U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

TUESDAY, JUNE 16, 2009

The meeting came to order at 2:00 p.m. in Conference Room H of 6130 Executive Boulevard, Rockville, Maryland, Lee Grossman and Ellen Blackwell, co-chairs, presiding.

PRESENT:

SUSAN DANIELS, Ph.D., Office of Autism Research Coordination, National Institute of Mental Health, and Designated Federal Official

ELLEN W. BLACKWELL, M.S.W., Center for Medicare and Medicaid Services and Co-Chair, IACC Services Subcommittee

LEE GROSSMAN, Autism Society of America and Co-Chair, IACC Services Subcommittee

GAIL R. HOULE, Ph.D., Department of Education (via teleconference)

CHRISTINE M. McKEE, J.D., Public Member (via teleconference)

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

CATHERINE RICE, Ph.D., Centers for Disease Control and Prevention (For Dr. Edwin Trevathan)

PRESENT (continued):

BONNIE STRICKLAND, Ph.D., Health Resources and Services Administration (For Peter van Dyck)

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

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PROCEEDINGS

2:02 p.m.

Mr. Grossman: We're going to call the Service Subcommittee Meeting to order. Welcome, everyone and those of you who are listening on the phone.

Ms. Perez: Do you want to introduce everyone?

Mr. Grossman: Yes, we'll introduce everybody around the table. I'm Lee Grossman. I'm President and CEO of the Autism Society of America and Co-Chair of the Service Subcommittee. I am also the father of a 21-year-old young man with autism.

Ms. Blackwell: I'm Ellen Blackwell. I work at the Centers for Medicare and Medicaid Services in the Disabled and Elderly Health Programs Groups. My son, Robert, is also on the autism spectrum and I'm Co-Chair of this subcommittee.

Dr. Daniels: I'm Susan Daniels

and I work at the National Institute of Mental Health at the National Institutes of Health in the Office of Autism Research Coordination and I'm the Designated Federal Official for this meeting.

Ms. Tepper Singer: I am Alison Singer. I am the President of the Autism Science Foundation. I have a 12-year-old daughter diagnosed with autism and also an older brother with autism.

Dr. Rice: I am Cathy Rice. I'm a Behavioral Scientist with the National Center on Birth Defeats and Developmental Disabilities at CDC.

Dr. Peacock: I'm Georgina Peacock. I'm a Developmental Pediatrician and work on the "Learn the Signs. Act Early." Campaign at the Centers for Disease Control and Prevention and will be presenting today.

Dr. Strickland: And I'm Bonnie Strickland. I'm the Director of the Division of Services for Children with Special Health Care Needs at the Health Resources and Services Administration's Maternal and Child Health Bureau. I'll be presenting with Georgina this afternoon and along with me is Deidre Washington, the Project Officer and Lead for Our State Implementation Grants.

Ms. Blackwell: Do we have any Services Subcommittee members on the phone?

Dr. Houle: We do.

Ms. Blackwell: Okay. Would you folks like to introduce yourselves please?

Dr. Houle: I'm Gail Houle and I'm with the Office of Special Education Programs with the U.S. Department of Education in Washington.

Ms. Blackwell: Thank you, Gail. Is there anyone else on the line?

Ms. McKee: Christine McKee, mother of a 9-year-old girl with autism.

Ms. Blackwell: Welcome to you

both. We can't see you, but we can hear you very well and we certainly appreciate everyone's participation today.

I think our first order of business is to approve the minutes from the March 26th meeting. Do I see anyone who objects to the minutes that were sent out?

Susan, I think we can approve the minutes.

Dr. Daniels: So, we have a vote and a second?

Ms. Blackwell: Okay. Lee, would you like to put a vote forward?

Mr. Grossman: We have a motion to approve the minutes.

Ms. Blackwell: A second?

Dr. Rice: Second.

Ms. Tepper Singer: Second.

Ms. Blackwell: Okay. Minutes are approved.

Mr. Grossman: Yes, that's good

co-chair working.

Ms. Blackwell: Today, we are actually going to be starting a really exciting project that the subcommittee decided to embark on at our last meeting which is to solicit and have presentations from our subcommittee members and also members of the public.

So, the folks that volunteered to go first are Dr. Georgina Peacock who just introduced herself. Georgina hails from Atlanta. She's with the Centers for Disease Control and Dr. Bonnie Strickland who is from the Health Resources Services Administration here in Washington and Georgina and Bonnie are going to be talking about the "Learn the Signs. Act Early." Campaign and also the Combating Autism Act Initiative that HRSA has underway.

So, Georgina, I'm going to turn it over to you. Oh, Bonnie, I'm sorry. I'm going to turn it over to Bonnie first and we will get this show on the road. So, thank you all so much for coming and offering to be first up to bat.

Dr. Strickland: Great. Well, welcome everybody. Georgina and I are both thrilled to be here. HRSA and CDC has an ongoing partnership around both of our campaigns actually. Around "Learn the Signs. Act Early." and around the Combating Autism Act Initiative as well as other initiatives around early screening and services for children and youth on the spectrum as well as those with other intellectual and developmental disabilities.

So, let's start though with the work that we're doing around ASD and other developmental disabilities. As all of you know, in the past decade, the number of individuals with autism spectrum disorder has risen dramatically and all of us -- most of us are quoting these days the one in 150 that CDC has provided with us. That is a dramatic increase.

It's an urgent concern for families obviously, for providers and for the Federal, state and local governments as well.

One thing we know, and I don't think we need a national survey to tell us this, but it always helps, we know that children with ASD fair significantly less well in the system. Not only less well that children in general, but in terms of other children with special health care needs and the findings from the National Survey of Children with Special Health Care Needs, the 2005/2006 survey, tell us that among other children with special health care needs, children on the spectrum had less access to important aspects of care particularly those associated with receiving adequate referrals. Thus the wait time often between first concern and diagnostic testing. Family support services, often families feel like they're in this alone. That there's not a lot support or delayed care. Again, that distance between first concern and actual service -- entry into services.

They're also less likely to receive family-centered care and when we talk about family centered care, we're talking about physicians listening to families, spending enough time with their kids, providing adequate information and honoring and respecting family values and beliefs and cultures.

And finally, families were far more impacted in terms of financial hardship, work, time spent away from work and time spent coordinating care.

So, I don't think that comes as a surprise to anyone, but the national surveys are telling us -- are providing the data that confirm what families have been telling us for quite some time.

And, of course, the guidelines published by the American Academy of Pediatrics have recommended earlier and more frequent surveillance and more aggressive management for autism spectrum disorders.

As we all know, there are many systemic challenges. The services are not well integrated into the broader system. If they were, it would probably be better for everyone, but we've just not been very effective in leveraging the services that do exist for children and youth with autism and there are certainly not enough services specific to autism to cover the broad population of children and youth and families affected.

There's lack of interagency coordination. Certainly ineffective transition planning to adult systems and services. There's some new legislation that's been introduced in Congress that potentially could begin to address this, but as many of you have already recognized, we think that the situation is bad for very young children. It's potentially maximized tenfold for youth and adults on the spectrum.

And then the inadequate benefits in public and private insurance programs and financial planning in general. We've seen some improvement here with states that have implemented insurance reform and many states now actually have legislation requiring payment for intervention, but whether the adequacy of that insurance benefit is appropriate, I think is still a large question in the minds of many families. So, we've still got a lot of work to do there. Thank you.

Thus, the Combating Autism Act. If you'll -- which is the Federal legislation under which HRSA is currently operating and CDC as well with many of their program as well as NIH. We're all sort of partners in this legislation.

