in the fall. We don't have a specific date yet. I believe that September 15th or so was under discussion.

So, there is a possibility you could always have some sort of public comment or Townhall-like event at that. I don't know if you really need to have two on the same topic in the same year. But if you wanted to cover more than one topic and get at different audiences, that might be another option because we are already planning that meeting anyway.

Dr. Insel: I want to move us on because we have got some other things to cover, but I hope the Subcommittee can take up that question. And you may tell us that one is enough and this is the place to do it, but I would like you to consider whether there is other options.

The next issue is hearing from the Services Subcommittee. So, Ellen, you will take us through this quickly.

Ms. Blackwell: Yes, quickly. We

met on March 29th, and we asked that we talk about -- and it seems very timely today -- the budget crisis in the states. So, I feel like I am pouring a bucket of cold water over a pretty good day here talking about the budget.

But one of our guests was Joy Johnson-Wilson. And Joy has worked for many decades for the National Conference on State Legislatures. They are associated with the National Governors Association.

So, Joy brought us a lot of information about the budget situation in the states, which where I work at CMS we hear about every day. And Jeff Sell, who works with Lee, talked about the impact that families and people with autism are feeling based on what is happening the states. And I talked a little bit about the new opportunities in the Affordable Care Act.

So, as a result of that, I thought it might just be a nice reminder to us because Medicaid is really the pillar of services for people with autism, especially adults in the United States, to just revisit a few of the basic concepts that Joy talked about, which are that every state runs a different program. We have heard that from several people today. Every state has to say what its Medicaid program looks like.

I would suggest that, if you are interested in your state plan, you Google it. You can actually read what services the state has elected to provide to its Medicaid population, particularly adults with Medicaid. Medicaid, some services are mandatory; most services are optional.

And as Joy said, Medicaid is not like your Blue Cross/Blue Shield program or your Medicare program. It is really a very unusual program targeted to people who are elderly, poor, or may have disabilities.

The last point is that states for the most part get to decide who is eligible for Medicaid, what services are covered, what they pay for these services, and who the providers of the services are. In other words, what are their provider qualifications? So, these are really important precepts.

States presently, the way this program is configured, they share the cost of Medicaid. We call that the FMAP. In most states, the FMAP, for example, in Maryland, it is 50 percent. It really depends on a very complex formula. The highest FMAP in 2011 was 71 percent.

So, for example, in Maryland, if Maryland puts up a dollar, the federal government puts up a dollar for whatever the services. And it is an entitlement program. So, there is really no cap on the way Medicaid funding is designed right now.

Some pieces of Medicaid, meaning that states can get additional money, we call that enhanced FMAP. It is only under certain circumstances, up to 82 percent.

So, even for a poor state -- I

won't cite any particular state -- that 20 percent could be quite a bit. It could mean that the state has a very lean Medicaid program.

So, there it is. That is the list of mandatory services in the Medicaid program. It's one slide. You know, it's one slide.

The difference between Medicaid and a lot of other private health services is that you will see in here the next-to-last service, nursing facility services. It is the only institutional service in our program. So, that is basically what you are entitled to under Medicaid.

These are the optional services, and these are services that you might think should be mandatory services, but they are not. They are optional services in Medicaid.

And the last one, I put it in italics because that is probably the services that most people are interested in, home- and community-based services. And I also included some of the new services that the Affordable Care Act added to Medicaid. These are really important opportunities. We have yet to see how states will use them to enhance their Medicaid programs, but those are optional services.

So, what are states facing right now? The enhanced FMAP that came through ARRA ends on June 30th. They have to balance their budgets every year.

And the Affordable Care Act includes what we call maintenance-of-effort requirements that mean that states can't tinker with their eligibility levels right now. So, they can tinker with their services and the amount, duration, and scope, but their hands are a little bit tied.

So, Joy suggested some of these. I don't want this to be a tip sheet for states. States are really smart right now, and they are all figuring out what they can do to deal with these issues in Medicaid. What are they doing? They are eliminating a lot of the optional services that you saw on that earlier slide.

They are changing what we call amount, duration, and scope of services. I guess an example would be, if a person could get 20 hours of speech therapy before, the maximum might be 10 hours now or five hours.

