

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
INTERAGENCY AUTISM COORDINATING COMMITTEE  
SERVICES SUBCOMMITTEE MEETING

FRIDAY, OCTOBER 10, 2008

The Committee convened at  
9:30 a.m., Ellen Blackwell and Lee Grossman,  
Co-Chairs, presiding.

PRESENT:

DELLA HANN, Ph.D., Executive Secretary,  
National Institute of Mental Health

ELLEN W. BLACKWELL, M.S.W., Co-Chair of the  
Services Subcommittee, Centers for  
Medicare and Medicaid Services

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

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

CHRISTINE M. MCKEE, J.D.

ALISON TEPPER SINGER, Autism Speaks

DENISE JULIANO-BULT, M.S.W., National  
Institute of Mental Health (for Dr. Thomas  
Insel)

CATHY RICE, Ph.D., National Center on Birth  
Defects and Developmental Disabilities (for  
Dr. Edwin Trevathan)

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PRESENT (continued):

ANNE SPERLING, Ph.D., Autism Team, National  
Institute of Mental Health

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

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## PROCEEDINGS

9:35 a.m.

Ms. Blackwell: Okay, so this is a meeting today of the Interagency Autism Coordinating Committee, Services Subcommittee. My name is Ellen Blackwell. I'm the cochairman. My co-chair is -- would you like to introduce yourself, Lee?

Mr. Grossman: Yes, this is Lee Grossman, president and CEO of the Autism Society of America.

Ms. Blackwell: And before we finish with our introductions, I just need to remind everyone that we are a Federal Advisory Committee Act committee. The call is being taped, and there will be minutes published to be available to the public later.

Our designated Federal official today is Della Hann from the National Institutes of Mental Health.

Would the other folks on the line like to introduce themselves, please? Alison, we'll start with you, because you have the

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"A."

Alison, did we lose you?

Ms. Singer: Can you hear me?

Okay.

Ms. Blackwell: Yes. We can hear you.

Ms. Singer: Okay. I'm Alison Singer. I'm executive vice president for Autism Speaks.

Ms. Blackwell: Okay, Cathy.

Dr. Rice: Hi. I'm Catherine Rice. I'm a researcher at the National Center for Birth Defects for Developmental Disabilities at the Centers for Disease Control and Prevention.

Ms. Blackwell: Christine.

Ms. McKee: Christine McKee, and I'm a stay-at-home mom. I have a child with an autism spectrum disorder.

Ms. Blackwell: Bonnie.

Mr. Grossman: Bonnie Strickland is on the call. She's attempting

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to log in. She should be joining us shortly.

Ms. Blackwell: Okay. Bonnie Strickland is our representative from HRSA, and we also have Denise. Would you like to introduce yourself?

Ms. Juliano-Bult: Sure. Denise Juliano-Bult, and I am a program officer in the Services Research Branch at the National Institute of Mental Health.

Ms. Blackwell: Did I miss anyone?

Dr. Sperling: This is Anne Sperling from NIMH.

Ms. Blackwell: Oh, thanks, Anne.

Anne is going to be talking to us in a few minutes about the request for information that we published and closed recently.

So our first order of business today is to approve the minutes from the September 12th, 2008 meeting of the Services

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Subcommittee. Does anyone object to the meetings that were sent out by the National Institutes of Mental Health?

Okay, so our meetings -- our minutes from the meeting are approved which means that, Anne, I am going to turn it over to you in just one second.

On August 11th, the Services Subcommittee released a request for information entitled "Priorities for the Interagency Autism Coordinating Committee, Services Subcommittee." This RFI was to seek input from stakeholders, including families, autism advocates, state officials, scientists, health professionals, therapists, educators, and the public at large, about what they consider to be high priority issues and concerns surrounding services and support for people with autism spectrum disorders.

The RFI closed on September 19th, and our lead for the IACC, the National Institutes of Mental Health, has done an

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excellent job taking an initial pass at consolidating the responses, which Anne Sperling, who is on the line today with us, is going to talk about.

So, Anne, I'm going to turn it over to you.

Dr. Sperling: Okay. Oh, great, here you have the slides. So the way we went about analyzing the responses was to first look at the RFI itself and see the topics that were listed there for people to potentially respond to. So what you see here in this graph is an overview of all the topics in descending order of the number of responses.

The total responses was 137. However, many people raised a number of different issues. So the numbers you'll see on the graphs that follow don't add up to 137, they far surpass 137.

But the main -- there was a division we made between questions and issues that people raised, and as potential topics

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that people raised that they'd like to see research initiatives covering.

So we'll get to those later on, but for the moment I'm going to focus on questions and issues that people raised, and the different topics.

So the largest group were topics related to health care and treatment, services and support that they'd like to see related to health care treatment.

I should note that this category does not include insurance coverage. That actually we decided to put in finances. This talks more about the actual treatment.

The next category is called education and awareness, and by that we mean - - which is -- actually this is a topic that we added in after the fact. It was not listed directly in the RFI, but many people raised this, and we made an extra category for it. This is public awareness to service providers of many different types -- everything from

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teachers and physicians and also emergency responders, that they should be educated about how to best interact with people on the spectrum.

Then we have finances, which included both insurance and also coverage for many different kinds of treatments and just finances in general.

Community inclusion, that was in some ways being involved in the community. There's also an aspect of awareness from peers. There's a number of issues in there, and we included in that category support for the family as well.

Transitions. That covered both transitions from public school into let's say a more treatment-focused educational program to a public school, from high school transitioning to college, transitioning from college to a job, and so on.

We have employment, which also includes career counseling, housing and

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housing alternatives.

Safety. In this we included again emergency responders, education for them. And I should say at this point that some topics really fell into multiple categories. So we counted it, however it seemed -- even if it included multiple topics, we counted it multiple times, just so that every topic got -- it reflects the total number of issues that were raised.

Guardianship. There were a number of comments on guardianship and alternative guardianship arrangements and education for guardians. Only three people responded specifically concerning estate planning, so I don't have an extra chart for that because there were only three. And in one case it was someone who simply listed the phrase "estate planning" without elaborating.

So I think in many cases people might have rolled that into their response about finances, but -- so but it was on there.

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So I don't know if we have all the -- oh, we do. Great. Okay. So here I have broken out health care and treatment issues. So the numbers in the parentheses refer to the comments, the comment IDs. So the numbers are ascending, and the lowest ones would be the ones we received first, then it goes all the way up to 137.

So you will see in many cases multiple numbers come up both times because, again, a single e-mail might have touched upon multiple topics.

Mr. Grossman: Anne, this is Lee.

Dr. Sperling: Uh-huh.

Mr. Grossman: And I'm not sure if the question that I'm about to ask is -- if it's the right question, so bear with me.