You'll notice the 2006 enactment date here. It actually took a couple of years to get this legislation -- even after it was enacted to get money associated with it so that we could actually implement it, but when we did, it amended the Public Health Service Act, as you see here, to combat autism through research, screening, intervention and education and we're going to tell you just a little bit about how the CDC and HRSA are going about that.

Here you see what the original appropriation was for the three agencies. It often turns out to be a little less than this once the agencies take their -- but, it's an estimate. This is what the different purposes were obviously and NIH is funded to do research into the causes, diagnosis and early detection and intervention and treatment and also helps support the IACC and the Services Subcommittee, the CDC's Disability, Surveillance and Research Program and then to HRSA to increase awareness, promote evidence-based interventions, reduce barriers to screening and diagnosis and to train professionals to diagnose and provide evidence-based interventions.

So, I'm going to turn this over now to Dr. Georgina Peacock to talk about the CDC "Learn the Signs. Act Early." Program and then Deidre Washington, the Lead for the HRSA State Implementation Program is going to join us to talk about the HRSA Combating Autism Act Initiative.

Dr. Peacock: Thank you, Bonnie.

So, I think many of you are aware of the "Learn the Signs. Act Early." Campaign. It is a campaign that is a parent education campaign to educate parents about developmental milestone and then orderly warning signs of delay including warning signs for autism spectrum disorders.

And there are really a number of different components to this and I'm going to talk about the first two and then I'm going to let Deidre talk and then finish up with the third.

So, I'm going to talk first about the Transitional Health Communication Campaign and then talk a little bit about some of the research and the evaluation that's going on and then afterwards, talk about a collaboration that we have with HRSA working together on stakeholder mobilization.

So, the campaign objectives are to increase awareness about developmental milestones and early warning signs of delay, to increase the knowledge and this is among parents and then also providers about the benefits of acting early and early intervention, to increase that dialogue between parents and providers particularly parents and their primary care providers. Because we hear over and over again from parents, you know, I had concerns about my child and the doctor say let's wait and see and so, we are trying to look at ways to change that relationship that parents have with providers or empower parents hopefully to talk to their providers about their concerns and then increase early action on developmental disorders.

The target audience is -- the main target audience as I said for this campaign are parents of children under the age of four. There are also other target audiences that we focus on sort of secondarily which are health care providers and early educators. Mainly, they are looked at as vehicles to get that information to the parents.

There are a few things that we're doing specifically with health care providers and then also early educators. In fact, Alison did a wonderful project reaching child care providers about early warning signs and the services that they -- teaching them about services.

And then as far as the one project, and then I'll get back to the campaign, that we're doing with HRSA related to health care providers is HRSA funds some maternal child health -- it's Maternal Child Health Developmental Behavioral Fellowship Programs and we have been collaborating with those grantees to create a curriculum about early identification and then autism intervention and autism treatment and what we're doing is we're going to create about eight different case studies that are going to teach different aspects of that so early identification, some diagnosis, some of the treatment -- medical treatment. Also, what early intervention services are.

And the goal of these case studies is going to be for fellows. So, those are -- developmental pediatricians in training are suppose to be teaching this curriculum to residents that are in medical schools and so, hopefully this -- so, this is one of the collaborative things that we're doing that's really just getting off the -- just starting right now and we've got different groups from different medical schools throughout the country that are working together to create these case studies.

So, getting back to the "Learn the Signs." Campaign and it's primary goal which is to reach parents about developmental milestones. We have a number of materials that have been created and this campaign was launched in 2004 and the milestones that are used are used based on the milestones that are from the American Academy of Pediatrics.

There's a number of different materials that are available. The materials for health care providers again are mainly information to reach parents, but they are materials that have milestones at different ages. Everything's in Spanish and English.

And then in the health care provider kit, there's also some resources for health care providers about different developmental disorders. So, there are brief fact sheets that give people information about autism spectrum disorder, about cerebral palsy, about other developmental disabilities and those are really used a lot of times by parents to share with other family members about -- when they've been diagnosed with a disorder, it's a way to share some brief information, get some resources so that they don't necessarily have to tell that whole story again or that can help them tell that story.

There is some information also obviously for parents on the website. There's an interactive milestone checklist which allows parents to put in their child's age and then milestones will come up and some parents and child care providers actually have used this resource to -- when they're concerned about their child or the child care provider is concerned about a child in their child care center, they've used those two check-off milestones and then this can be a speaking piece. It can be something that you take to the doctor that maybe gives some more objective evidence about what you're worried about and hopefully helps to avoid that wait and see that parents experience a lot.

There's also a developmental growth chart which has height on one side and then milestones on the other and there's a number of other resources on the website for parents.

And then finally, the resource that is called the early educator kit and I'd have to say these are somewhat arbitrary which kit goes to which person. The reason why this was called the early educator kit is because all of the information that I've spoken about is on a CD because early educators told us, you know, we don't have access to the Internet in our child care center, but we often have a computer and so, all of the resources then are on the CD instead so that they don't need to have access to the computer.

Switching gears a little bit, I wanted to share a couple of the different projects that we have funded through our cooperative agreement with the Association for University Centers on Disabilities or AUCD. Looking at some different issues around early identification, the first two are research topics of interest that have been funded in

Oklahoma and Wisconsin and this is specifically looking at the issues around developmental screening among family physicians. Because we know that there are different issues or there are differences between family physicians and pediatricians in their development screening practices and so, these grants are specifically looking at how to reach family physicians and how to increase screening among family physicians.

Also through our cooperative agreement with AUCD, there's some collaborative research awards. One is looking at some of the positive parenting materials that our Child Development Studies Group has developed and combining those with some of the developmental milestone and early warning signs materials that we have and so, there's a woman who's a psychology post-doc and she is looking at combining these materials and then doing some focus testing to see how these help parents not only learn some positive parenting techniques, but also at the same time are learning milestones and learning how to recognize delays.

We also have another collaborative research award working with a speech language pathologist who is looking at how speech language pathologists can help get children to this diagnosis of autism. We know that children often enter the early intervention system because of a concern about a speech delay and so, often that first person who sees them in early intervention is a speech language pathologist, but that doesn't mean that that's -- that's not always -- the primary diagnosis is just the speech delay, but they need to get to that diagnosis of autism and so, this particular project is looking at how to involve speech pathologists in helping parents navigate the system.

The woman working on this has

developed a survey and she's going to be surveying people throughout the country, speech language pathologists to find out how best to involve them in this process and we should have some preliminary results by the end of the year.

And then we also have some research topics of interest that are under peer review right now and they will be awarded in the fall. These are looking at how to adapt the "Learn the Signs. Act Early." materials and the messages to different populations with health disparities and I don't have a lot of information what those particular grants will be right now because I'm not sure which ones are going to be selected. So, those are under peer review right now and will be awarded in the fall.

We are also undergoing an evaluability assessment which is basically looking at where the campaign is right now and then with the help of Danya International, looking at which parts of the campaign need to be evaluated, which parts need to be changed, where we're going to move in the future and so, that is going on right now as well.

Now, I'm going to switch back to Deidre and then we'll finish up talking about our "Act Early." summits at the end.

LT. WASHINGTON: Good afternoon. I'm Lieutenant Deidre Washington and I work with the Material and Child Health Bureau and I'll be talking to you this afternoon about our Combating Autism Act Initiative.

The overall goal of our initiative is to enable all infants, children and adolescents who have or are at risk for developing autism spectrum disorder and other developmental disabilities to reach their full potential.