They are changing eligibility criteria for certain services. They are reducing what providers are paid, which are traditionally very low in Medicaid. In some cases, they are imposing provider taxes. Many states are looking at using capitated payment methodologies or managed care to deliver services less expensively. They are requiring groups, including seniors and people with disabilities, to participate in those arrangements, which they have not done before.

States are really looking closely at that group we talked about earlier, people who are dually-eligible for Medicare and

Medicaid. And we are helping them at CMS to try to figure out how to streamline services for those very costly people, the most costly in Medicare and the most costly in Medicaid, a very small group of people using most of the funding.

They are trying to use more efficient drug-purchasing techniques. They are looking at program integrity and minimizing waste, fraud, and abuse.

They are increasing cost-sharing to people who are enrolled in the Medicaid program. And as Joy said, this is very unusual. I had not seen this before or heard of this before.

Jamie, maybe you can attest to this.

Because Medicaid and education are the top budget items in most states, they are starting to shift funding from their education budget over to the Medicaid side, where they have to maintain eligibility. So, that is very unusual. I think Joy said she had never seen that in her 30 years with NCSL.

Dr. Insel: Ellen, you said, prior to this, that the Affordable Care Act does not allow states to change eligibility requirements.

Ms. Blackwell: Actually, it is ARRA that stopped -- Jamie, you can help me out here, but ARRA and the Affordable Care Act both put certain parameters on states. They can't cut people out who are eligible as of a certain date.

So, because they actually have more people eligible for Medicaid right now because of the economy, they are sort of stuck with looking at how to manage the service end of things.

Dr. Insel: The eligibility is the same. So, the services are reduced to --

Ms. Blackwell: You've got it.

Dr. Insel: Okay.

Ms. Blackwell: You've got it.

Ms. Kendall: And, actually, Joy was at a conference I was at on Thursday and was talking about this very thing.

Ms. Blackwell: Yes. So, you can see their hands are really tied here. They do have to provide benefits to children through age 21 because of our Early Screening, Periodic Diagnostic and treatment, EPSDT, program. So, it is really the adult sector that is starting to feel the pinch the most.

So, there you go. Whoops, I am going the wrong way. I apologize.

So, the Secretary -- and I highly recommend everyone take a look at this letter -- is well aware of the fiscal stress facing the states. And on February 3rd, she sent a letter to the Governors outlining ways that CMS, my agency, could help the states in their quest to balance their budgets.

This is a very lengthy letter. It has an attachment with it that you can find at this link.

She expresses her concerns about state budgets and the strain faced by the Medicaid and the State Children's Health Insurance Program. She offers in the letter immediate technical assistance from CMS to states. And I can attest that we are vigorously providing that technical assistance to states.

She also goes through a range of options for states to efficiently manage and enhance their Medicaid programs. There are in some instances ways that states can get this enhanced FMAP, but one of the issues that Joy mentioned is, and that we are well aware of at CMS as well, that state staffs have been reduced or furloughed or folks have been encouraged to retire.

So, there is also sort of a hole on the state end as far as their understanding of what can be done. They are just trying to keep the trains running right now.

So, the Secretary, obviously, she

is aware of that. We are certainly aware of that at CMS. We see what the states are doing. As Lee will attest, it is being -- and others, I'm sure, here at this table -- it is being felt in the advocacy community.

So, people are trying to deal with the reality of what I think of as the new Medicaid coverage. We don't know what the essential benefit package in the Affordable Care Act will look like. That is the benefit that kicks in 2014.

States are also trying very hard to maintain adherence to the Olmstead Supreme Court decision in the Americans with Disabilities Act, which not only encouraged, but requires states to help people live in the most integrated setting possible in the community and not in institutions.

And lastly, you know, as Joy said, the autism community should really be thinking about what services it believes are essential for people with autism. She called this "picking your babies". So, if there are 10 services on the table in 2010, which three or four do you think that you just cannot go without in 2011?

So, we talked a little bit, you know, Lee discussed possibly sending the Secretary a letter regarding the budget crisis. I think it is very clear that she is aware of the budget crisis, as is evidenced by her February 3rd letter. It might be a good idea for the Committee to send her a follow-up letter supporting her actions and encourage her in providing assistance to states who are trying to really struggle with these very enormous issues.