Dr. Sperling: Uh-huh.

Mr. Grossman: But how were these subject lines approved, like health care

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and treatment issues? The reason I say that is because when I looked at it, in the last couple of days where I've had access to this, I've been in a nonstop series of meetings with academics and service providers and others, and when I was talking to them about this category, for example, because it was just in front of me in some of these meetings, we were looking at this and it really didn't relate -- that subject line "health care and treatment issues" really didn't relate to them.

Dr. Sperling: Uh-huh.

Mr. Grossman: I mean they were looking at -- strictly at some of these or many of these fell into what they would describe as services and/or support.

The same question came up in looking at a specific topic area around educational issues, as that not being there because we had all assumed that what was meant by education as the subject category was dealing with public awareness more than it was

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with public education.

So I'm just trying to get a sense on how definitive these subject lines are and if there is room to change them to make them more reflective.

Part of that is I've been asked to speak about the RFI at an upcoming meeting, and I'm just trying to figure out how I'm going to present this to people.

I mean they're going to have a hard time relating to these -- how it's laid out here, if it's under a category of health care and treatment issues, for example.

Dr. Sperling: Okay. Well, I'll tell you how we did it, and of course you could certainly shift it as you wished.

The way we viewed this particular health care and treatment, it includes services and support that someone would receive in either a health care setting, in terms of diagnosis, in terms of medical treatment, and also behavioral treatment.

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They're all wrapped into this category.

So, for instance, it includes screening, it includes diagnosis, it includes diagnosis of co-occurring conditions, it includes topics on therapy, like ABA therapy. Let's see. Finding the most effective therapies by which that -- the person writing that e-mail was referring to biomedical or psychotherapy types of interventions.

We wrote all those sorts of things into here. We also wrote in dietary conditions and nutritional needs, comments on vaccines; anything that might have occurred within a situation in which there was an interaction with a physician or dentist or a nurse or any other kind of health care provider, including psychologists.

Dr. Hann: Also I would like to ask Anne -- this is Della Hann. This content analysis was only meant as a starter to provide information, try to provide one way of looking at this information for the committee

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to use.

By all means the committee can redo it and find other ways of doing it. So there's no implicit or explicit direction here being provided. This was just a way to help the committee begin to figure out how to digest some of the comments. So we are more than happy, and actually would value, turning it all over now to the committee for you all to determine how best you wish to use the information.

Mr. Grossman: Thank you.

Thank you, Della, for that clarification.

Ms. Blackwell: This is Ellen.

And I would just say -- I've been sitting here thinking about it. I mean here we -- I guess I think about it as services that are delivered in medical settings, services that are delivered in school settings, and there could be other services that are delivered in residential settings.

Sometimes services are delivered in all three

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settings.

But I guess I do agree with Lee that I think there's room here for a category called services and support, you know, other than the services and support that are delivered in primary health care settings.

Dr. Sperling: Okay. Some of those might be covered in some of the additional categories.

Ms. Blackwell: Yes. I agree, there is going to be overlap, especially in school settings.

Dr. Sperling: Yes. There's certainly an option. If you want to take some out and make an additional category, that's certainly possible.

Ms. Blackwell: Okay. So maybe the members of the committee could be thinking about this after we let Anne finish.

Go ahead, Anne.

Dr. Sperling: Okay. So let's go on to the next slide. Okay. Next topic,

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guardianship issues. So this ranged from establishing guardianship to finding more guardians to alternating -- making alternative arrangements. Not as many comments as the other, but there were definitely some ones here.

Go on. Okay. Safety. So, again, safety included both safety in various environments and also public awareness programs for police and other security service providers, emergency service providers.

So we write that down here, even though again those folks will be mentioned again in the education slide, but they are also mentioned here because really that's an issue of safety, that there should be ways to educate people who are going to work with people on the spectrum to ensure their safety.

And also -- okay. Great. That's fine. Go on.

Transition issues. This really covered the whole range. The most common ones

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were really focused on adulthood, and that's something I should say that there were a lot of people who commented about adults, and adult support. So here's where you really begin to see it. People becoming members of the community, functioning participatory members of the community. So they wanted to have support to make that transition happen from let's say school environments or home environments, now more independence or more integration.

Transition also could be something that's really at all ages, both from early childhood through seniority.

Employment transition, college, adolescence. So this was a topic that had concerns across the lifespan.

All right, next slide. Community inclusion. Okay, so here we have the top one is where we folded in requests for support for families, respite help, recreation activities, family

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preservation support. That was mentioned a number of times.

Helping with community awareness, which in this case is everyone from say librarians to peers, a child's peers in school, that they should understand what it means, that a child is on the spectrum and interacting.

There were a number of general requests for community inclusion that weren't so specific, but I put up there, and then there came some more specific ones that had to do with social interaction, whether it was in a friend or a dating or even a marriage skill workshop. Continuing education and opportunities for recreation for adults. Different kinds of summer camps. Different kinds of mentorship and support and including the viewpoints of people on the spectrum in decision making, especially adults.

And then we had a couple of other additional ones. Extracurricular activities,

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and just other kind of support from the community that made it easier for people and families with ASD to have more ease of access throughout community engagements.

Okay. Employment. There were requests for retaining employment, for obtaining employment. Job coaches for maintaining employment. Adequate vocational development, and also that people on the spectrum should have an opportunity to have a range of possible careers and employment opportunities, not be restricted to certain types of jobs, whether it's civil service or other types of positions, that it should be meaningful, that they should have special training in how to network. That might not be something that comes as naturally to them, so they might need that kind of -- in addition to say social friendship networking, which really was included in the previous slide, this is talking about networking and training for jobs specifically.

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Okay. Housing issues. So there was a call by a lot of folks, both parents of children on the spectrum who were say adolescents, and they're wondering what will their housing options be, and also self-advocates who talked about having more independent housing opportunities and options.

There were also a number of people who wanted to see improvement in the quality of group homes and efforts made to retain high quality staff at such places.

And then the need for adolescent care facilities, in addition to adult facilities.

Okay. Finances. Okay, so this wraps multiple topics that have both insurance coverage or health care, but also life insurance, coordination of different funding services, coordination of Medicaid funding -- let's see, insurance coverage especially for some of the more behavioral type of therapies, as well as some of the more complementary and

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alternative type therapies.

Better relationships between schools and insurance companies. Let's see. Financial management skills training for adults, and just a number of other additional concerns that all related to finances, and a certain degree of independence for adults.

Okay. Education for service providers. Also, we do have police officers on here. We also have teachers and school therapy providers, better trained and more specifically in a more specialized way to work with people on the spectrum.

