

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

MONDAY, SEPTEMBER 15, 2008

The teleconference and webinar was held at 9:30 a.m., Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

PRESENT:

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

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

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

DENISE JULIANO-BULT, M.S.W., National Institute of Mental Health

JUDITH COOPER, National Institute on Deafness and other Communication Disorders

CHRISTINE M. MCKEE, J.D.

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

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PRESENT (continued):

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

ALISON TEPPER SINGER, M.B.A., Autism Speaks

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## PROCEEDINGS

9:30 a.m.

Ms. Blackwell: The first item of business today is going to be approving the minutes from our June 13th meeting. Does everyone have a copy of this? We just need to take a vote to approve the minutes. Is there anyone who votes not to approve the minutes? Okay, then I am going to say that the minutes from the June 13th meeting of the IACC Services Subcommittee are considered approved. Also, before we get started I need to remind everyone that this is a public call. The IACC is a facet committee and the call is being recorded. The first item we wanted to get to was if anyone hasn't had a chance to see them at our last full meeting we did adopt a vision statement and a mission statement and if you're on the webinar you can see them up here. The mission of the IACC Services Subcommittee is to assess and improve services

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and support for people with autism spectrum disorders division of the IACC Services Committee is so that all people with ASD have the services and support they need and desire throughout their life span to lead productive lives in the community and reach their fullest potential. We did approve the mission and vision statements at our full meeting on July 15th 2008. I also wanted to draw everyone's attention to our Request for Information. We spoke with the Autism team about the RFI. It closes, I believe, on September 19th - is that correct, Della?

Dr. Hann: Yes, that's correct.

Ms. Blackwell: This was an RFI that we issued the IACC issued to solicit information from the public about autism services and support and we have 71 responses to date. I would remind all of the public members on the phone that this is your chance to tell the IACC what you think about where we should be going with services and support in

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this country, where you believe that we are, and I know that NIH will be accepting responses through Friday and we highly encourage everyone who has an interest in these important facets of autism to weigh in. So the RFI was issued on August 11th and again it closes on September 19th. It's RFI number NOT-MH-OA-016. So that brings us to the next item on the agenda which is our November IACC full meeting.

Mr. Grossman: I just want to solicit the group to see what they've done and actually we're going to do another block on it. We have been getting some feedback from people that started school the end of August and have fallen off the radar screen. So hopefully that will generate some more. It's just kind of a bad time of year for people to be involved in these types of activities like producing RFI's, etc. I was curious to find out if others had any input or feedback on what they've been hearing in

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relation to the RFI.

Ms. Singer: We publicized in a similar way. We posted on our home page and sent it out. We have not had that much response directly to us but then again the request did not tell people to respond to us. My hope is that people respond directly to the email address that was enclosed.

Ms. Blackwell: Is there any way to get an update, Allison? Let's say early this week so that people that perhaps responded before have another opportunity.

Ms. Singer: Well, our weekly newsletter goes out on Friday and that's the deadline. So, I'm not sure but we still do have it on the home page. Not sure we would do another e-block because I'm not sure there will be enough time for people to respond, but we did do one already.

Ms. Blackwell: We really do try to get it sent out to our directors and to our state directors on disabilities. We really

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need to try to get it out to our state partners. The responses are actually a little disappointing.

Dr. Rice: We have sent it to all of our grant teams and partners and similar, we don't get a direct response. We haven't heard questions about it or anything, no one has asked for more information.

Ms. Cooper: Just for comparative purposes - we sent out the email to request for responses to the strategic plan at the same time. Have there been more responses to the strategic plan? I'm just trying to figure out whether its interest or whether it's a bad time of year or what the issues might be.

Dr. Hann: The date for the draft of the strategic plan only has a few responses when we checked last - it was around 30.

Ms. Cooper: That's awful disappointing! Is it possible to extend the deadline because of the issue that we raised

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about being back to school?