How are we going to do this? The strategies for achieving this goal.

Obviously, we're looking to develop a system of services that include screening children as early as possible for ASD and other developmental disabilities, conducting early interdisciplinary evaluations to either confirm or rule out ASD and other developmental disabilities and if the diagnosis is concern, provide evidence-based early interventions.

Specifically, our programs have several components. First, we will address ASD and other DDs by increasing awareness. Second, reducing barriers to screening and diagnosis, supporting research on evidence-based interventions, promoting the evidence-based guideline development and finally, we have a huge focus in our initiative on training professionals to utilize valid screening tools.

Under MCHB's Combating Autism Act Initiative, we have four program areas. The training program area, most recently we've expanded that training program area to include 34 expansions and five new LEND programs and LEND is a short acronym that we use for Leadership, Education in Neuro-developmental and Related Disabilities. We've really expanded that program quite a bit.

Expansions also to our developmental behavioral pediatrics training programs and finally, we, in this initiative have also funded a technical assistance and training center, AUCD, and that serves as our national interdisciplinary resource center.

One thing is very unique about our training programs at HRSA. Is that they really focus on educating interdisciplinary health professionals. In our LEND program, we have psychologists, psychiatrists, social workers, family members, nurses, OTs, physical therapy, communication specialists just to name a few.

Also, we focus on providing continuing education and technical assistance to other providers, increasing awareness and evidence-based tools and finally, one of the big aspects of the majority of our programs at MCHB is to contribute to building systems of care and you'll hear a little bit more about that later on when I talk about our state grants.

This is a list of our LEND programs. I won't read all the states out to you. You can see that there.

This also here is a list of our Developmental Behavior Pediatrics Programs. We have ten of them total.

Moving on to our second area after training is the Autism Intervention Research Networks and we do have two really large networks that we funded. Both we have a physical health focus which is with the General Hospital Corporation of Boston and we have the behavioral health focus that is funded through the University of California at Los Angeles.

The purpose of our -- well, we call them AIR Networks are to improve the health of children and adolescents -- and adolescents with ASD and other developmental disabilities by the following. Establishing and maintaining a network infrastructure which is very important to the way they have their research programs designed and also utilizing the networks as platforms from which to conduct research on evidence-based practice for interventions.

Our behavioral focus what we affectionately call as AIR-B, the purpose of that -- it really has sort of two concepts. First, they're looking at conducting a randomized control multi-site study to test the efficacy of a care giver training model that looks at joint attention and joint engagement and the second is to determine if improvements can be made in speech and language of children with severe impairment in communication using the joint attention and joint engagement approach and with this particular research study, they'll be looking at ages from 2 to 5.

The intervention, we looked at children who will be staying in the home, one time a week with a one-hour training and they'll have 12 sessions with the trained interventionalist on a manualized treatment.

The second concept that is included in the behavioral research component is to look at social skills and to test the efficacy of two social skills interventions on child social interactions and with this particular intervention, they will be looking at children and adolescents with ASD in an older age range, 5 to 7 year olds.

Also, I wanted to just discuss

quickly about the ARP which is our physical health component of our particular program and with that particular program, we're looking at also another -- two different concepts. We're evaluating the efficacy of grief versus extended sleep education programs for parents of children with ASD with hopes of improving sleep and behavior outcomes. That's the first concept.

Then the second concept that our researchers will be looking at is to evaluate the nutritional intake in diet patterns of children and adolescents with ASD and the our hopes are that they will be able to develop evaluation tools and nutritional guidelines for practitioners that can be discriminated.

I've talked already a bit about this, but with the AIR Networks, they'll be conducting the research that I just talked about on evidence-based practices. Also, as I mentioned before, they'll be developing evidence-based guidelines on the topics that I've discussed and really most importantly especially given at MCHB we not only have the research networks, but training and also the states, they'll be responsible for disseminating their information on research guidelines and tools to health professions and the public especially the family's impact of ASD and other developmental disabilities.

The third area that I'll be talking to you about today is the State Demonstration and Policy Programs and I serve as the Project Director for that particular program. We currently have nine state grants that will implement state autism plans to improve the systems of services for children with ASD and other developmental disabilities. Six of these states were funded as of September 1st, 2008 and we'll be adding an additional three starting September 1st, 2009.

In addition to the state grants,

we also are funding a State Public Health Coordinating Center which is through AMCHP and they have a role of not only supporting the states, but also taking the information and the lessons learned from the state programs and disseminating that to a wider audience. Because at MCHB, we really are looking at this state program to serve models for other states.

With the state programs, one of the things that we ask them to focus on even in their initial applications and their projects are built upon this is what we call our components or measures for looking at systems of care. At MCHB as we develop our guidance and send out applications and different grant programs, these are the areas that we focus on: One, partnerships between professionals and families of children and youth with ASD, access to a culturally competent family center medical home which coordinates care, access to adequate health insurance and financing of services, early and continuous screening of ASD and other developmental disabilities, community services organized for easy use by families and finally, with transition to adult health care.

What our states have done is they have taken their activities and they've focused it on these various areas with hopes of improving the entire system of care in their states.

These are the organizations that are currently funded. You'll see we have it in Alaska, Illinois, Missouri, Utah, Washington and Wisconsin. The last three Rhode Island, New Mexico and New York will be our new state funded programs that start as of September 1st, 2009.

Just to give you a tidbit of sort of what they've been doing thus far, some of the unique pieces that I've seen with the states, in Alaska because they have such a huge problem with location and their geography, actually getting to their clients, they have really focused on using sort of a tele-medicine concept where they are having their providers do in-home assessments through technology and train the parents.

Also, some of the similarities of components that you'll find in each of the state programs, provider training. A bit different from the training that we're doing with the LEND program. This provider training actually is where they're having experts sort of go into the physicians' offices and provide training to them and also the family component is pretty huge in each of the states.

And also, we've been doing quite a bit of work in talking with CDC. The majority of our states are implementing their "Learn the Signs. Act Early." Campaign.

And before I get on the

evaluation, just one more thing about the state programs. Because they're looking at the system of care, you'll find that our state programs combine the other pieces where they have their LEND program included, they have developmental behavior pediatrics, they're talking to the researchers. So, I'm very excited. We're very excited about this demonstration program.

Finally, the national evaluation, I serve as the project officer for this national evaluation and it includes all of the programs that I just talked about. All of MCHB's autism activities. It is required by the Combating Autism Act of 2006. We develop logic models, research questions for the entire initiative and as of right now, we've gotten feedback from the grantees. We're working with insight policy research as well as mathematical policy research and we're in the process -- we're pretty moving -- we're moving along in the process of going through OMB clearance.

And finally, the evaluation results will be reported in the HHS Secretary's report to Congress on the progress related to ASD and other developmental disabilities along with the other agencies that will be feeding into that same report.

Finally, we do have a website. You'll see it right up here and we do keep this updated. So, to find out what's going on with our program as well as updates come along, please visit our website.

Thank you and I'll turn it now over to --

Dr. Rice: Can we ask questions now or do we have to wait? Okay.

LT. WASHINGTON: Go ahead.

Dr. Rice: I just had a quick question for you, Deidre. What is the average funding for the State Demonstration Program?

LT. WASHINGTON: The first -- the ones that started in September of 2008 are three years.

Dr. Rice: Um-hum.

LT. WASHINGTON: And the second set are currently two years.

Dr. Rice: And how much money?

LT. WASHINGTON: Three hundred thousand each year.