General practitioners and pediatricians, daycare workers, dentists, employers -- that was requested a couple times -- administrators. A number of people requested that there just be more education for how to maximize relationships between people on the spectrum and the different service providers.

Okay. Now this slide represents -

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- is a summary, I should say, of all the folks who responded requesting research initiatives on topics mentioned in the RFI. So this was an issue of more like I'd like to see research on the topic. The largest category was health care and treatment, so much so that we have an additional slide after this that just looks at that.

But you can see almost all the topics, they were people who wanted to see research on these things. Like research to find the best kinds of housing options. Research on how to maximize employment. Research on the best way to go about supporting transitions and so on.

Okay. So we can talk a little bit more about health care and treatment research initiatives. There were a number of calls for clinical trials, calls to investigate some of these complementary and alternative therapies to establish an evidence base. Research on the psychotropic medications. Research that

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focused on more specific populations, that is high functioning or females and so on. Early intervention and screening methods. There should be screening -- I'm sorry, research on that. Research on the aging process. Research on how HIPAA has affected quality of service and so on.

So I think that's a full summary of all the responses, and now if you'd like to ask more questions, please do.

Ms. Juliano-Bult: I don't have a question other than these slides will be available to us; right?

Ms. Blackwell: Azik?

Ms. Perez: Yes, these slides are available. In fact, everything being presented today will be available not only to the committee but also to the public.

Ms. Juliano-Bult: Okay. Because there's definitely some implications on the research side of things, of the areas that folks are saying are important for research.

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Ms. Blackwell: And I neglected to mention that the comments themselves, absent personal information, are available on the IACC Web site, which was at the beginning of the Webinar.

Ms. Juliano-Bult: Okay.

Ms. Blackwell: So you can also take a look at that.

I guess my overall comment would be that I would like to see the health care treatment category perhaps parsed into our services and support category. Maybe Lee and I can work with you, Anne, to help you segregate that out. All right?

Dr. Sperling: Well, actually, Ellen, I was really hoping that this would become more a function of the committee and less so of the staffing. But we can talk about that.

Ms. Blackwell: Okay. Does anyone on -- would folks in the committee like to weigh in on that, or are you okay with

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calling services and support health care and treatment?

Dr. Strickland: This is Bonnie.

Can you hear me now?

Ms. Blackwell: Yes.

Dr. Strickland: Okay.

Ms. Blackwell: Hi, Bonnie.

Dr. Strickland: Hi. I agree with you, I would rather see it under a category of services and support. And I think that there's plenty of opportunity to do that. I mean I think it's just an organizational issue.

Dr. Sperling: Yes, that's kind of what I think, too.

Dr. Strickland: I'd be glad to help.

Dr. Sperling: Thank you.

Dr. Rice: This is Cathy Rice, and I would just note that we -- because I think when we talk later about the priorities of this committee, something that was very clear

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in the services roadmap was the need for coordinating services, so even if we need to break it out in terms of services and support needed in different settings -- you know, school, home, community settings, for instance -- that we make sure that we still bring it together, that there's a link between those even if it's the same type of services, that there's some effort to make sure that we are not just parsing them out to separate settings and not making note to bring them back together and coordinate those services.

Dr. Strickland: I fully agree.  
This is Bonnie.

Ms. Blackwell: Okay. So maybe what we can do is sort of work back and forth and, you know, folks can send their comments perhaps to Della. Does that sound reasonable, Della?

Dr. Hann: Sure. I think sending it to the three of us -- to you and Lee and myself -- would be great.

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Ms. Blackwell: Yes. And then maybe we could just make a few revisions, and I believe the plan is to present this at the November 21st meeting; is that correct, Della?

Dr. Hann: That's completely up to you. You have a section, a small section of time in the morning to give an update on the activities of the committee.

Mr. Grossman: This is something that we put out publicly that we definitely have to present it at the next IACC meeting, and that we could parse out a little bit of time in the morning to do so.

And if you can help me a little bit here, Della, just with the logistics as being a FACA committee. Getting that information to Ellen, myself, and you, is it permissible for us then, the three of us, to get together and wordsmith it to reflect what the committee's asking?

Dr. Hann: Yes, that's fine, as

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long as it's the three of us, as long as I'm involved in the conversation. And also what I would assume, too, is once we make any sort of changes like that, that we would send it back out to the subcommittee for their review and concurrence.

Mr. Grossman: Yes. Definitely would want to do it that way.

Ms. Blackwell: Yes, that sounds exactly right to me as well, and then if anyone has comments on the revised version, we can make sure that they're incorporated before we bring it before the full IACC on November 21st. It sounds to me like we might need about a half an hour in the morning.

Dr. Hann: I'm not certain we'll have that much time.

Ms. Blackwell: Okay.

Dr. Hann: I think we'll have probably 15 minutes.

Ms. Blackwell: Okay.

Mr. Grossman: But we'll make

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it work.

Ms. Blackwell: We'll make it work.

Okay, does anyone else have anything on the RFI? I mean this was the first time that the subcommittee has done anything like this, and it certainly doesn't preclude from us doing -- you know, issuing another RFI in the future. Hopefully all of us have learned, you know, a little bit about how to distribute RFIs and Anne and the autism team, and NIH, I think it's helped you folks, you know, to try to look at how to organize comments and as everyone on the subcommittee knows, we have another RFI that closed recently for the strategic plan, so I think this is a really good exercise in terms of, you know, how do we do this, and how much time do people need to respond, how do we distribute it, and how can we do it again in the future.

So we thank the autism team for

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its support.

Ms. Singer: What was the total number of responses?

Ms. Blackwell: I think, Anne, didn't you say 137?

Dr. Sperling: Yes, 137. And most of them came in at the end, Alison. There was kind of a big push, you know, midway through, I think, at our last call we were at about 50 responses. So I know that several of us made an effort to try to, you know, push the responses.

I think if we had more time next time, we might want to leave the RFI open longer and, you know, we were trying to get the responses together so we could present them at the November 21st meeting, which is going to be devoted to services, at least in the afternoon.

But this is a really good first start. Does everyone agree? (Chorus of yeses.)

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Ms. Blackwell: This is great. So thank you so much to the autism team for your hard work on this team and, you know, now we know we can -- it's a great way to solicit comments from the public and everyone can participate.

So if we're done with RFI, our next item is to talk a little bit about the November 21st IACC meeting, which -- hold on one second. I just lost my Webinar -- which will be devoted to the topic of services and support.

We have a really good group lined up, and unfortunately I sort of feel like I -- I assigned 30 minutes to myself to talk about the services system in the United States, and I certainly cannot do justice to the services system in 30 minutes. But I will be trying to talk a little bit mostly about how children and then adults receive services in this country.