We also discussed possibly sending a letter to the Secretary supporting ADA and Olmstead enforcement, in the hope that the Committee might be interested in hearing from Tom Perez, who has done some amazing work on behalf of the Department of Justice. I think it would be great if we could have him come and speak to us at our July meeting, and it would be very appropriate for us to send a letter to the Secretary after we hear from Mr. Perez, who is just amazing.

As Susan said, we are going to meet with the Safety Subcommittee in May. We talked about the townhall meeting, and we still need to plan the fall services workshop.

Dr. Insel: Terrific.

Lee, do you want to add anything?

Mr. Grossman: Yes, I do I guess. I am thinking about what Mike said earlier today, Mike Strautmanis. He said that pushing the Administration is your job at the IACC. I think that that is something that we should take full advantage of.

I was very moved by Joy Johnson-Wilson's talk at our Services Subcommittee meeting. She is with the National Conference on State Legislatures.

She painted a dire picture. She said, as Ellen said, it was the worse that she has ever seen in her 30 years at NCSL.

And I asked her, what is it that we should be doing from the IACC to support our cause? She, first of all, said that the advocates need to work together and they need to push as hard as they can for their objectives.

She did say this thing about the babies, "You've got to choose your babies." And I interpreted that a little differently than what Ellen said because -- and excuse me for my strong bias here -- but my baby has autism, and this Committee's baby is autism. I think that it should take a strong stance in terms of making recommendations in its capacity as an advisory committee to the Secretary to support autism and the autism community as it faces a crisis that is in many cases beyond repair.

This is an extremely dire situation. The states are experiencing anywhere from 19 to 30 percent-plus cuts in services. These are cuts that are irreplaceable for our community. We should advocate as strongly as possible with strong recommendations to the Secretary on how to best address that. And that is how I felt we should be doing with this.

I think waiting is not an option, but it looks like that is our only means at this point.

Dr. Insel: Let's open this up. We don't have a lot of time, but I think we have got an issue in front of us. In a way, we have come full circle. This is where the day started with Mike Strautmanis' comments as well.

Comments from others? Questions? Issues about this?

Ari?

Mr. Ne'eman: Yes, I do think there is a role here for a letter. Some component of this is probably praising the Secretary for her current actions. And clearly, it is always good to start on a high note.

But there are other levers, particularly from an Olmstead enforcement perspective within HHS, that can be utilized. I would really like to see more work around systemic Olmstead complaints come out of the Health and Human Services Office on Civil Rights.

CMS, actually, did some very good work, I think it was last year, it may have been the year before that, with regards to sending out some "Dear Colleague" letters and guidance as to what states can and cannot do with their Medical programs around home- and community-based services.

I think, more broadly, the function of the letter is to get HHS collaborating with and really coordinating with the great work the Department of Justice is doing to try and stop some of these budget cuts. So, you know, substantively, I do support the idea of sending a clear message to the Secretary that this is a crisis situation with regards to these severe budget cuts and lack of access to services, and we want HHS to act above and beyond the admittedly positive initial steps that have been taken.

Dr. Insel: Would this be telling her something she doesn't already know?

Mr. Ne'eman: I think it is less a question of telling her that there is a crisis in the states. Clearly, she knows that. I think it is more of a question of looking to the Services Subcommittee to craft some specific policy recommendations as to what the federal government can do around that.

To me, the promise here is to see that interdepartmental collaboration, because we do know that the Civil Rights Division is taking action around this sort of thing. It would be very positive to ensure that HHS can take the same action.

Dr. Insel: Ellen?

Ms. Blackwell: I think it is really important that everyone on the Committee understand, and I said this at the Services Subcommittee meeting as well, that a lot of people on the Committee are not as familiar with the Americans with Disabilities Act and what Olmstead means for states. So, I think before we send the letter, it would be great to educate everyone on the Committee about what this really means and why it is important, and how it does impact services for people with autism.

Dr. Insel: Alison?