Dr. Rice: Three hundred thousand. Okay. And then at the end, is there a component that at the end of those three years to pull together sort of a summary of what the key components to a successful demonstration are or is each site going to be reporting individually?

LT. WASHINGTON: No, actually, through our evaluators in addition to the report that they are doing for -- working with us to submit to Congress, we also have a second component that will be coming to MCHB which actually aggregates the data and really looks at what are those best practices in the states.

Dr. Peacock: So, now, I'm just going to finish by talking about a project that we've worked collaboratively with MCHB on which is these Act Early regional summits and by way of talking about this collaboration, I also just wanted to share that because of the overlap in our activities around autism and CDC and HRSA have quarterly meetings where we sort of meet by video so that we can make sure that we know everything that each other is doing and so, that's been a really great thing that we started last -- I guess it's been a year now. Last June was our first meeting between the CDC/HRSA Autism Work Group.

So, the Act Early Regional Summits came out of an idea. You know, I think a lot of people talk about awareness. We're going to have awareness about finding children with autism spectrum disorders, but what happens next? We all know that we can keep finding children, but if there's nothing going on between that time of identification to getting into services, then, you know, there's -- myself as a pediatrician is very concerned that we're not getting children into the services that they need and so, the Act Early summits really came out of that concern that people were having that we need to not only just focus on awareness, but we actually need to bring those people together that maybe can move that dial and get that -- get children to services faster.

And so, the first Act Early summit that was held was actually done out of the National Autism Medical Home Initiative which was run out of the Waisman Center which was funded by MCHB and this was held in 2007 and it was held in Chicago and it brought together people in five different states. State teams that came together with a plan that looked at things in their states and tried to come up with some activities that were needed in those particular states to move that dial of getting children identified and into services as soon as possible.

From that model, we created this Act Early regional summit model and we've now held another six regional summits. Two in 2008. One was held in King City, Missouri, another in Albuquerque, New Mexico and then this year, we've held summits in Nashville, Salt Lake City, the Bronx and just recently last week in Sacramento and so, what they are doing is they're bringing -- the states are a little different. Each state's a little different, but about 12 to 15 people come together for a day and a half and with a combination of these teams meeting together and talking about the issues that are going on in their state through a logic model process, they come up with the things that are really the barriers in their state and then they try to sort through what activities can go on that are going to help move this forward.

The stakeholders really represent a lot of different groups. They represent people in education in both part C so birth to 3 services and then early childhood special education. These summits are really focused on getting those children to services. So, they're really focused on that very early part of a diagnosis of an autism spectrum disorder.

There are health care professionals that are there. Often there is representation from both specialty care so developmental pediatrics or psychiatry as well as primary care physicians often as a representative of the American Academy of Pediatrics, but on a state level.

There are people from state agencies. There are people from advocacy groups. There are lots -- often lots of parents. Sometimes those parents are holding different roles or different hats. So, they may be part of one of the systems and then also representing the voices of parent and so, these teams in this day and a half come together with a state plan and they identify three activities that we're going to work on within that first year.

I need to mention that the host of each of these teams is someone from the University Center on Excellence in Developmental Disabilities. So, in that umbrella of AUCD, the host of each or the head of each state team who helps sort of decide who's going to be invited to come and be part of this team is from that UCEDD or from a LEND.

And so, some of the outcomes of these regional summits are we do want to increase awareness about the "Learn the Signs.

Act Early." campaign. So, a lot of these states are saying we have awareness activities and rather than recreating materials, they use these materials. Sometimes they adapt them by putting their own phone number or their own website on the materials and so, we can sort of save the state that expense of printing or creating more materials and then they can use this in their awareness activities.

As I said, they come together with a state team that focuses on enhancing early identification, diagnosis and service provisions and, you know, through this discussion, they talk about a lot of the problems, the challenges and the opportunities they have.

On the AUCD website, there is all of the different state plans as well as each state shares something during the meeting called a State of the State and so, they talk about what's going on in their state, what they think are the best things that are going on in their state and then different states can learn what other people are doing.

We, in Sacramento, preliminarily just talking about so, what are we going to do next? You know, so, we've had these regional summits and we really think that the teams are coming up with some good ideas and they really -- we have anecdotal feedback. So, people are saying, you know, this has really made a difference.

One state told us that by that team coming together, they were actually able to get some legislation moved forward in their state and they really felt like it was the summit that brought that team together and mobilized them so that they could then work through that over the next year.

And so, we've been talking with HRSA about, you know, what we're going to do next. We know that these state teams are continuing to meet. A lot of them when they go back to their states they expand their membership. They say gosh, I wish we had invited this person.

Also, anecdotally, a lot of the people in the state teams have said, you know, it's very strange, but I had to come 400 miles to meet someone who worked down the street from me in the same area. We're all trying to do the same thing and I've never met them before and so, we are trying to fulfill that need for convening or getting the right people in the right place together without telling them what they should be doing.

We're not wanting to tell states you need to do this, this and this. We want states to sort of talk about what's going to work best in their state and we've found that states are very, very different.

We know that the state teams have -- there's been ongoing collaboration since the state teams have meet which is very encouraging.

As I said, there has been some legislative advocacy and some systems change that has come out of some of these teams. We know that there is -- that the Act Early messages are being used to increase awareness. There does seem to be anecdotally at least some coordination across systems that haven't been happening before and there's some groups that are really saying you know what? We need to focus on a specific or under-served population.

We do offer after the meeting some small seed grants. They're very small grants, just $3,000 and at first, you know, we thought, you know, people aren't going to -- that's not going to be enough for people to apply for them and they actually -- most states have applied and most states have said, you know, we can use this small amount of funding, often we get matching and we do focus on that access issue. So, early identification to services and they use these seed grants either to continue meeting together or do some awareness activities around these issues.

I really sort of already covered that, but it's -- so, we're now at the stage of what do we do with this project now. We will have completed the regional summits by spring of next year and are really interested in what people think about where this should go. I don't think we just want to have another round of summits. I think we need to sort -- you know, we need to talk about what the next steps would be as far as keeping this interest that these states have and they really do report to us that they have made a difference, but where we go next with this project.

And so, I think that the goal that

we all have for these children and families with autism spectrum disorder is that we want to identify them as soon as possible so that every child can reach his or her full potential and I think it's been great to work with HRSA on some of these activities because we feel like we're complementary in the activities that we're doing and so, it makes sense to be knowing what each other are doing and then as much as we can collaborate on our projects so that we can improve the lives of our children and these families.

So, thank you for inviting us to present and we can take any questions.

Ms. Blackwell: Thank you so much, Georgina, Deidre, Bonnie. We really appreciate it. I mean you've done a great service to all of us and the folks listening in as well to help educate us about the programs.

I have a question about the

transition activities. We didn't talk much about what's going on in transition world. Could one of you maybe expand on that a little bit?

LT. WASHINGTON: A few of our states are working in transition activities. Specifically, Missouri has it as their major goal. The University of Missouri, Thompson Center has it as one of their major goals to implement transition activities and I think they're right now coming up with the curriculum and some training to work on and partnering with some other agencies.

Mr. Grossman: I just want to clarify what you mean by transition because there's so many different definitions out there.

LT. WASHINGTON: Activities through adulthood.

Mr. Grossman: Okay. Thank you.

Dr. Strickland: But, you know,

Lee, I think that's a really good point. Because the Combating Autism Act focuses primarily on early identification.

Mr. Grossman: Right.

Dr. Strickland: So, it's been a real stretch for us to try to us those funds for older youth. That's why we are so hoping that the new legislation that's been introduced is going to take legs and move forward because I think there's a lot more there for older youth and adults that we could really do something with.