We have talked with the autism

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team about in the future, and we will talk about it in the morning at the November 21st meeting that, you know, this short amount of time on the 21st is certainly not adequate to really do justice to what is going on as far as services and support for people with autism spectrum disorder.

So we are going to be asking that time at future full IACC meetings could be devoted to having other services presentations. For example, Autism Speaks, as Alison mentioned at our last meeting, has an adult initiative under way.

The head of the National Association of State Developmental Disabilities director, Nancy Taylor, is going to be with us on the 21st, and I think Nancy would make a great presenter. She could talk a little bit about the challenges being faced by states' service delivery systems.

We will have also with us the head of the National Association of State Medicaid

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Directors who are, of course, very interested in autism services in their states. So there is just a full array of issues other than what we have on the docket for the 21st, which is the start of the overview of the services system, followed by Cathy Pratt, and Lee knows Cathy very well. Cathy -- Lee, do you want to talk about Cathy for a second and what she's going to be talking about?

I think we might have lost Lee.

Cathy is at Indiana University, and Cathy is going to be talking about, you know, just a quick overview -- everything is quick on the 21st -- of the challenges facing the services system in the United States.

Then we have Nina Wall Cote, who is the director of the Bureau of Autism Services in the state of Pennsylvania. Nina and her colleagues in Pennsylvania have been very aggressive in terms of trying to deliver services to adults, and the state of Pennsylvania presently operates the only

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Medicaid home and community-based services waiver that is directed only at adults.

The state is also engaging in activities to try to develop a managed care model that would run concurrent with the fee-for-service waiver. So Nina will be telling us a little bit about what's happening with adults in Pennsylvania.

Then we have Kathy Reddington from the state of Connecticut, who is going to be talking about a very unique program that helps high-functioning adults with ASD get very individualized job assistance. This is a program that the state funds with its own monies. It's been very successful, and they hope to expand it a little bit in the future.

So that's a really interesting program that I think the committee will like to hear about.

Then we have Lee will be moderating a panel discussion. A fellow named Jeff Strully will be coming from an agency

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called Jay Nolan Services in Los Angeles, outside Los Angeles. This was an agency that struggled to serve adults with autism, and over a fairly long period of time has managed to do a fairly good job providing very individualized services, again to adults with autism.

Then we have a provider coming from -- Emily Homer coming from a national company called VOCA. Emily took over the VOCA site in the Maryland that the state of Maryland was poised to close, and she has a number of adults with autism. She serves about 30 people in her agency, and Emily is going to talk about, you know, what it's like to try to turn an agency around in 2008 and serve some very, very challenged individuals, and the group of problems that her agency faces are pretty much endemic to providers across the country.

We also have a lady named Pam Bett coming. Pam is using an option that the

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Medicaid Program is starting to see, and that is in programs across the U.S. called Self-Direction. She has taken over her son Brandon's budget and is hiring, firing, and managing his services, she and her husband, and Pam can talk a little bit about why her family -- she will be talking about why her family decided to exercise that option and, you know, the success and the challenges that they have faced in doing that.

So we have two-and-a-half hours, and as I said earlier, everyone will be talking very quickly. So we hope the committee will, after this presentation, have at least a snapshot of some of the very challenging issues facing the services system.

Does anybody have any comments or questions about the November 21st meeting?

Dr. Rice: This is Cathy. I would just say thank you to you, Ellen, and Lee for getting even much this time on the agenda, given that all the IACC is trying to tackle,

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and that research has been the priority. I know it's been a lot of work on your part to get services on the table, and in the discussion every meeting, and I really appreciate all that work that you have done.

Ms. Blackwell: Thank you. Mr.

Grossman: Thank you,

Cathy.

It's an effort. I think there's a realization on the IACC, the entire IACC, that services needs to become the priority, and I think this committee has been great in moving that forward.

Dr. Rice: My only -- I think the whole program sounds great. My only suggestion is rather than saying panel discussion on care, I suggest saying support to make it a little less passive, since we're talking about folks with autism and encouraging active involvement as much as possible.

Mr. Grossman: That's a good

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point, yes.

Dr. Strickland: Yes, I agree.

This is Bonnie.

Mr. Grossman: Yes, that's a very good point.

Ms. Blackwell: This is Ellen. I think we should, you know, probably just stick to services and support, which are the words that we at CMS use in providing services and support.

There were treatment -- I mean I think as we harken back to the strategic plan, I would remind everyone that when the IACC first undertook this effort, services and supports were housed under the term "treatment." So in our strategic plan, that's pretty much where we are right now. So I think all of us could agree that, you know, services and supports are, at least in my mind, a separate category from treatment. To a great degree.

So that is where we are in the

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strategic plan, and we should continue to use the words that we used, when we're providing the services and supports.

Okay, so we will, I think, have a great November 21st meeting and hopefully whet the appetite of the rest of the IACC to hear more about, you know, what's going on with people who have ASD.

Our next item is to take a look again at the roadmap, and Cathy, thank you so much for your synthesis of the items in this roadmap.

This was a document that the previous iteration of the Services Subcommittee published in May of 2005, and I believe that we have talked previously in this iteration of the Services Subcommittee about updating the document, and I think that would be a really -- after reading it again, you know, I do think there's a lot of room for improvement and what we thought we would do and what we have talked about previously is to

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sort of go around and ask folks to pick out a couple things from the old roadmap that you think that your agency or organization might be able to contribute to over the next four years as this IACC moves forward.

So I did that for our agency, and I guess I'll just start, and Cathy, your chart was very helpful.

CMS, as I have mentioned before, has embarked on a research endeavor, a task order, where we will be looking at services and supports provided to children, youth, and adults with autism spectrum disorder. So that made it a lot easier for me, actually, when I looked at the items in the roadmap, which at this moment I can't find, okay, but there were a couple here that I thought we could touch upon.

Lee, do you want to go ahead and take over for a second while I find my chart that Cathy sent out?

Mr. Grossman: Okay. Sure.

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Does everybody else have this? It was in a memo that the NIMH team had sent to the Services Subcommittee, I think it was yesterday or the day before. It's an Excel document.

Ms. Blackwell: Yes.

Mr. Grossman: Okay. Again, thank you, Cathy, it's great to have this summary in front of us. And Ellen and I have kind of struggled just trying to figure out how to go through this to see who is willing or wants to pick up portions of this, or to find out who is already handling some aspects of what's summarized here.

For example, when I went to section 6, which was the appropriate financing of care, there's a number of initiatives here that ASA is actively involved in, for example. But it almost seems very, very difficult to do these one-off types of conversations or even doing it on a conference call. And I'm wondering if the committee would want to try

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and get together to really go over these to see -- to meet face to face to find out what it is that each is doing and to find out if there are aspects to this that agencies or others would want to start tackling?