Ms. Blackwell: Allison, that's what we're talking about. What we thought about initially was being able to present something at the November meeting but if we talk in a few minutes about what we're going to be doing in November I don't know if we're going to have time. Della: is it a possibility?

Dr. Hann: Well, I think in large part it is possible. We can do an extension. That means we would have to file. The problem is it's not going to be able to get out, we're running so late right now that I'm afraid it will elapse and then we would like to have to reopen it again. In order for us to get it into the guide it would have been last week to be able to do the extension. Obviously for Federal Register Notice we have to have about 15 days in order to change it because we also have to publish it in the Federal Register as well. So it would be a lapse, essentially it

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would be reopening it.

Ms. Blackwell: An interesting comment I received not from this RFI but from an earlier one about IACC Research Plan was that someone who is not involved directly with advocacy or really up on the ongoing efforts with the IACC felt like they commented but then it goes into a void, they had to actively seek out well did my comment mean anything. And so, I don't know if there's a way in the future that information. Do the people that respond get any kind of response back like to check back on the status of this initiative, go to this web site, or they just comment and it goes into the voice.

Dr. Hann: I can't really speak to the past effort but in terms of the current effort people do receive an acknowledgement as soon as we send them an email to let them know that email is received. And then in terms of the comments our intentions are to take all of the comments our intention has been to take

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all of the comments and after some privacy concerns that the comments will become documents and be posted. Then the Subcommittee will also be using the comments and use them as they see fit.

Ms. Blackwell: Thanks, Della. So again, it sounds like we're pretty much stuck with the Friday deadline and perhaps everybody could make an additional effort to you know. I will also send it out especially after you told me there were 50 responses Della I did resend it to so we will see what we can do on our own.

Mr. Grossman: Before we drop this subject I wanted to know what the plans are, how we will be looking at the information that has been submitted and kind of get a discussion going with the committee in terms of how this information will be utilized, what we're going to do when we go forward.

Ms. Blackwell: Well, I think Della and I talked about the first issue which is

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sorting it and I believe that the autism team is going to take the first pass at giving the responses into certain categories and you and I look to make sure the categories contort and how we normally look at services support. We don't always speak the same language everyone else does so I at least wanted to make sure that the responses fall into categories that are consistent with the language that we use and also that we recognize that the responses that come, for example, from associations like ASA, Autism Speaks, that those are flagged a little bit differently from responses that come from a parent, an advocate, or someone with ASD so that we can kind of see where they're coming from. Does that sound reasonable?

Mr. Grossman: Yes, I guess that this committee will have an opportunity after we receive this but it won't be done before November, but then to review this and somehow to hopefully, if there is some information

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there to act on the information that comes in. Cause it seems as though our intent is to get feedback so that we would have a better idea of where the interests are what the needs are in the communities and then we can better prioritize the workings of the committee.

Ms. Blackwell: Well, I guess my hope is that we certainly get more than 71 responses between now and Friday. Because I guess my question would be are they really representative if there are only 70-80 responses. I think we'll have to take that into consideration. Okay, do you want to move on, Lee?

Mr. Grossman: Does anyone else have any input or comments or opinions on this? It would be great to hear that as well, and if not, that's fine too.

Ms. Blackwell: Okay, well for those of you that don't know the Center has decided to showcase services and support at our next full meeting which will

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be held on November 21st at the NIH campus and one of our main objectives today is to sort of talk about what we think a tentative agenda might be. Actually we sort of need to decide where we're going with the agenda so we can get folks lined up and my understanding is that the Services Subcommittee has the afternoon session. We have a Committee report in the morning but we will have the 2-1/2 hour slot after lunch on the 21st and Lee and I came up with a tentative plan that we want to run by you and get your ideas - you like it, you don't like it, you think you have some great ideas about folks. So let me start with where we thought we would start. We wanted to allot 30 minutes at the beginning of the afternoon as a general introduction to services and support and the Director of NASC suggested that it might be a good idea to split that into people ages 0 to 21 and then the adult population which is primarily the

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group served by Medicaid. I'm happy to do that. I'm feeling like 30 minutes to talk about and overview of how the system works in the United States and I will be talking very, very fast. I think that kind of groundwork is very essential to helping the Committee understand how the system works in the United States. I've done it before so I'm happy to do that piece and we thought that the introduction could be followed perhaps by...did we want Cathy to go next Lee? Or did we want Cathy to start? I'm getting my order mixed up here.