Ms. Singer: Before we spend time doing another letter, I am not certain that writing a letter actually results in meaningful action taking place. We spent a lot of time writing that wandering letter, and the Secretary responded -- and we haven't discussed this as a Committee, but I am just speaking for myself now -- what I can only describe as minimalist and unsatisfying language that she is now aware of these issues and will consider taking action. But no action has yet been taken.

And to me, it seems that the appropriate response to that letter was "I'm instructing my staff to set up a meeting with the Department of Justice to talk about the AMBER Alert. I'm instructing my staff to talk with, call a meeting with the CDC to look at data collection."

So, you know, I am not sure what the value is of these letters. I think what we are going to do as a Safety Subcommittee is go ourselves and meet with the Department of Justice. And now we have the letter, but it didn't result in action.

So, I think, as a Committee, we have to think about what are the strategies that we should use that result in meaningful action.

Dr. Insel: Ari?

Mr. Ne'eman: So, first, I think

it is important to take into account that public policy always does take some time. But, second, more broadly, we do have certain statutory abilities to issue recommendations to the Secretary. I really would encourage us not to -- first, I think we are discussing right now the Services Subcommittee, not the Safety Subcommittee.

But, second, I would encourage us not to underestimate the value of that statutory responsibility. We do have the ability to put the autism community on the record on critical issues. That is something that I think the Secretary takes note of. I think that is something that Members of Congress and other policymakers take note of.

So, whether it is going to only result in our voices being added to other voices in the call to take action on these budget cuts, and maybe serving as some kind of tipping points to encourage greater federal action within HHS, or whether it is going to result in some new ideas around potential policy steps, you know, I do think there is value in communicating directly to the Secretary about this crisis in the states around budget cuts.

Dr. Insel: So, we are really going to run out of time here. And I don't hear any quick resolution, and I don't think we have a letter in front of us to discuss.

But if I am reading you right, it sounds like within the Safety Subcommittee there is a somewhat difference of opinion about the value of this at this point.

Could the Subcommittee come back to us with a brief set of recommendations that they would like to see taken forward, not so much as a "We want you to know this," which is important, but, also, anything that you think you could offer to the Office of the Secretary in the spirit of these would be helpful solutions to what we are facing?

I have already, Ari, your comment

that it would be useful to say, "Thank you for your February letter," which is great. But, also, if you feel that there is more that needs to be done, it is part of our obligation to let the Secretary know when that is an issue we are hearing from the public, which is what you have just described.

So, I think, in addition to providing that kind of public input, it is also useful to give, like was done with the Safety Subcommittee letter, a few ideas about things that could be done as next steps. And, then, we can talk about that as a group.

I don't think we are ready to do that today. We don't have the time and we don't have a letter. But it sounds like there is enough concern, and even from Mike's comments earlier this morning challenging us to do something like that, that we ought to take that on. But let's make it brief and direct and as solution-based as possible, so it is not just defining a problem.

There are a couple of other things we need to do. We want to hear from the Safety Subcommittee, and we have to have a discussion about the public comment. We have all of about six minutes left.

So, Alison?

Ms. Singer: Okay, I will be quick.

The Safety Subcommittee met. We had a conference call. We talked about the letter that was sent to the Secretary. At the time we met, we had not gotten the response yet from the Secretary. So, as I said before, we had not had time to discuss it.

But I think we will have to move forward with our plans to meet directly with the Department of Justice, which the full IACC agreed at the last meeting that we should do. So, we will have to schedule that for over the summer.

Coleen gave an update on the conference call on the ICD-9 meeting. The CDC recommended that there be a code for wandering in relation to a wide variety of other primary diagnoses. There was a period for public comment on that issue, and the period closed on April 1st.

We had an update on the IAN survey. We were going to be measuring the scope of the wandering issue. That survey is now in the field. It went in the field the last day of March. Over 700 surveys have already been completed, and preliminary data is expected to be reported on April 20th. So, I think that is good evidence of how we can move with urgency and how we can organize a survey and get data in a short amount of time.

I want to thank Paul Law, who is the PI behind this and has really pushed to get this survey in the field and to get preliminary data reported in a very, very timely way, so that we can start to take action based on that data.

We then had a discussion of issues

related to restraint and seclusion. These are huge issues. I think a lot of our conversation focused on how we can try to narrow this down to some sort of manageable scope by focusing on a few levers where we can really affect change.