Mr. Grossman: You mean the AATA?

Dr. Strickland: Yes.

Mr. Grossman: Okay.

Dr. Strickland: Yes. But, the other thing that I think we should mention is our ongoing systems efforts. I mean at HRSA we've connected the Combating Autism Act Initiative to our ongoing work around systems development for children and youth with special health care needs. So, we not only have Combating Autism Act funds, but we've got state implementation grants out there intended to build that system of services, those six points that Deidre was talking about for all children and youth with special health care needs and so, in a lot of states, the states are building self-advocacy groups. Kids of Self-Advocates is one. I don't know how many of the states, but I bet we've got ten to 15 states who have established youth groups to help self-advocate.

So, we've got a lot of things going on that aren't specific to ASD that are certainly inclusive of. We've just here today talked about the things that we are funding through Combating Autism Act.

So, we'd love to talk another time about that bigger, broader initiative.

Ms. Blackwell: Does anyone on the phone have any questions for Bonnie, Georgina, Deidre, Cathy?

Mr. Grossman: I have more questions. I have more questions.

The legislative activities that you touched on, can we get some more specifics on that? Are they just entirely around "Learn the Signs. Act Early." and getting support for that or is it a broader initiative?

Dr. Peacock: The particular state that I was talking about actually it was a waiver. So, it was an autism waiver. It was just more of an example that they said that bringing that group together gave them the opportunity to sort of continue to work together and they actually worked. It was towards an insurance waiver and we are gathering more of this -- we're going to go back into the field and gather information from these different states and say, you know, as a result of being a team, what do think that has done for you and for your state. So, we'll have more information about that soon. So, really right now, just anecdotal stuff.

But, no, not specifically around the awareness.

Ms. Tepper Singer: In the early part of the "Learn the Signs. Act Early." campaign, there were grants that were specific to the campaign in that they were focused on educating parents, health care providers and early educators and now, the focus seems to have shifted really to state grants, but there are still a lot of "Learn the Signs." projects that are across state where you could do it one time and it could be applicable to all 50 states.

So, I'm wondering if there are any plans to move back in that direction or to fund anything like that again.

Dr. Peacock: Right now, we have sort of new leadership for the campaign and so, actually, I think that that is definitely something that's going to be discussed and certainly, even though over probably the last year we've done a lot of focus on this "Act Early.", certainly there are always new parents and new people who need to learn about awareness and I think that there probably will be opportunities again. Yes.

Mr. Grossman: The state teams that are coming out of this -- there's a number of different types of state teams around autism though. Have you seen any collaboration of your state teams with the state teams that are developing in education?

Dr. Peacock: Yes, I think there's quite a bit of overlap. When I went to the NATAP meeting last fall, a lot of the people -- so, the education teams that were there had some of the same members and then they were broader. You know, there were more members of the education at the NATAP meeting, but a lot of the same people had been on both teams.

Mr. Grossman: Any ideas on how to -- I mean it sounds like there's a lot of recreation of the will here. Is there any suggestions or any interest in your state team to just kind of pool those resources?

Dr. Peacock: Yes, I think so. I mean if you -- I think it just takes getting everybody together to figure out. I mean I think having education at the table with services and with awareness would be a tremendous accomplishment. To get us altogether and all these state teams working together. Absolutely.

Dr. Strickland: One of the things that we made clear to these teams is that we're really not interested in creating and supporting yet another team in the state. We challenged them from the beginning to figure out -- if they're the only game in town, that's one thing. They're the only team in the state. It's their responsibility to figure out who the major players in that state are and bring them together.

But, if they're not the only game in town, they've got to decide, number one, are they the most important. I mean if there's a governor's initiative in the state or if there's some entity that's already got a lot of momentum going, they've got to become part of that initiative not a separate piece and so, there's no intention here to create yet another state team to do yet another group of things that an isolated group decides is important.

I think the value here is figuring out what the momentum is in the state, join it, bring your agenda to that, but keep the momentum going and don't fragment it with, you know, yet another group of priorities that may or may not take legs in a state and I think that all of the teams were very, very aware of that and had no investment as best I could tell in creating teams just to push a particular agenda.

Mr. Grossman: Yes, with that said, I'm trying to figure out a way that we can get -- share names. We're having these education state teams meet at our conference and then at the OCALI conference in November again and there's no -- and I've been encouraging on my side for these education teams to work well beyond. Get your department of health people in your state. Get your vocational folks. Get their early intervention on there and actually, we have a great partnership now with NASDE. It's not the developmental disabilities, but the special ed -- state administrators for special ed.

And since they're pushing obviously the education agenda, they're also joined with us to broaden this collaboration of these teams right now. So, I guess at some point in the near future, we should sit down and figure out how to broaden these teams or to combine them. Because it's -- because we keep hearing about other teams being developed in there -- in the state and it just doesn't seem to be very practical.

Dr. Strickland: Yes, I think that would be great. I mean I don't -- I think -- yes, we just have to figure out how to get everyone there.

Certainly there were -- at the meetings last fall, I think there was some crossover. Because some of the teams said yes, we first met at an "Act Early." meeting and now, we're meeting at the NATAP meeting and so, I think they were the same and part of that, I think, is getting everybody to inform what's going on so that if they can't be there in person, that maybe we can sort of keep those -- broaden those teams and get them to keep meeting. Absolutely.

Dr. Houle: Hi. This is Gail.

I think -- yes, I know that there is some collaboration and Bonnie was with me at the first advisory board. You're still an advisory board member as are you Lee for the National Professional Development Center on Autism.

Dr. Strickland: Right.

Dr. Houle: And they just had their two-year meeting here in D.C. with us as the funding agency and they are going over the next several years to be increasing their efforts in early intervention. They meet with the leaders in the state and the state can determine what areas of autism professional development they deem to be of greatest need and many of the states thus far have wanted them to focus their work on elementary or high school students, but they have some upcoming states that are very interested in focusing on the -- continuing to focus on early intervention. So, we should see more work in that area over the next say 3 years.

Dr. Peacock: I know that one of our states from one of the earlier regional meetings actually used -- that state team decided one of their activities was going to be to write a National Professional Development Center Grant and so, that was one of their activities that they did over a year and the National Professional Development Centers, they presented at each of the "Act Early." meetings as one of the speakers.

Dr. Houle: That's good.

Mr. Grossman: Any other questions? I still have more.

Dr. Rice: I have one and this is just to see if anybody is aware. In the Combating Autism Act, isn't there some sort of provision that -- it's very vague, but that every state should have some sort of state plan for autism? Does anybody know?

I mean what I'm thinking is if that is the case I mean can -- oh, do you know? Sorry.

Mr. Roy: You're right. I don't have the legislation with me, but I do think you're right. But, that's --

Ms. Blackwell: Speak into a microphone.

Dr. Rice: He said yes. So, is there -- just like the IACC needs to report back on our activities related to Combating Autism Act, is there some sort of reporting back on that effort and can we use that as a way to sort of -- let's catalog what these state teams are and try to connect everybody that way.

Mr. Grossman: I'd have to look at the legislation, but I think it was just a recommendation. There was no funding put behind it at all if I recall and not much really has come out of that.

Anybody else?

Dr. Strickland: Well, maybe that's one of the things Georgina was talking about looking at the future of the summits and we don't want to just keep holding summits and holding them, but maybe the next iteration is to think about what is going on in any individual state? What are the players? The folks from education. Where is the overlap?