Dr. Strickland: Well, Lee, this is Bonnie, and I think that's a very good idea. We've got to remember that the roadmap is three years old.

Mr. Grossman: Yes.

Dr. Strickland: And I felt like the RIF -- RFI, there was a good bit of synergy between the two documents, I think, with the RFI providing a more formal, updated view on some of the old things that were in the roadmap. And I think a face-to-face discussion about how the old roadmap translates into some of the things we found through the RFI would be really constructive.

The other thing is, as she said, since 2005 a lot of us have been working on the roadmap and some of these things, as you

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say, are under way. I mean we worked on the services guidelines and a lot of our grant initiatives are going to be trying to implement those now.

But I do think it's a difficult conversation to have just on the telephone, and it would benefit, I think, from a focused conversation among committee members.

Ms. Blackwell: Okay. Well, maybe what we could do is, you know, we had talked, Lee and I had talked about having a meeting in December, and Larke Huang, who is not with us today -- I'm not volunteering Larke for anything she hasn't already volunteered for -- she offered to host a face-to-face meeting at SAMHSA, the Substance Abuse and Mental Health Services Administration, in Bethesda.

So would folks be agreeable to getting together for a face-to-face meeting after the IACC meeting in November to maybe just focus on going over the roadmap and, as

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you pointed out, Lee and Bonnie, maybe taking the information we got from the RFI and taking a -- you know, starting to update this or look at it in a different way?

Dr. Strickland: That works for me.

Ms. Blackwell: Okay.

Dr. Strickland: Are you saying after the meeting, on the same day of the meeting?

Ms. Blackwell: Oh, no, no, after. I'm talking about in December, Bonnie.

Dr. Strickland: Okay. Yes, that's good.

Ms. Blackwell: We'll have to pick a date in December that looks good for everybody, especially Larke, since she has volunteered to be our hostess.

Mr. Grossman: Does that work for the NIMH team?

Dr. Hann: Hi. Yes. This is Della. We should be able to do that. We have

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to coordinate with SAMHSA and the room, though, to make sure that we can have public access.

Mr. Grossman: Okay.

Ms. Blackwell: And we will also have to publish public notice of the meeting. Do we have adequate time to do that, Della?

Dr. Hann: Yes, we do.

Ms. Blackwell: Excellent. Okay. So we'll plan to meet in December to talk about the roadmap and the RFI, and you know, Della, I know one of the questions I had for you is when are the next two full IACC meetings?

Dr. Hann: And I came prepared.

Ms. Blackwell: Okay.

Dr. Hann: As we have just mentioned, the next IACC meeting is on November the 21st, and it will be at the Ronald Reagan Building downtown.

The next meeting following that,

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we haven't firmed up the absolute date because of booking concerns, but it will probably be the first -- sometime during the first week of February.

And then following that it appears to be April, April 27th.

Ms. Blackwell: Okay. So if we meet in December, we may want to meet the end of February or the beginning of March, it sounds to me like.

Lee, what do you think?

Mr. Grossman: I got my -- well, I'm --

Ms. Blackwell: And then we may want to -- we may want to meet at the end of February and then maybe sometime beginning middle of March before the April 27th meeting.

Mr. Grossman: Yes, you know, I think just for logistical reasons, if we are going to meet in December, the earlier in December that we can make it the better.

Ms. Blackwell: Okay.

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Mr. Grossman: Just because, as all of us know, it gets pretty crazy as we get closer to the holidays.

Ms. Blackwell: Okay. One of the issues may be that -- we'll have to talk to Larke. She is on a rotation in Atlanta working for the Centers for Disease Control, so she may not be here. So although she's offered to be our hostess, if she's not here, do the folks on the autism team have any other suggestions, or is anyone else, you know, willing to host a meeting?

Dr. Hann: Ellen, we can probably arrange and find adequate facilities here some place on the NIH campus, if Larke is unable to do so.

Ms. Blackwell: Okay. We'll have to check in with her because I -- actually I've forgotten exactly when she's going to CDC. I think she said she'd be there for three or four months, but it may not be -- I just cannot remember offhand.

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Okay. So what we'll need to do is we'll have to send some dates around to the Services Subcommittee because we have to publish public notice, and maybe we could publish public notice for the December and then say a February meeting and a March meeting all at the same time. So we have something on the calendar.

Okay, should we go around and, you know, just each of us sort of give an update about what's going on at our agency or organization?

Lee, I'll let you start.

Mr. Grossman: Where do I start? Well, there's a number of conferences that are coming up over the next -- it seems like we're heading into the conference season right now. Many of our chapters are doing statewide conferences over the next few weeks that are going to put my team all over the place.

The more significant meetings

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coming up are an international meeting in two weeks in Toronto. It's fostered by the Geneva Centre. Defeat Autism Now is going to have a meeting that same week, and then the other big conference that's coming up is the NATAP meeting which is made up of technical assistants, many of the youth eds, and I believe we have 42 states who have state teams that are coming to that meeting, and there will be a series of breakouts, bringing the teams together, to work on coordinated efforts of services and support in the states, and trying to develop educational standards for that.

One of the other things that we are about to introduce is educational standards that are going to be up for review before the CEC panel, and once those are approved, then any academic center that is providing training for autism would have to be in compliance with those accredited standards.

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On developed services, we have a number of initiatives going on, and I'll probably have to save those for some of the face-to-face meetings because I could probably talk for hours on that and what's going on.

We're drawing up a model legislation for states, and have been in touch with many, many states in terms of autism, the potential for autism legislation that's going to happen in the next sessions. I believe that the number that I got yesterday, that there are 18 states right now that are considering some sort of adult legislation in their state legislatures coming up next year.

I'll hold off right now because, again, I can go on and on, but that's just a brief update of some of the things that we have in the pipeline.

Ms. Blackwell: Okay. Cathy?

Dr. Rice: Sure. I'll primarily talk about our early activities. Some of the things that have been going on over the past

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year are convening regional summits, basically trying to get folks within states who are concerned about early childhood identification intervention services, those organizations that work together, to get focused on autism and to come together to have a meeting forum for different agencies and individuals who work in those areas around states and in different regions to come together and to have a way to collaborate, to work together, so CDC is offering some mini grants to those regions and the states to continue their collaboration. And there's information on those regional summits on the AUCD Web site, Association of University Centers for Disabilities, at [aucd.org](http://aucd.org). So if you look under regional summits, there's a lot of information there.

And they will continue throughout next year. The next one will be for the southeast region. It's going to be in Nashville, Tennessee on January 8th and 9th,

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and again there's information on the AUCD Web site.