Mr. Grossman: I think that was yet to be determined. I thought that Cathy would be a little bit more effective after a couple of other presentations.

Ms. Blackwell: Okay, well another idea that is on the burner is that I would really like to see a couple of our states present. We can only allot them a very short period of time and we may want other states to

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come back later because the Committee has certainly not precluded doing more service presentations at other meetings but there are a couple really great programs that I think the Committee would be very interested in hearing about. The State of Pennsylvania has done some very progressive work with adults. They have the only community based waiver specifically directed at adults with autism and we approved it in the spring of 2008. They also have a managed-care model in development, again, to serve adults through managed care and I think that Pennsylvania has gotten pretty deep into these adult issues and it might be of interest to hear especially if we introduce the Committee to how these two waivers work, how the one program works and how the state anticipates the other program working. The State of Connecticut is also running, what I think is a really unique program. It is not a State-Federal program. It is being run with state only dollars and it

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serves people with high functioning autism matching them individually very, very well to jobs in the community. And it's a very small program right now. It's only about 30 people. The state hopes to expand it and ultimately make it Federal home community based waiver but it's a program that we presented to the Committee in one of our promising practices papers. When you hear this gal that runs the program talk about it, it's just very uplifting. The program has had a lot of success with basing individuals with jobs within their needs. That was an aspect of a potential afternoon program that we talked about. Lee, do you want to talk about your ideas, talk about who Cathy Pratt is, and what she might do?

Mr. Grossman: I think most people on the phone know Cathy Pratt. She's the Head of the Indiana Resource Center for Autism at the Indiana University and Professor of Special Education at the Indiana University. She's been in the field of autism for 30 plus years. Perhaps she's the most

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respected educator and trainer in the country. She lectures around the country. And pretty much where we need to be, where we're going, and what the future should look like and she would be kind of the keynote and she would present an outlook of what's currently happening and really where we should be going, which is kind of the direction the Committee is going to want. What we're trying to accomplish here is to give the Committee a sense of what services are like around the country for autism. It just seems as though people don't realize what it's like out there. So, that's one of the things that we definitely want to get across to the Committee - what the reality is, why it's so important to focus on this and concentrate on service delivery and to also show them what good service and good programs look like at a national level.

Ms. Blackwell: And, then, I guess the last piece that we talked about and we

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actually got this piece because we couldn't figure out exactly what was right and Lee mentioned putting together a small panel which he would moderate to include a couple providers. By providers I mean provider agencies that provide services exclusively to people with ASD or to people with developmental disabilities and a parent of an adult who has ASD, and I also thought it would be very instructive to include the parent of an adult who is self-directing his or her child services and support. This is an option that has gotten pretty deep over the past couple of years and it's my impression, although I don't know this for certain, that some families are defaulting to self-direction because they may have failed in the present agency based service system. People with autism have a lot of challenges. There are some parents who have very challenged family members who have gone into self-direction with success so

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I thought that might be interesting to include someone who might be on that route. So, that's kind of where we were guys. I don't know what you all think, but maybe you would like to weigh in with your thoughts about but that brings us to 2 hours and 15 minutes.

Dr. Strickland: This sounds good. I think Lee is right on to tell the Committee the contacts of the upcoming meeting and we've got a couple of hours to do that. I think we really need to get some time on every meeting at the IACC to keep that conversation going. I was sitting here saying "oh, we need to talk about new programs with the 32 million dollars from the combating Autism Act" and we've got some coordinating centers and we've got state implementation grants that we just awarded but the context, I think, is critical in this first meeting. If we had the whole day we could do a show and tell and do the context but I think given two hours is absolutely right that we need

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to paint the picture first and then sort of talk about what we're trying to do about it. Did I miss something? Is the focus of the next meeting on adults?