I mean I think there should be. I mean whether Combating Autism requires one plan or not, the ultimate goal should be that there's a plan in every state that takes into consideration all of the aspects and to me, it needs to be something that is in the best interest of families, that families want and can help drive and that people can get behind. I mean the momentum I think is the important piece.

So, I mean we could think about the strategy for what the second iteration of summits are making sure that we're inclusive of all the teams as you say, Lee, that are already in the state developing these plans.

Ms. Blackwell: And if there were to be a plan, I think it should include not just the transition piece, but also the adult piece.

I mean the DD agencies, the vocational rehabilitation agencies. I mean everybody who -- because this doesn't stop.

Dr. Peacock: And that has been suggested as whether or not this "Act Early." summit model would work again throughout the life span. Because ours definitely has been focused because of where "Learn the Signs." is on that early access, but definitely, it may be a model. Because you'd have different players at the table, but maybe a model to replicate through the life space.

Dr. Strickland: Well, and you mention that every state is very different, but have there been core themes? At least core agencies or, you know, across the life space where, you know, we could have one -- you know, a summary for each state in terms of well, these are the agencies that cover these age ranges and these types of services.

Dr. Peacock: Yes, that's definitely. We have somebody that is going to be working on that over the next year. Is bringing together. For lack of a better name, we were going to call them state profiles though I know there are lots of different state profiles. We were going to have someone and I think it's a great idea.

Also, I think what we would have is this person contact the education teams that are going to be meeting also to summarize them in this bringing together of all the information that's happened with these teams.

So, that may be the first step in connecting the two groups.

Dr. Houle: Yes, that should work quite work. Each state who's participating in the education teams has to appoint and identify a liaison in their state. So, there is one point of contact who can represent each of the state and provide the information as to what the status is and actually work on doing the connections at the state level.

Dr. Peacock: So, Gail, would I get those contacts from you or Lee, from you or both or --

Dr. Houle: Well, I can get them for you from the grantee at the University of North Carolina and I know that they're in their -- they're reviewing applications for their third cohort of states, but I can tell you the states that they're working with right now. They add three states a year. Right now they're working with Indiana, Kentucky, Wisconsin, Minnesota, New Mexico, Michigan and they're getting ready to add three more states for intensive work probably this summer.

Dr. Peacock: Okay.

Dr. Houle: The work continues for the licensed grant.

Dr. Peacock: Right.

Dr. Houle: But, they're bringing on board three states to work intensively --

Dr. Peacock: So, I think we should include those, but then also the group that Lee is talking about as well.

Mr. Grossman: Yes, I mean at the NATAP meeting we had 38 state teams that were there. So --

Dr. Houle: I'm talking about the state teams that are getting the professional development services from -- that are funded Professional Development Center on Autism which is at the UNC, University of Wisconsin and University of California at Davis.

But, there are other. I'm sure that every -- well, I would think that almost every state would have some initiative and then on the early childhood end, with the National Governor's Association, they're spearheading an initiative for early learning council that's suppose to bring together all child development and early intervention, early learning programs within each state.

Mr. Grossman: Yes, with so many teams out there, it sounds like we should start a league.

Ms. Tepper Singer: As part of the demonstration grants, is there any component for involving the Parent Advocacy Organization so that there's some real world feedback with regard to the experiences that parents are having on the ground in the states?

LT. WASHINGTON: Yes, we've asked for our state demonstration grants to specifically partner with their family groups in the area and they've been part of family voices, families health information centers and various different advocacy groups in their states, but we specifically asked them to include a strong family component.

Dr. Strickland: They can't have a grant without it.

LT. WASHINGTON: They can't. Right.

Mr. Grossman: Switching gears though, I want to ask about "Learn the Signs. Act Early." and how that's impacting the medical professionals, pediatricians, primary care providers, family practices. If the message is getting to them, if they're providing this information, if there's any part of this plan that's geared specifically for expanding not only their awareness, but their implementation of this information.

Dr. Peacock: So, you know, most of the materials up until now have been really focused on parent education and so, really this collaboration with the MCH developmental behavioral grantees I think is our first big push to be really educating. These in particular are physicians in training. So, residents, but the materials, the way they're going to be developed could easily be continuing education as well.

I think what we thought we would do first was -- what it is is it's a fellow faculty payer, a different university. They're actually -- the different MCH grantees that are listed in here, they're each working on a module and I didn't bring the modules with me, but there's one on early identification. There's one on differential diagnosis. There's one on different treatment options. There's one on early intervention services.

One on -- that's going -- the whole case is going to talk about how to deliver that news to the parents. Because one things that we hear a lot is that the reason why doctors don't want to bring this up is because they don't know how to talk to the parent about it. Right. So, they don't want to do screening because they don't want to -- they're uncomfortable with that conversation if they do a screening and they find that a child might have a risk factor or might be -- have early warning signs of autism spectrum disorder.

So, there's one case that's going to focus on that and I don't have lots of details yet because actually the cases are being developed right now, but over the next year, those are going to really take form.

Hopefully, they'll be very interactive. They're going to have video in them and we're going to test them and then we're going to have some pre and post-tests to make -- to see if they really make a difference and they really do teach physicians what they need to know and hopefully, if we get people that are in training doing this, that when they get out into the field, they're going to remember this and hopefully not say wait and see.

I mean I see patients, you know, every week. I see patients. You know, I ask them over and over again, so, when were you first worried? Oh, I was worried around 2 and these are all children that are 4/5/6 years old and so, that wait and see is something that we really, really have to focus on and so, this is attempt to sort of really focus on hopefully empowering physicians to move this diagnosis along and quicker.

Mr. Grossman: So, these modules are being developed so that they can be just kind of plopped down into a CME program or made available for grand rounds or --

Dr. Peacock: Yes, so, that's our idea. You know, we don't actually know exactly what the product's going to look like, but I -- what makes sense to me is that they would be web-based. Because then they can be -- they can be used by lots of different people. If changes need to be made, they're not on a static CD that, you know, can't be changed. So, yes, that would be and we will go through the process of getting them approved for continuing education credit as well.

Mr. Grossman: In your experience, other than the AAP, have you gone out and just interviewed the doctor in the street, for example, the guy who's running his own small clinic to find out how impactful this information is or if it really is relating to them?

Because the reason I'm asking is because I have talked to a lot pediatricians and primary care providers and most of the reluctance in doing the screening -- well, there's a couple. One of which is the fact that the incentives, financial incentives just aren't there. I mean when they have so much to do and their reimbursement is so low, they have to see so many kids in their clinic on a day-to-day basis for them to take the time to do the screening is just -- they -- it's actually a money loser for them.

So, the financial incentive isn't there and that's just real world. The reality that they live with.

And the other thing that makes them reluctant is not so much breaking the news to the family. They just don't have the information for the next steps for the family. They don't know where to refer them to at that point.

Is that perhaps like a network or a database or some sort of additional resources being made available to the doctor so that then they know what the next steps are? Because a pediatrician really isn't going to want to become the case manager for the family.

Dr. Peacock: Right.

Mr. Grossman: And they're not prepared to do that, but somebody else in the community should be doing that.

Dr. Peacock: So, our plan with this is to have a guide that goes along with the curriculum. So, whoever is teaching the case study would also have a guide of how to teach the case that they were presenting.

The idea is that if you were presenting sort of in a grand rounds fashion, they would take about 30 minutes, but you could make it last an hour. You could do it in ten minutes and I think that resource-wise it seems that resources are local and so, it actually is going to have to depend on -- you know, we can prompt people to come up with their resource list and I think we can give some national resources, but we also need the people who are going to be doing the trainings to also know what those resources are locally that are going to help those local providers and so --

Ms. Tepper Singer: The resources list is where you have to partner with the parent groups.