And we've completed the innovative initiatives where we have partnered, I think Alison Singer mentioned in the past and she'll probably talk more about this in a video, that CDC worked with and supported Autism Speaks to produce, so she'll probably mention that, and also worked at ASA, or First Signs to do real targeted education and outreach to different areas to increase access and information on the early signs of autism.

So those are the primary work. We have some other small projects going on where we funded some sites to improve looking at research in terms of health care practice and improving screening and identification of children with special needs in those settings.

So those are the primary activities right now.

Ms. Blackwell: Okay. Alison, would you like to talk a little bit

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about Autism Speaks? I had a great conversation recently with Peter Bell, who works with you, about the adult initiatives that you mentioned on our last call. In fact, I think maybe once your effort gets fully under way, Peter might want to come in and talk to the full IACC or the IACC might be interested in hearing Peter talk about the outcome of that project.

Ms. Singer: I think it would be great to have Peter speak at the IACC. It's a really broad-based project that's bringing in a lot of different groups to really focus attention on this issue, so I think that's a great idea.

As Cathy said, our DVD is out, the talking to parents about autism DVD and toolkit that was produced by the CDC and Autism Speaks. It's designed for preschool teachers and Head Start providers to help them have the often uncomfortable conversation with parents, letting them know that their child

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may need to be screened.

Our research showed that preschool teachers knew the signs. They just didn't want to get involved because of the emotional reaction and the difficulty of that conversation. So this toolkit is specifically focused on conversation starters and a role playing to help the preschool teachers to have that conversation so that we can speed the time to diagnose it.

The idea is that we are not asking preschool teachers to make a diagnosis. We are simply asking to suggest to parents that they take their child to a physician or health care provider for a screening and future referral.

So we released it about two weeks ago and we already are sold out. We printed 5,000 DVDs. We have over 5,700 requests for the DVDs. So we'll be coming to Cathy for supplemental grants. Actually, we're looking for additional funding to print more DVDs

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because we don't want to have to tell anyone that we're out. It's available for download online, but unfortunately a lot of the group didn't request it. They sent us letters. They don't seem to have access online.

So we're looking at how we're going to solve that. But it's very heartening that people are interested in the material and the response so far has been that people think it will be a useful tool.

We also last week held our United Nations World Focus on Autism where we announced our global public health initiative. This is an effort to increase early diagnosis, treatment, access to services and support globally. So that took place at the United Nations two weeks ago, and that effort will continue.

We are also again trying to get more countries involved in participating in World Autism Awareness Day which takes place on April 2nd.

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And then finally I'll just add that we are working on several additional toolkits, many of which were called out in the RFI. I was happy to see that. One is a toolkit for first responders, and we are also working on toolkits with respect to other providers who work with our family members, including dentists and barbers and other haircutting professionals.

So those are our headlines.

Ms. Blackwell: That's great.

Thank you so much.

Christine.

Ms. McKee: I only blab when you turn to me.

Ms. Blackwell: Oh, come on.

Ms. McKee: But the last time I spoke about the spending freeze in the schools, and my daughter attends a public school. Just to give you an example of what's going on there, my daughter is in a new classroom. They added a classroom this year,

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and the teacher's requisition for a desk was denied. She's operating without a desk. So the assistant principal gave up his desk, so I can tell you how much this is impacting schools. It's hurting the services and I don't know what lies ahead.

In light of the freeze, we have parents joining together and organizing and actually hosting fundraising events. They raised, I heard, \$17,000, and they're using the money to help support teacher training initiatives since they said there's no money to train the teachers. So it's just an interesting twist on how things are getting funded these days with the freeze.

I was excited to see, when I went into my pediatrician's office, they usually have a big poster up on an easel that talks about how to deal with your toddler's tantrums and all that kind of stuff. It's now focusing on autism. It's a poster that describes early screening processes and actually says for all

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developmental delays, but it specifically includes autism. So I was really happy to see that poster up.

Ms. Singer: Whose poster is that?

Ms. McKee: You know, it looks self-made. They host a lot of parent outreach workshops and stuff, and they bring in people just to speak. They're free clinics, and this is now -- it just talks about the screening process. So it's an -- I'll see if I can get it printed it off and send it to you. Is that Alison who asked?

Ms. Singer: Yes.

Ms. McKee: Okay. Yes, I'll see if I can get a copy of it just to show you what they have posted.

And the last thing I want to mention that I thought was kind of interesting is in the Services Subcommittee we talk a lot and we focus on Medicare and Medicaid, we talk about the IDEA, but we kind of have to also remember that the ADA is out there, and

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although I had kind of taken for granted that people know enough about the ADA, I've been having birthday parties for my daughter. She's now turning nine. I was told for the very first time last month that a facility does not do birthday parties for disabled children.

Ms. Singer: Oh, my gosh.

Ms. McKee: So I'm going to be --

Ms. Singer: You are kidding.

Ms. McKee: We decided to figure out what kind of education I could provide them with.

Ms. Singer: You should out them immediately. What place is this?

Ms. McKee: It's the Free State Gymnastics. And since this is public, I don't want to go into too much detail. But, yes, it's a mom-and-pop kind of shop, but we need to make sure that facilities aren't turning parents away. So, you know, if we can offer educational assistance -- there are lawsuits,

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but parents don't want to be tied up in that kind of stuff. But every advocacy group can talk to parents to figure out how common this really is and what can we do about it.

Mr. Grossman: It's very common. We deal with this every day. I mean there -- it's quite -- it is quite shocking, not only in autism, but over -- for all disabilities, so the discrimination occurs, but, yes, this is something we deal with every day.

Ms. McKee: And it has to be ignorance. I mean more than anything else. I think just not knowing what the law is, not knowing, you know, what autism looks like, and if there's a way that we can maybe put together a packet for parents to send to these people other than just printing out the ADA, I'd be interested in trying to see if we could do something there.

That's the end.

Ms. Blackwell: Okay. Thank

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you so much.

Bonnie, do you want to talk about what's going on over at HRSA? You always have a long list.

Dr. Strickland: Sure. Well, you know, I talked about our long list last time, so I'm not going to take up a lot of time this time.

I think I sent to you guys the list of our LENDs expansions -- actually, all of our new grants under our Combating Autism initiative, which is brand new. I don't know if it got disseminated to the rest of the committee or not, though. Maybe I'll resend it.

Della, I don't know if you still have it. But essentially we have a seven-pronged initiative, and I talked about it in depth last time, but we've now awarded all of those grants. The one piece is a LEND expansion. I think it's a 17 LEND to focus more specifically on ASD and other related

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disorders.