Ms. Blackwell: No, it is not. When I do the introductions about the services work, I will also talk about how children in this country with ASD seek services through that piece of the statute.

Dr. Strickland: And, health care, I think is important too.

Ms. Blackwell: Actually Lee brought that up Bonnie about private insurance but it is just going to be awfully hard to do in 2 hours and 15 minutes. Can you imagine?

Ms. Strickland: No, I don't think we need a long discussion, but I think it helps the health care pieces and the CDC effort in what is happening around the public awareness. There is a need to be sure that early medical screening and referral is important. But I agree with you in that we

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need to decide what's most important for this meeting but also think about a longer range plan of how we want to lay this out over time.

Ms. Blackwell: I really like your idea. Della has mentioned a services piece at every meeting. We can talk about services at every meeting. We brought that up today and we can certainly bring that up in front of the full IACC in the November morning piece. You know that we'd like to keep the momentum going. A service does not stop after November 21st - I think that's a very good point, Bonnie.

Ms. McKee: I think in some subsequent meeting, if we're short on time, I really think Gail from the Department of Education covers kids but with the budget cuts I know that we're looking at cuts, looking at wait lists at AC devices and parents are really struggling this school year and the schools are struggling as

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well. I don't want to overlook the kids because I know the adults are in a dire situation but for a later meeting I'd love to have some kind of presentation as to what's going on in the implementation of the IDA as the budget is being cut.

Ms. Blackwell: So that's two future meetings, Della, one for HRSA to present the new grant program and maybe Gail to give us an in-depth on the status of IDEA which was recently reauthorized.

Dr. Hann: Sounds good. I encourage you, Ellen, in your comments to raise this issue.

Ms. Blackwell: Okay. And you'll put us on the docket for the morning as well as the afternoon, Della?

Dr. Hann: I'm going to try my best. Maybe we'll have a subcommittee update in the morning and then the full thing that you're talking about now in the

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afternoon.

Ms. Blackwell: Okay. Are there any other ideas? Did we overlook anything because I feel like we tried to jam pack things but I sort of feel like without them we're sort of grounding and understanding how people get services we're kind of lost because I don't even know if the committee understands that there really is no mandate for all services and how IDEA works. That's a lot to squash into 30 minutes.

Dr. Strickland: I agree with you entirely. I would only say that this is going to be critical in this first presentation to make it clear it's not just a system, that this is an issue in the adult system, a problem in the education system, a problem in the health care, and financing system. It's not just one sector of problems. Actually, Ellen, we just did a paper on pediatrics which has been accepted which I

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think would help and be in the nut shell talking about some of the issues in healthcare that would be helpful. It would be a slide in your PowerPoint presentation.

Ms. Blackwell: That would be great. If you could send that to Della that would be fantastic.

Ms. Singer: Who are you thinking of as the panelists?

Ms. Blackwell: That was our next question. If anyone has ideas do you want to bring them up today or would you like to send them to Della?

Mr. Grossman: Yeah, right now this is all preliminary. Ellen and I didn't want to get too deep into this and we haven't thought much through it until we got the feedback from the subcommittee that this thing is definite. Any suggestions that people may have or possible talent would be great.

Ms. Singer: I don't know if you

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guys are aware of the new project that we've been working on with other autism organizations - it's called the Advancing Teachers of Adults with Autism which is really to take a broad view at what's needed and how it is to be implemented. It's really still at the thinking stage. Our side of it is headed up by Peter Bell who would be a great panelist. I would love for him to talk about this new project because we are trying to get more organizations involved. Right now Autism Speaks is involved, Care Center for Autism COSAC for SARC, and you definitely want to bring more groups into this so it might be a good opportunity to get the word out.