Sharon Lewis actually suggested two areas where we should focus, where we could make meaningful change. One was on the Children's Health Act of 2000, which addressed issues of restraint and seclusion, although there are still no regulations in place for the Children's Health Act of 2000. So, that is something where we clearly need to put some effort in.

And her second area of focus was to work with the Department of Education to really focus on the issue of restraint and seclusion in school-based settings, again, because there is a huge opportunity here to try to improve people's lives in school-based settings.

So, we talked about just the breadth of who has jurisdiction in restraint and seclusion issues: the Department of Education, the Department of Justice, the Department of Health.

And we agreed that we should have this joint meeting with the Services Subcommittee specifically to focus on issues of restraint and seclusion. As we said, that is going to happen on May 19th. And we are also going to look at that time specifically at issues of chemical restraint and caregiver abuse in relation to restraint and seclusion.

But the idea, at least from the Safety Committee's perspective, is to really try to narrow down the scope. I think so often these conversations on restraint and seclusion, there are so many problems to tackle. If we don't choose one and get a foot in the door, no change is going to happen. So, let's try to start with some small, meaningful change, and, then, after those are done, we can move on to other issues. But let's try to get something done.

That was basically our meeting.

Lyn, do you have anything to add?

Ms. Redwood: No.

Ms. Singer: Okay.

Dr. Insel: And any comments or questions from the rest of the Committee?

Ellen?

Ms. Blackwell: Quickly, I know that you did talk at your meeting about the interim final Children's Health Act regulation on seclusion and restraint. I would just point out that there is an interim final reg. If you are not familiar with it, you should read it. It is a very good regulation. I worked on it eight or ten years ago, and it really is a lot of great protections for children.

Dr. Insel: And only in the government could you have an interim final regulation of anything, but that is a term of art that means it is out for comment, and pending comment, becomes final, right? So, that is quite typical.

Lee?

Mr. Grossman: Yes, I just want to mention on that as well that the Keeping All Students Safe Act that was passed in the House last year, by at the time Chairman George Miller, has recently been reintroduced into the House. That deals specifically with restraint and seclusion.

Dr. Insel: Okay. The final part of the agenda is on our response to public comment. That includes both what we heard and what we read. So, these are both the written comments sent in since the last meeting as well as anything we heard today, and even the written comments from the people who were not able to give oral comments today.

So, the floor is open for responses to any of those.

Lyn?

Ms. Redwood: Okay. Officer Reyes had a specific ask about providing educational materials. I would like everybody to look over those. I think that we should consider as a Committee preparing educational information for parents as soon as possible, in the same way that we provide scientific summary of advances.

I know these seem like no-brainer-type questions in terms of installing an alarm or identification. I would hope that this would be something that the Safety Subcommittee could take up at our next meeting, along with the concerns that were brought forward to us from the National Autism Association as well.

Data collection, again, understanding of autism abuse, restraint and seclusion in schools, all of those things I think are important for us to work on. I would like to see them added to our next agenda.

The last item I was going to comment on, too, with regard to Mark Blaxill's presentation. When I was listening to Dr. Piven's presentation on MRIs, it just struck me that there were 14 studies that essentially said the same thing. And so, I Googled MRI and autism, and there were 876 studies that looked at MRI images and autism.

And I know when we were doing our Strategic Plan for question 2, there was a really large percent, 54 percent, of what we had funded was not specifically in the Strategic Plan. When we were trying to figure out why, a lot of those studies were on MRIs.

So, I guess I just have to ask the question of the Committee and of the Institutes and the funders, if we continue to fund those types of studies when we already have a lot of good leads and data, we have got to keep moving forward. I would ask that the Committee or the funders be really smart consumers of the science and not fund studies over and over and over again. Let's fund as many as we need to have the data replicated and, then, move in the direction we need to move to work toward effective treatments and prevention.

So, that is all I have to say.

Dr. Insel: And just by way of response, and others may want to respond as well, MRI is really only a tool, and it is used in lots of different ways. So, you heard one example of trying to come up with biomarker for very early diagnosis which uses MRI. But that is quite different from a lot of the other research that you may be referring to where it is mostly trying to understand social information processing or something like that.