We are also supporting a coordinating center at AUCD. We are supporting a coordinating center to assist state title V programs and other entities through the Association of Maternal and Child Health Program, and we have awarded six new grants with the specific purpose of coordinating services across service sectors. We're a health agency, but we recognize the need to connect health care, the medical home, with education, childcare, leisure activities, and that's the focus of these grants, is to figure out innovative ways to make service integration and service coordination happen. And those grants, I think -- I'm at home so I don't have the list, but I think it's Illinois, Missouri, Alaska, Washington, Utah, and Wisconsin were the successful applicants.

And what we're hoping is that at the end of three years, three to five years, we will have some five or six models that we

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can hold up.

We are also launching, actually on Tuesday, this coming Tuesday, an evaluation component that's going to evaluate all of these pieces, and it will be there for five years, and so hopefully we can work with CDC and other agencies and CMS, you, Ellen, on -- so that we can integrate our evaluation efforts.

I just want to say just a few things, and I might need to put my three pieces in here, because I'm going to have to leave at 11, my pieces from the roadmap.

We're having a grantee meeting in December, and anybody that would like to participate in that is most welcome, and we're working with regional summits. So it's exciting, very exciting.

So can I say my three things?

Ms. Blackwell: I think we might actually just table that, Bonnie, until the December meeting, so you're free.

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Dr. Strickland: Okay.

Ms. Blackwell: But I wanted to ask you if maybe you could send some of this information to Della so that she distribute it to the subcommittee after today's meeting.

Dr. Strickland: I'll resend it. I thought I sent it last time. I sent it to Alison, but I thought I also sent it to Della.

Ms. Blackwell: Well, what we have, actually there's a link in the minutes to the full press release that describes each of the things that -- many of the things that you just covered.

Ms. Blackwell: Well, I was also thinking, Bonnie, about the grantee meeting.

Dr. Strickland: Oh, okay. As soon as we have the final information, I'll be sure to send it out.

Ms. Blackwell: Okay. That's great. It's nice after every meeting to get

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another e-mail so you can, you know, find it.

Denise, do you have anything?

Ms. Juliano-Bult: Just one little thing. Something I mentioned in a previous meeting that I think was a cryptic statement I made that you asked me to clarify. We got in one application, it hasn't been reviewed yet, looking at service transitions from youth with autism spectrum disorders, transitioning to the adult service system, and it's exciting. It's a junior first-time researcher, first-time applicant wanting to look at what are the -- in a broad way looking at what are the barriers or facilitators for a smooth transition with the idea that once we know what those barriers are, he will start working on services types of intervention to help people overcome the barriers.

So it's going to be a while before we know the outcome of the review, but we are starting to have people develop applications in this area.

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It does also meet one of the --  
let's see, it's one of the objectives in the  
strategic plan, is to fund research in this  
area, so we're working on it.

Ms. Blackwell: That is great.  
Thank you. That's fantastic.

Ms. Juliano-Bult: The person's  
name is Paul Shattuck, and he's in the School  
of Social Work at Washington University in St.  
Louis. So you may be hearing more from him.

Ms. Blackwell: Okay. Great.

Ms. Juliano-Bult: Yes.

Dr. Houle: This is Gail. Did you  
know that I got on?

Ms. Blackwell: Oh, Gail, hi. I  
apologize.

Dr. Houle: That's all right. Now  
I'm able to speak.

Ms. Blackwell: Oh, oh, wonderful.  
Well, you were a silent partner there for a  
while.

Dr. Houle: Well, yes, I came, I

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had another meeting, so I came on late and then I realized I couldn't speak until we went through the alternative process, and now I can talk.

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

Dr. Houle: Hi. I'm Gail Houle from the Office of Special Education Programs at the U.S. Department of Education. I jotted down a few notes -- are you interested in just a brief update of some of the things that you all might not know about?

Ms. Blackwell: That would be fantastic.

Dr. Houle: Okay. From education. One is that our National Professional Development Center on Autism Spectrum Disorders at the University of North Carolina, with Sam Odom, has on their Web site their request for applications from states to participate in the professional development opportunities that we fund through that

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center. And they have trainers and training teams that will go out over a period of several years and work with teams from states, state education agency, consultants in autism, training and development of consultants that work in state education agencies, and just offer them a lot of support to actually improve the programmatic offerings within their states.

So we have -- the center is funded at \$1 million a year, and they've got three sites. The headquarters is at the University of North Carolina, Chapel Hill, and then they've got a site in the University of Wisconsin, and they've got a site in California, and every year they enroll three more states who get, for just a very small state contribution, very intensive professional development opportunities.

The first year -- they solicited applications on the Web site. The first year, the first cohort is Indiana, Wisconsin, and

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New Mexico. Last year they started -- they keep those states going, then they started working with Kentucky, Minnesota, and Michigan. And now on their Web site they are encouraged to apply, states that have not yet been selected, fill out the application, they're reviewed by a national panel. They have to have sort of some degree of ability to benefit and hit the ground running from the training and bring some state resources as well and have some key players willing to give their time within the state, so that at the end of this five-year period, the work that the center does keeps going within a state.

So I just wanted folks to know -- and I can send Della that information to send out, and we can also mention it at the meeting, that the opportunity is now available for state education agencies to apply for this available technical assistance for autism services.

Ms. Blackwell: Gail, this is

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Ellen. I have a question.

Dr. Houle: Uh-huh.

Ms. Blackwell: Does the invitation have to come from the state education agency, or --

Dr. Houle: Yes. Yes. And they have their application process, the Autism Professional Development Center in Autism, on their Web site, and it talks about, you know, they've got some requirements, they have to have the procedural plan for state involvement, they have to have state liaison requirements, they have to have collaboration with other resources within the state. But it does -- since it's education and it's funded by the Office of Special Education, they work primarily through state education agencies.

Ms. Blackwell: I'm just wondering if it would be helpful at all for us to distribute the link to our state Medicaid directors, since Medicaid has a relationship with the state education agencies in most --

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Dr. Houle: Sure. Sure. They could not -- you know, they wouldn't be the primary applicant, but certainly the more key players within a state who are willing to show collaboration, the much more likely it is that we'll put the resources there because they're fairly limited for this intensive TA at this point in time.

Ms. Blackwell: Okay. Well, I'd be happy to take a look at it, and, you know -  
-

Dr. Houle: Should I send it to Della and then you distribute it to the group? I mean it's available. It's --

Ms. Blackwell: Della, is that okay? Since you're going to be sending out other things?

Dr. Hann: That will be fine. I do want to say, though, for any materials that we're discussing today that they do need to be in the public domain, and when they're sent to me, they will become part of the official

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record for the meeting.

Ms. Blackwell: Well, that's great. That's great. The more it's out there in the public, this is the public. It's in the public domain, and the more it's out there to the greater public, the better off it is, the more partners who will collaborate.