Ms. Blackwell: Well, it also sounds Allison, like it might be another topic for a future afternoon at the IACC. You know - a future slot, you know what I mean? Instead of putting Peter on this 45 minute panel you could actually come in and talk

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about your project. So, that sounds like another one, Della.

Dr. Hann: I heard it. We're just going to be filling up that afternoon agenda.

Ms. Blackwell: So, folks, if you think about other people...I know a lady who lives in my community who just absolutely gave up on the agency-based model after complete failure with several agencies and Maryland doesn't have direct options. Maryland nationally runs a separate waiver for self-direction. We try to encourage most of our states to offer self direction to anyone enrolled in a waiver, but there are a couple of states, actually Maryland and California, recently withdrew a self-directed waiver, a separate waiver, but she's had great luck in servicing her son's needs, who has a lot of needs. It is certainly a full time project for her and her husband, but she might be a good one. Anyone who thinks of

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anyone, please submit them and we'll try to nail that panel down. Does anyone else have any comments on this topic? I think the 2-1/2 hours is going to go really fast.

Mr. Grossman: Yeah, and this is the first people are hearing about it today, so think about it and please feel free to comment and email Ellen or I with your thoughts and ideas.

Ms. Blackwell: That would be great because we've got to start getting things nailed down pretty quickly.

Dr. Rice: I think what was laid out sounds excellent and I think it will be helpful when we have the notes from this meeting to reflect on it a little bit more, if there is any additional input, but I want to show encouragement for the thought you put into it - you gave good direction.

Ms. Blackwell: Thanks, Cathy. The next item on our agenda is to revisit the roadmap. In our June meeting we asked the

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folks, and not all of you were there, so you're definitely going to get a pass today on this one. What we asked at the June meeting was, and this was attached to the meeting for today, that people take a look at the roadmap that was developed for the previous IACC, by the previous Services Subcommittee, issued on May 16, 2005. What Lee and I were thinking is that, really, the easiest way to approach this is for folks to go through this and identify a couple items that you think we might be able to achieve. During this particular, our new IACC, I believe Mark referred to it previously as the low hanging fruit approach. Obviously we can't achieve everything in this document and I'm not even sure all of it is appropriate. So, if people could take a look at this and maybe pick out a couple of things that you think we can identify as future goals for the Services Subcommittee. I know that Lee can attest that a lot of time, energy and work from really talented people went into

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this so when we next meet, the Subcommittee, or even before that, if you could send us an email with a couple of things that you think are critical that are already in this document that would be very helpful.

Mr. Grossman: Yeah, I think there's been so much good work put into this not to use it as a foundation to move forward from would be a mistake for us. So, please do look through it and provide us with what you see are - I think a reality check on what can be done from what the expert panel has put together in the roadmap. I think, at some point, we're probably going to have to have a face-to-face down the road just around the roadmap itself because, again, it's such a good document that we should move forward from it and take advantage of what others have done before us. That's not to say that it's totally right. I don't believe it is. Things have changed since the roadmap was first developed, but it is a good document for

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us to work from.

Dr. Rice: I have a potential suggestion. I think I'm finding it hard to just wade through the text and say here are the goals and recommendations. Maybe it's just my preference, but it may be easier for all of us if we had the summary, Excel type grid like the IACC General Research Plan to just take out and use the primary goals and here's the recommendations that have been made and that might make it easier for us to go through them and see them quickly without all the text and have discussions about which ones need to be updated.

Ms. Blackwell: Is that something that the team can help us with, Della?

Dr. Hann: I'll have to look again at the document. I think it may require quite a bit of interpretation on our part. In which case, I would have to rely on several members of the Subcommittee with that interpretation.

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Dr. Rice: I was just thinking the basic. I would even be glad to do it if I had a non-PDF version of it to pull out the goals and the recommendations. So I don't know if anyone has a non-PDF version but if you could send it to me I would be glad to do that.