So, I think it is a point well-taken that that has been very heavily funded. Some of that work has yet to really bear fruit. But I wouldn't assume that just because everybody uses the same tool they are doing the same thing or even asking the same question.

But, Ari?

Mr. Ne'eman: Yes, two things. First, I certainly agree with the sentiment that we need to be shifting research funding to gap areas. In that spirit, I just want to take a moment to highlight the fact that, according to our portfolio analysis, less than one percent of autism research funding is going towards the needs of adults, and only three percent is going towards services. So, it would appear that if we are going to be having a conversation as to what we are underfunding or what we are not funding, those two areas should be first on the list.

Beyond that, I want to take a moment to sort of call attention to one of our written public comments. I really hope people are taking the time to read from Maggie Nygren, the President and Executive Director of the American Association on Intellectual and Developmental Disabilities, which I believe is the country's oldest developmental and intellectual disability organization.

I think she raises a lot of things that we really need to keep in mind with regards to this broader conversation around wandering, specifically, the very real risks associated with pathologizing a behavior that many people utilize as a form of communication.

So, I think very often there has been a lot of discussion back and forth and this perception that people who are concerned that the creation of some type of a creation of a medical diagnostic code for wandering, there is this perception that the people who are concerned about that are really only speaking out of the perspectives of people with less significant impairments or people who are higher functioning. And I think the terms high and low functioning have a lot of problems with them in and of itself, although that is another matter.

But I think when you read a comment like this, it really drives home the fact that, frankly, a wandering diagnostic code could be the most dangerous for people with the most significant challenges in communication, for whom an assumption that an attempt to leave a situation, to escape from abuse, represents some type of medical symptom as a form of communication, could put them at very real risk of serious injury or death.

So, you know, I wanted to call attention to that written public comment because I think it really reinforces the point that this is not quite so simple or clear-cut an issue as some people would have us believe.

Dr. Insel: Any other comments about what we heard or what we read?

(No response.)

I do want to make one clarification because there was a comment that we heard that we are spending next to nothing on environmental research. It is worth looking at the portfolio analysis, at least for 2009. We will have more data soon about 2010.

But it's instructive. By my count, it is about $31.5 million going into environmental factors, maybe still not enough, but that is a huge increase from where we were a few years ago. So, I am not sure I would call that next to nothing, and it certainly hasn't given us yet the answers we are looking for, but it does say that we have got some people working very hard on just that set of questions.

Any other comments or points of reference here?

Ellen?

Ms. Blackwell: Just one thing, because I heard an echo of something Lyn said at the beginning of the day and our commenters as well. And I just want to leave us maybe with this positive thought.

Lyn said that she knew someone who was enrolled in SSI, Medicaid, and receiving Food Stamps who would never be able to do certain things; for example, lead an independent life. And I think that everyone who serves on this Committee can believe that a person with autism can do anything. I would never preclude anyone with autism from achieving their highest potential with the right services, supports, and assistance.

So, I hope that that person gets the assistance that they need, Lyn.

Dr. Insel: Well, it has been an interesting day, given that we started off with guests from the White House and the Department, who I think, besides being grateful for what the Committee has done, were also asking us to do more and saying they need us to be a bit disruptive and to be very vocal about what we are hearing and what we are seeing.

So, we may only have a few months

left in the life of this Committee, but I want to make sure that we use it well and that we keep ourselves focused on those things where we can really have an impact.

I think this was a good day for hearing some of the emerging science, lots of evidence that we are doing better with early detection and early intervention, and certainly what we heard from Sally Rogers is incredibly promising. But there is so much more to do.

And as Geri mentioned with respect to that translational meeting, we are at a very, very early stage. We have a long, long way to go in terms of the research. We are at what I think Lee called a crisis point in terms of our services, the challenges.

So, we are not going to be able to slow down much over the next few months. We will have a lot more to do.

I look forward to seeing many of you at IMFAR, if you are able to attend that in May. And if we don't see you there, I am sure we will see you July 19th at our next IACC meeting.

I want to thank everybody who attended, all those who joined us on the phone, by webinar, and those who are in the room.

And the meeting is now adjourned.

(Whereupon, at 5:10 p.m., the committee adjourned.)