Dr. Hann: That's wonderful. Thank you. I just wanted to make sure that we weren't discussing anything that was sort of in the works and wasn't yet viable for the public.

Dr. Houle: No, no, no. And the other thing I wanted to mention is that hopefully as a committee, I would like to suggest and recommend that we try to include in whatever suggestions for inclusion any committee members would have the Department of Defense in our Services Subcommittee discussions or certainly as -- certainly make them aware of what we're doing as a Services Subcommittee and any strategies to do that, I

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would be interested in. Because we have had some discussions with them around a small aspect of the NDAA 2008 Section 587, where they collaborate with Education, and they do have a fairly large mandate from Congress to provide information to Congress on the nature and extent of services available to military families with children with autism.

So that is very related to the mission of our Services Subcommittee, and I think I would recommend that we look at ways to link that agency in with the Services Subcommittee as well.

Ms. Blackwell: Yes, this is Ellen. I agree with you 100 percent. We have talked about this before. The DOD has an initiative through -- you know, in cooperation with DOE and, as you mentioned, also an insurance program. Would the committee be agreeable to inviting the DOD representatives to the February meeting?

Dr. Houle: Definitely.

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Ms. Blackwell: Okay. So since that's our next meeting -- I mean the December meeting, it sounds like we're going to focus on trying to, you know, get the roadmap, an updated version, so why don't we shoot for -- is it Rebecca Pisant and Robert Demartino?

Dr. Houle: No --

Ms. Blackwell: I can't remember exactly, Gail.

Dr. Houle: Well, it's certainly - - it started out as Rebecca Pisant as our contact person, but she's moved on to another position.

Ms. Blackwell: Okay.

Dr. Houle: So recently we've been contacted by Robert Demartino, looking at the group, and actually our assistant secretary met with -- there's an HHS representative on the list named Lee Shackelford. I'm not familiar with Lee Shackelford from HHS.

Ms. Blackwell: Okay.

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Dr. Houle: Robert Demartino and Lori Sebastian, and then there's a Colonel Major Carol Copeland. I'm just looking at the list of people who have been on the DOD and Ed calls, where we talked about there's a very small section, there's a very small item in section 587 that talks about when they do their report on the status for military families, and they actually have an authorization for DOD to do demonstration projects, that they collaborate with us on that. So we've been having some meetings and conferences on how we can collaborate with them on their congressional mandate.

Ms. Blackwell: Okay. Well, I will be happy to call Captain Demartino and, you know, maybe see if we can line up something for the February meeting.

Dr. Houle: At one point they did not -- well, the people I spoke of were not highly aware of the work of the IACC, so there was even a suggestion from one of the DOD

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staff that Tom Insel might want to discuss at a higher level with DOD the work of the IACC generally. But we said that should not hinder us from the services.

Ms. Blackwell: No, it doesn't hinder us at all. In fact, when I speak with them, I will also mention the November 21st meeting to him. That might be a good time for him to come and, you know, meet some of us face to face.

Dr. Houle: Uh-huh.

Ms. Blackwell: And I'll -- you know, before the February meeting.

Dr. Houle: Right.

Ms. Blackwell: And hear more about the services system. So that would be a great idea, Gail. Thank you so much.

Okay, so I guess that leaves me to talk a little bit about what's going on here at CMS. Our state Medicaid, we find increasingly that we are receiving additional requests for technical assistance on autism

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issues, and that would be me, so we are also receiving additional requests from states to put some home and community-based waivers and other programs in place mostly for children with autism. As I mentioned earlier, Pennsylvania is quite interested in adults, but we have Nebraska, Iowa, Montana -- I'm trying to think -- Washington kind of in the hopper right now.

These are very small programs that are coming in here.

We also, as I alluded to earlier, are going to be getting our autism task order under way today, in fact. I will be meeting with the contractor, which is Impact International. CMS was able to award the first two pieces of this, which is an environmental scan to look at evidence-based services and supports. We hope to help our states try to figure out what they should be paying for and where there's value.

So we are really looking forward

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to getting that. That is the first year of this contract. The second year is a nine-state study to try to look at practices that are going on in our states. As we have talked about previously, OMB rules -- it's just such an odd thing. We can only work in nine states at a time, so that's -- we're a little bit hampered, but we hope to come up with some, you know, really good information from this task order. It has other parts that we were not able to fund this year that we certainly hope to be funding in the future. One is development of promising practices and models for children, youth, and adults. The other is a Web site, you know, that we'll be talking about more in the future.

So those are the other two pieces that did not get funded, but we are going to be under way very, very quickly. The contractor seems, you know, really ready to go, so we're excited about that, and the state Medicaid directors meeting coming up in

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November, there is a lot of talk about autism in our states, so, you know, as fiscal restraints become more and more -- come more and more to the fore, you know, Medicaid directors are looking for ways to fund services very efficiently and effectively, and CMS hopes to help them.

So that's kind of where we are. But our states are facing some very, very large budget cuts, and I'm sure you read about it in the news, and it's a very, very challenging environment for them right now.

That's all I have.

Dr. Hann: Ellen, I would like to say a few words, if I could.

Ms. Blackwell: Oh, of course.

Dr. Hann: Thank you. This is Della again.

First of all, I want to thank everybody for their patience and persistence in getting on this morning. I genuinely do

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apologize for sending the inaccurate information yesterday. We will try to do better in the future.

The second thing I just wanted to mention, too, is that we've gone through a bit of change here with regard to the staffing for not only the Services Subcommittee but also for the Interagency Autism Committee, and we have graduated and we have now actually formed an office. It's called the Office of Autism Research Coordination. So we're no longer the autism team, we're the Office of Autism Research Coordination, which we fondly refer to as OARC.

So I just wanted to pass that along as well.

Then the third point actually I already covered, which was any of the documents with regard to today's meeting will be public documents. We'll be making them available to anyone who requests them, and that would include then follow-up in terms of

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some of the documents that folks said they were going to be sending to help further explain some of the programs and topics that they discussed today.

That's it. Thank you.

Ms. Blackwell: Well, congratulations on becoming the OARC.

It's very nice to have your support at NIH and I know the entire Services Subcommittee and I'm sure the IACC itself really appreciates your hard work and your staff's hard work on all this activity.

All right. Well, I guess that's it for today, unless anyone has anything else. We will be sending out tentative dates for the December meeting and the February meeting to try to pick dates that everyone's okay with before we finalize dates.

So I guess we'll try to pick a set of dates and then folks can prioritize and then we'll finalize those and publish notice in the Federal Register.

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Okay. Well, thanks for participating, everyone. It's 11 o'clock. We got it done.

(Whereupon, at 11:04 a.m., the subcommittee meeting was concluded.)

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