Ms. Blackwell: That would be great, Cathy. Do we have something like that, Lee?

Mr. Grossman: I'm trying to think in the first iteration of the Subcommittee if they had ever done that and I don't recall this being broken down into a more summary fashion than what we have, but, yeah, that's a great idea, Cathy. I agree with you. It is hard with a lot of text and information to go through and it would probably be better for all of us if you could summarize in a much better fashion and priorities are highlighted so we can take a good look at those.

Ms. Blackwell: Della, could you

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look into that?

Dr. Hann: Yeah, we'll look into if we can find the Word version of the PDF, and, if not, we'll make sure that there is one so that we can give it to Cathy.

Dr. Strickland: Della, if you don't find the Word version, I might be able to find one since it originated here.

Ms. Blackwell: Fabulous, there you go! Thanks, Bonnie.

Mr. Grossman: And I'll look through some of my old files too to see if I have some draft of it, and, Della, whenever you have that you see the team wants to start working on it, feel free, call on me and I'll come in there and we can sit down and kind of go through this.

Dr. Hann: Well, I believe Cathy just volunteered to do that.

Ms. Blackwell: Yes, Cathy said she would take the first half of that.

Dr. Hann: Yeah, I'm just looking

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through my files and I don't remember if I had a final version. I have an earlier draft so if anyone finds that if you could send it to me.

Ms. Blackwell: Okay, that's fantastic. Okay, we'll work on that and we can revisit it at our October meeting. The next item on the agenda is to talk about future activities and I just wanted to sort of bring this to the floor - at the last full IACC meeting in July Tom brought us the possibility that the IACC hits the road. We had talked as a group about having at least one town hall meeting, and I believe I suggested this at our last full meeting, that Health and Human Services has ten regional offices across the United States in Boston, New York, Philadelphia, Atlanta, Chicago, Dallas, Kansas City, Denver, San Francisco, and Seattle. I'm probably more familiar with these offices because Medicare and Medicaid have a very large presence in them but all of them have capability and all of them have a fairly large meeting room that seat at least

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100 people. My suggestion was that if the IACC hits the road or if the Services Subcommittee hits the road that we perhaps utilize those facilities to broadcast remote simultaneously so that people could participate across the country even if the Services Subcommittee already is in one region at a time. Does that sound like something that makes sense?

Dr. Strickland: I think it sounds like it makes sense.

Ms. Blackwell: Thank you, Bonnie. Are you familiar with our regional offices?

Dr. Strickland: Sure. MDA used to have a large presence in the regional offices.

Ms. Blackwell: Exactly. That is another reason that our sister agencies are always there. It is a great opportunity to get to more people at one time, but hopefully Tom will bring that up in the morning session of the November meeting since he did seem interested after the Sacramento meeting and

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pursuing at least having one or two IACC members meeting with the public. So, that's all we have. I guess we can kind of go around the room at this point and have everyone update people on activities at their agency or organization so, Lee, would you like to start?

Mr. Grossman: Okay. Things are always busy here and since our last meeting in June we had our conference with over 2000 people there. I saw a lot of our good friends, like Bonnie and Cathy were there, and we're gearing up for a number of activities this fall at a meeting which will be in November, which is the largest peer-to-peer professional conference in the country with educators and people that are providing services. Primarily there are a number of presentations on adult services primarily 0 to 21. There will be a number of state teams. Last year we had 38 states there that had their autism teams there and there will be a number of activities and events geared around

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these teams to get them together to try and market from each other and perhaps do some collaborative efforts as well. I don't know what the latest is on the confirmation from the states, but I assume that we are going to have 38 or more at this year's meeting. I can go on forever, but I'll just leave it at that for now.

Ms. Blackwell: Bonnie, would you like to go next?