Dr. Peacock: Sure.

Ms. Tepper Singer: Because the parents know where the resources are.

Dr. Peacock: Sure. Absolutely. Absolutely.

LT. WASHINGTON: And that's actually what we're doing with the state grants. Because they're working on systems improvement, they're also going out to the communities. They're doing provider training and with that, taking resources with them and sort of trying to complete the full circle. This is what you do. This is how you screen and then these are the resources that we have in your community.

Mr. Grossman: Gail or Christine, do you have any questions? I'll take that as a no.

Dr. Houle: No.

Dr. Daniels: May I?

Mr. Grossman: Please.

Dr. Daniels: What are the cultural barriers to early diagnosis?

Dr. Peacock: We know that there are cultural barriers. I think some of the grants that we are going to be awarding this fall are going to focus on very specific populations. Like I said, I don't know which ones are going to be awarded. I've seen the letters of intent and they're focused on different -- many different populations, but clearly, there are differences in different populations and I know that Cathy can talk about the differences that they see in identification of -- or in diagnosis of children and so, hopefully, those grants will help us answer some of those questions and help really focus materials that will speak to different populations.

Dr. Rice: Yes, but I think that's definitely something that we don't have enough information about and we know that children, particularly Hispanic children, are under identified and the screening tools -- we have another project for early surveillance of doing screening in young -- particularly focused on several Hispanic clinics in California that are finding incredibly high positive rates for screening. Now, is that because there really is that much autism and developmental disability or is it a problem with the translation and the implementation and the appropriateness of the tools?

I think, you know, that's a big area not just for services implementation, but for research that we need to figure out in terms of are there cultural implications?

Ms. Blackwell: You guys did a great job. Thank you so much. I think listening to you has made me really think a lot about, and I said this to Lee, what the landscape looked like 20 years ago when my son was diagnosed and what it looks like today and then talking about what we hope for for the future.

I mean we have come a long way, but we still have a way to go down this road. So, it's really exciting to hear this.

Wouldn't you agree, Lee?

Mr. Grossman: Oh, yes. Yes, I think so. It's great that there's this collaboration now between the states and the Federal Government. I find that most positive. Because really, everything that happens should happen locally. That's where the greatest impact is.

Ms. Blackwell: Well, we don't

have a lot left on our agenda. So, we might just want to move forward and push right through.

Mr. Grossman: We're plowing ahead.

Ms. Blackwell: We have a big activity coming up, okay, on Friday, July 24th. So, Lee, I'm actually going to let you talk a little bit about this and I'll be happy to chime in, but the larger group, our mother committee, the Interagency Autism Coordinating Committee, charged us with having a town hall meeting and this will actually be the second town hall meeting. The IACC had a town hall meeting in Sacramento I believe it was last year.

So, this will be a Services Subcommittee town hall meeting and it's going to take place in concert with the Autism Society of America's annual meeting which will be held outside Chicago and we're really excited about this. We just spent a lot of time working with Lee to nail down the details.

So, Lee, would you like to talk a little bit about what's going to be happening on Friday?

Mr. Grossman: Yes, the town hall meeting's going to follow the general session in the morning at the conference. It's the second day of the conference.

Actually, the first day of the conference is going to feature -- as a start, the general session is going to be a keynote panel and on that panel is going to be Judy Palfrey the incoming President of AAP, Mark Friedlander who is the head of Behavioral Health at Aetna Insurance, Cathy Pratt, Stephen Shore and our own or NIMH's own Tom Insel and they're going to be talking about the future of autism and I think that's a great lead-in to the next day at the town hall meeting where we're going to be talking about services primarily.

The program starts at 10:45 and is going up to 2:00. We have a room. It's an amphitheater. It's actually a theater. This hotel where we are holding the conference is the mid-west's largest entertainment resort and they have a resident theater in there. Summer theater and we're having it in that theater hall and it seats about 350 people. I believe it's about 350 and so, all the mikes and lighting and everything will be set up and it will be very good. Everybody that can do a song and dance, they'll have the stage there for them.

The agenda is broken down generally like this. It's about 30 minutes of presentations, introduction and presentation and we're going to ask -- in the public notice that goes out, we're going to be asking people to respond to questions 5 and 6 from the strategic plan and then to address any other issues that they have.

It's a lot of time, 10:45 to 2:00. So, we're hoping to get as many people as we can to respond and participate.

Ms. Blackwell: Members of the public who want to participate do not have to come to Chicago to participate because there will be a way for folks to submit questions to the people who are -- all of us Services Subcommittee members who will hopefully all be there in Chicago. So, we'll be able to answer questions and talk with folks from across the United States who aren't in Chicago.

I think Lee would attest that the ASA annual meeting normally gets over 1,000 sometimes close to 2,000 people in attendance. So, we hope to have a really good crowd.

And we had some discussion this morning, I know everyone in this room wasn't here, about -- we have another subcommittee, the Strategic Planning Subcommittee, ad we'll be looking for input from the public on our entire strategic plan. So, this is just another opportunity for folks to sort of build on that and our subcommittee can come back and report to the other subcommittee and to the larger body.

So, all these are really good ways for the public to continue to participate and help us, you know, figure out how to make life better for people with autism.

Mr. Grossman: Yes, our conference averages about 1700 to 2,000 people and for the beginning part of this town hall meeting, there is no other sessions going on. People are either going to be at the exhibit hall, playing golf or at the pool or at our town hall meeting. Those are really the only options available and so, we believe that the attendance will be fairly large for the town hall meeting.

And for any of the members of the committee that are going to be there since you'll be there for the day, we have a very interesting Science Track scheduled for that day. So, after the program is done, you might want to attend that and it's being put on by -- the Course Chairman for the Science Track is Dr. Martha Herbert and the Science Track is entitled Science That Makes A Difference. So, there's going to be very, very what we believe cutting edge and practical science that would be presented throughout the day and I think it's actually going to be some of the things that we'll want to add to the workshop in the fall.

Ms. Blackwell: So, everyone, mark your calendars. July 24th, that morning and there will be further information coming out on the IACC website at www.iacc.hhs.gov. Correct, Susan?

Okay. You know, today was great.

It was really the beginning of our, as I said at the beginning of this meeting, our plans to have folks come in and talk a little bit about their member agencies and Gail, are you still on the line?

Dr. Houle: Yes, I am.

Ms. Blackwell: I believe that Gail has volunteered to be our next presenter. We have not talked about a date yet. Is that okay with you, Gail?

Dr. Houle: Yes, it is.

Ms. Blackwell: Okay.

Dr. Houle: But, the more notice you can give me, the better.

Ms. Blackwell: Okay. Well, I think --

Dr. Houle: Because --

Ms. Blackwell: Since our next big activity is the end of July, I'm thinking that it probably wouldn't be appropriate for us to meet again until say the end of August.

Does that sound reasonable to folks?

So, Gail, perhaps Lee and I could work with you to pick a date that's --

Dr. Houle: Yes.

Ms. Blackwell: -- and a venue that's convenient for everyone. That would be terrific and Gail, of course, is the IACC representative from the Department of Education. So, Gail can talk to us about how education programs work for children and youth and also some of the very interesting autism related grants coming out of the Department. So, that would be great.

All right. So, let's go around the room and folks can just kind of -- Alison, we'll start with you. How's that?

Ms. Tepper Singer: I just wanted to make a suggestion. Which is now that we've received the funding list from the other subcommittee about who's funding services' research, it might be a good time to sort of broaden our invitations and encourage people who are funding research to come and present to this committee as well.

Ms. Blackwell: Actually, that's definitely our plan. We were going to start with our member agencies and then sort of work our way out. You might not have been at that meeting, but yes, that's absolutely part of the plan. So, that every single meeting we can have presentations from stakeholders and others who are interested in autism and services.

So, thank you for reminding me that that is on the docket.

So, Alison, would you like to start. We're gong to do a quick round robin?

What's going on at the Autism Science Foundation?

Ms. Tepper Singer: Okay. The Autism Science Foundation is a brand-new, not-for-profit organization. We were launched on April 18th. So, we're not even two-months old yet, but our intention is to fund research looking at causes of autism, treatment of autism and particularly focus on building the evidence base for services interventions particularly targeted at teenagers and adults.

Ms. Blackwell: And you have a website that people can look at?

Ms. Tepper Singer: Yes, our website is www.autismsciencefoundation.org.

Ms. Blackwell: Okay.

Ms. Tepper Singer: We also have a very active blog at autismsciencefoundation. wordpress.com.

Ms. Blackwell: Thank you so much and I know that you've been doing some lunches, New York, Washington and you have another one planned.

Ms. Tepper Singer: We're doing a series of lunches. We're calling it science and sandwiches where we are inviting in researchers to come and present on their latest work.

Our next one is going to be in July in Washington, but we're scheduling them for different parts of the country. It's really -- the goal is to create opportunities for researchers and other stakeholders to interact in a smaller environment to really have an exchange of ideas. That's not always possible in the big lecture halls where there are 3,000 people and extensive lighting.

But, it's a good opportunity for people to really talk about their personal experiences and have a dialogue with regard to what's needed and where the evidence base is going.

Ms. Blackwell: At CMS, we continue to work on recent pieces of legislation that have had a significant impact on our operations. Not just the Recovery Act, but also the re-authorization of the Children's Health Insurance Program.

Medicaid state budgets have, you know, suffered over the past year. So, we continue to see states reacting to their fiscal situations and so, we are doing our best to work with them to try to maximize their flexibility and options.

Mr. Grossman: Well, at the Autism Society, we refer to this time of year as our conference season because it seems like everything else shuts down as we prepare for the conference and that's generally what we're focused on right now. Is putting together this event that we have in July.

The other two keynotes are going to be -- one, is going to focus on public policy and we're going to have people from the administration, people from Congress and people from state legislatures present on current activities in autism and talk about where we should be heading.

And on the last day, the keynote session will be on the culture of autism which is a continuation of our last Autism Advocate which was put together and entirely written by people on the spectrum and talking about their experiences, their choices, their goals in life and we're using that as a bridge for -- primarily most of the presentations on that Saturday of the conference will be related to adult services and research going into adult services.

So, if I'm not as available as I usually am which is not that available now, over the next couple of months, you'll know why. It's gearing up for the conference.

Dr. Strickland: Well, we've told you about everything that we're doing at HRSA specifically around autism spectrum disorders, but I do want to reiterate that we do more than just ASD and I think that's important because we can never have just a self-sustaining system for only ASD.

So, I think it's going to be really important to be sure that as we raise the bar for children and families with autism that we make sure that we bring that the rest right along with it and so, I do -- I want -- as we think toward next year, I just want to remind the group and everyone that's listening that HRSA has Title 5 programs out in every single state and we would like to utilize and maximize the Title 5 state block grant to help us in our work.

We also have a very large -- well, very large for us cooperative agreement with the American Academy of Pediatrics to promote medical home.

And Lee made some very good points earlier about pediatricians or any primary care provider and their reluctance to deal with issues around not just ASD, but just about any chronic condition or disability and we're working with -- I think we have an opportunity here with what is called the Patient-Centered Primary Care Collaborative which is industry, Exxon, Walgreens, the world at large not just government to change the model of health care in this country where we do reimburse for the things that are important, that secondary prevention is important, that screening is important and that we evolve into a team approach where it isn't just the doctor that has to take responsibility for this, but there's a well-trained team in a practice that feels comfortable with the issues that are not just important to the disability world, but to children and families in general.

So, we're working very hard to be sure that we stayed connected to the medical home movement in this country as health care reform evolves and that we keep our work with the American Academy of Pediatrics front and center.

I also wanted to reiterate with Ellen's comments that we also have a national center entitled Healthy and Ready to Work that is focused on transitioning from pediatric to adult health care and work and independence. But, they're all very, very much connected.

So, we plan to use those resources to help bring our work and special health care needs together with -- even closer with what we're doing in ASD.

Thanks. It's been fun today.

Dr. Rice: Okay. Georgina's already spoken about CDC's activities in terms of service overlap. Primarily focused on early identification, but in terms of providing the background for services and need, we do have our prevalence work and we are working hard on getting out our next prevalence report with updated figures by the end of this year. So, that will be hopefully coming out later.

We also are continuing other research in terms of risk factors and have enrolled hundreds of families in our cadre studies. The seed project looking at early risk factors. So, that's up and running and ongoing and we've got many families involved.

Ms. Tepper Singer: The prevalence data that you're going to report before the end of this year, is it the same states or are they different states than last time?

Dr. Rice: It is a subset of the same states from last time. So, there's one site that didn't report last time. So, they'd be a new site. The others have earlier data and there were a few sites that were last time that we didn't -- weren't able to refund the next time. So, it's a subset. Lots overlap though.

Ms. Blackwell: And, Cathy, the

information will be up on the CDC website? Ultimately.

Dr. Rice: Ultimately, it will certainly.

Ms. Tepper Singer: It'll be everywhere.

Dr. Rice: It'll be everywhere. We'll be certainly -- as soon as we possibly can, we'll be giving IACC members an update as well and we'll provide, you know, a copy of the report, but again, that's sort of still in process. We don't have a publication date at this point.

Ms. Blackwell: Thank you so much.

Ms. Tepper Singer: We won't have to look far for the data.

Ms. Blackwell: Well, everyone -- Christine, do you have anything for us? Gail?

Dr. Houle: Well, this is Gail. Like I said, our major Autism Professional Development Center is now reviewing applications to select their third cohort of states to work intensively with. They've completed quite a few teacher training modules and have been out training in the states that have already signed up and are part of the program. The ones I had mentioned earlier. Those six.

And we have a new set of smaller personnel preparation grants that have recently been awarded to universities to train master's level providers to provide services either as service providers, speech language pathologists with focus in autism or teachers with focused areas in autism as well.

So, when I do the actual presentation, I can bring some more in-depth data about the current investments that we have.

Ms. Blackwell: That would be great. Thank you so much, Gail. We'll really look forward to that at our August meeting and again, we encourage all Services Subcommittee members to participate, come to Chicago with us in July and we hope that everyone listening today will spread the word about that meeting because it's really a great time to have this interaction with the committee that isn't always possible.

And as Lee said, prior to the time when the public will be able to raise their issues, each of the member agencies will be doing a quick presentation. So, folks that are coming could plan on doing a five-minute presentation on what their agencies interaction is with autism.

That would be great. We don't want to spend a lot of time on that, but we do want people to understand the background of the folks who are on the Services Subcommittee and what their role is in this whole project.

So, that's how we plan to start out and then we'll just kind of let people help us decide where we're going.

Lee, do you have anything else?

Okay. So, I think we can close the meeting and we'll see everyone hopefully and hear from you in Chicago on July 24th.

Thank you.

(Whereupon, the meeting was adjourned at 3:36 p.m.)