Dr. Strickland: Sure, I'll be brief, but as I mentioned earlier, we're starting a new program, the Combating Autism Act. We had about \$32 million, we started work in several different areas - one is the expansion of what is known as the LEN program, their education in leadership and development of disabilities have been around for a while and some refer to them as UAF (University affiliated program). We've expanded their capacity for early detection and identification of children with autism and

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related disorders, public awareness campaigns, and most of the leadership work going on nationally, we will be supporting to the program as well. We've also used a little of that money to expand the capacity of Pediatric Pulmonary Centers. They're typically the arm that would do the medical diagnosis of autism. One of the things that we're really excited about from the service perspective is the funding of six new state implementation grants that are specifically dedicated to improving the service networks at the state and community level. Those grants have just been awarded and they've been awarded to Washington, Wisconsin, Missouri, Utah, Alaska, and Illinois and they all score very well in the objective review and what we're hoping is that at the end of five years these states, and hopefully others, in future years, will become national models for how services can be organized at the state and community level so that children and families can get

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comfort and services that they need. So that's a big part of our initiative. Also, it's \$1.8 million that can get a lot of impact from a services perspective. We've also expanded the research network this year. We have two national coordinating centers, one with the AUCD, and one with our own professional organization, the association with the child health program. And to cap all that off, we're soon going to be awarding a contract to do an in-depth evaluation of our combating autism initiative and we plan to be coordinating all of these activities with CDC and we've got a core group with CDC and we communicate regularly on how to better coordinate our activities. And we expect to be doing that with our sister agencies as well.

Ms. Singer: When do you expect to release those grants?

Dr. Strickland: We have. I don't have the list of those 18 that received

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additional funds. I can get that for you and we can put it in the minutes. Okay, I can let you know who they are. I just don't have the list with me.

Ms. Blackwell: Well, thanks, Bonnie that was great. That's a lot of work and a big achievement. Denise, would you like to go next?

Ms. Juliano-Bult: I can say from the Services Research Branch that we have a couple grants that we anticipate and hopefully will come in October or November that are to take a look at adult services. At the very beginning, very preliminary level how for people to act about these services and where there are even services available. So, something in the future, but nothing happening just yet.

Ms. Blackwell: Okay, that's great. Cathy?

Dr. Rice: Our primary services are (inaudible) campaign that continues pretty

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much in the same state as it continues to outreach. We attend a variety of professional conferences trying to encourage early identification and trying to coordinate which is very important to do. Otherwise, pretty much the same. On the other comment that I made about finding the Word version of the document for the roadmap, I found it.

Ms. Blackwell: I know that when I was on the phone last week with respect to a strategic planning meeting, the possibility was brought up that CMS, CDC, the Department of Education, and I believe, possibly HRSA, getting together as sort of an off-site IACC activity to talk a little bit about identification and surveillance so you may be hearing more about that in the future. I'm actually reminding myself too. So that could be coming in the future. Allison, would you like to talk a little bit about what Autism Speaks is doing?

Ms. Singer: Sure, I mentioned a

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little bit about our Advance in the Future for Adults with Autism. That's still very much in the planning stage. Projects that we have worked on in the past couple of weeks are first, our 100 day kit for families, and we have gotten many requests from families who were not English speakers for that material in Spanish, which we have made that available. We also have our school community tool kit available and that's a resource for principals and school teachers in public schools to help them work with kids who are diagnosed with autism who are attending public schools to help them understand some of the social issues and focus more on helping the kids do well socially as well as academically. And then, finally, next week we are going to be releasing a great new product that we did together with the CDC. It's called, Talking to Parents about Autism and it's directed at the school teachers and head start providers who are often in a great

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position to notice that a child is not meeting milestones, but from our research we learn that these directors and centers were reluctant to tell parents because it is a very difficult and challenging conversation to have with parents. So this new DVD, which will be available in both English and Spanish, is really focused on role playing and helping these school teachers to have that conversation with parents. Although the parents may respond negatively at first hearing this news, months down the road they will often come back and thank the school teacher profusely for helping them. So that's coming out in two weeks and we're really very grateful to the CDC for working on this project with us - it was very helpful.

Ms. Blackwell: It would be great that maybe at the November meeting if everybody could have a copy of the material in their packet. Is that possible? Della, isn't that something we always encourage?

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Dr. Hann: Certainly. Allison, it sounds like brochures, the announcements off the web, or whatever you feel like would be appropriate.

Ms. Singer: Yeah, we could do that. How many IACC members are there?

Ms. Blackwell: I want to say 18, but, Della, do you know?

Dr. Hann: Yeah, there are around 19, but we could work with you, Allison, in terms of the precise number of copies and then we'll probably want to have some of it available too for any public people who walk in the door.

Ms. Blackwell: That will be great, Allison. Christina, what's new?

Ms. McKee: The concerns that the parents have are ones that we always have - the child with IDA and no child left behind and how that gets implemented. Around here it means a narrowing of availabilities. Learning centers are closing down and more kids are

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being mainstreamed and that means that the services, for the very first time, there are wait lists for augmentative communication devices in the area that I'm in for budget cuts, and, can you imagine - this is a communication device for children who need them and there's a wait list. There are 20 children waiting for one specific device. So the budget cuts have hit hard and we have a direct impact on the services that are available for our kids. There are also some delays in approval of one-on-one, so the teaching staff from the special classrooms are pulled out to handle the one-on-one mainstreaming opportunities so there is a resource pool from the smaller classrooms to accompany a child and so parents feel bad. They can't believe the staff is being pulled to go with their child because of the one-on-one situation. Like we said, it is a very hectic time of year; parents are going crazy trying to work with the schools to get the

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IEPs and to actually have all the plans that were put in place happen. It's chaotic and we'll see what happens from here.

Ms. Blackwell: Okay. Judith?

Ms. Cooper: Nothing to report.

Ms. Blackwell: I'll go last. Actually I do have something to report. Here at CMS we issued a task order I guess a couple months ago now that we're just getting ready to award. I was able to secure some funds to do research on services and support. This particular project has four pieces and several of them are optional, but at the beginning we are planning to engage an environmental scan including interviews that will look at services in the United States to children, youth, and adults with ASD. The second piece is to go out and survey nine states and take a look at what is happening. We haven't decided which nine states yet - it is quite difficult to survey nine states, but that is

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what we will be doing to get the project off the ground. The third piece is to start looking at - when I use the word, model, I'm always very cautious - but look at what sort of combination of services and support might be working well for children and adults. And then the fourth piece is something very interesting is to put together an ASD information journal that would link news feeds, databases, Department of Education, etc. So, we will be awarding this task order shortly and embark on it very quickly. I'm really excited that CMS agreed to get this started. The folks at IAMH are partners with us in this activity so we can't wait to get started - we're really excited. So, that's what's going on here. I think that kind of brings us to the end. Does anyone have any other issues that they would like to raise today? Della, when is our next meeting? It's in October, I know that.

Dr. Hann: It's the 10th of

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October which I believe is on a Friday.

Ms. Blackwell: Right, October 10th, on a Friday, from 9:30 to 11:30 and we will be meeting by phone that day. As we mentioned we'd like to get together another meeting at some point early next year and for it to be another face-to-face meeting. Does that sound like a good idea to everyone? (Everyone agreed). With that, do we have any closing words?

Mr. Grossman: Just thank you very much. I want to thank you, Ellen, for running the meeting. My timer on my phone just indicated that we hit one hour so we are about 59 minutes ahead of schedule and I think that means major props for that.

Ms. Blackwell: Well, I hope that momentum continues in November when we have to make all these presentations in a very compressed amount of time. That goes as well for the meeting on the 21st.

Mr. Grossman: Take care everybody,

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and all those out there in the telecommunication land who are also listening in on this. Thank you for your time and interest in what this Subcommittee is doing.

Ms. Blackwell: Well, okay, well thanks everybody.

(Whereupon, the above-entitled matter concluded at approximately 10:30 a.m.)

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