

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

TUESDAY, FEBRUARY 24, 2009

The committee met via teleconference and webinar at 9:00 a.m., Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

PRESENT:

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

ELLEN W. BLACKWELL, M.S.W., Centers for Medicare and Medicaid Services

LEE GROSSMAN, Autism Society of America

LARKE N. HUANG, Ph.D., Substance Abuse and Mental Health Services Administration

JENNIFER JOHNSON, Ed.D., Administration for Children and Families

CHRISTINE M. McKEE, J.D.

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

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PRESENT (continued):

AZIK SCHWECHTER, Ph.D., Office of Autism
Research Coordination, National
Institute of Mental Health

STEPHEN M. SHORE, Ed.D., Autism Spectrum
Consulting

ALISON TEPPER-SINGER, M.B.A., Autism Science
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PROCEEDINGS

(9:05 a.m.)

Ms. Blackwell: Hi, this is Ellen Blackwell. I am the co-chair of the Services Subcommittee of the Interagency Autism Coordinating Committee, and my co-chair, would you like to introduce yourself?

Mr. Grossman: I'm Lee Grossman, and hopefully everybody can hear me. Can you hear me?

Ms. Blackwell: Yes, I can hear you. I'm going to let folks go around and introduce themselves. I think that should probably be our first activity, so folks on the line, go ahead and take turns. How's that? Larke, would you like to start?

Dr. Huang: Yes, this is Larke Huang. I work in the Office of the Administrator in the Substance Abuse and Mental Health Services Administration in Tampa.

Ms. Blackwell: Jennifer?

Dr. Johnson: Yes, this is Jennifer Johnson with the Administration on Developmental Disabilities in the Administration for Children and Families, HHS.

Ms. Blackwell: And Alison?

Ms. Singer: Good morning. I'm Alison Singer. I'm a public member of the IACC. I am the mother of an 11-year-old daughter with autism, and I also have an older brother with autism.

Ms. Blackwell: Do we have anyone else on the line?

Dr. Rice: Yes, hi, this is Cathy Rice from the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention.

Ms. Blackwell: Hi, Cathy. Welcome. Is there anyone else?

Dr. Daniels: Susan Daniels. This is Susan Daniels, and I'm the designated federal official at this meeting.

Ms. Blackwell: Thank you, Susan.

Susan is with the Office of Autism Research and Coordination at the National Institute of Mental Health, and I'm Ellen Blackwell. I work at the Centers for Medicare and Medicaid Services.

We're here today to talk a --
sorry. Go ahead.

Ms. McKee: Just wanted to check in. Christine McKee.

Ms. Blackwell: Oh, great.

Ms. McKee: Public member of the IACC and parent of a nine-year-old girl with autism.

Ms. Blackwell: Welcome, Christine. I wasn't trying to cut you off. It's hard to tell who's in the room when you're on the phone.

Ms. McKee: Absolutely.

Ms. Blackwell: Well, if anyone else comes into the meeting, I hope that they'll feel free to interrupt and introduce themselves. I thought we'd start with some

housekeeping issues today.

We have the minutes, and the Subcommittee members should have been sent the minutes from the December 10, 2008 meeting, and we need to approve those today, so do we have any dissenting votes on the minutes that were sent out to the Subcommittee? In that case, I'm going to say that the minutes are approved. Lee, do you concur?

Mr. Grossman: I do, indeed.

Ms. Blackwell: Okay. We also wanted to talk for a few minutes just to mostly remind Subcommittee members and anyone else who is interested, of course, that our next meeting will be held on Thursday, March 26. Susan, correct me if I'm wrong, but I believe it's an afternoon meeting. I want to say 2:00.

Dr. Daniels: It is.

Mr. Grossman: The meeting -- right now, the meeting is scheduled -- different information. I'm sorry. It's scheduled. We

had blocked the whole afternoon from 12:00 to 5:00, but the times have not been --

Ms. Blackwell: Firmed up?

Mr. Grossman: Yes.

Ms. Blackwell: Okay. Well, the meeting will be held the afternoon of Thursday, March 26, at the Hubert H. Humphrey Building, which is the headquarters for Health and Human Services in Washington, and our guest, our speaker that day, will be Captain Robert DeMartino, who is with the Behavioral Health Division at TRICARE, and he'll be talking to us a little bit about the Department of Defense activities related to autism, and so we look forward to welcoming Captain DeMartino and hearing more about what's going on over at the Department of Defense.

Lee, do you have anything to add?

Mr. Grossman: No. I'm looking forward to that meeting. It should be great, whoever can join us face-to-face.

Ms. Blackwell: Yes, and that is a face-to-face meeting. Thank you for flagging that for me, and as usual, the public is invited to participate if anyone wants to come to D.C., and there will be a call-in number, as well.

We thought -- before I start, I just wanted to make sure that everybody is -- you know, we've done all our housekeeping, because our next part of the discussion is actually could be a little bit long, and what folks need to do is pull the paper that was sent to you that starts with 137 commentators.

We thought we'd talk a little bit about this updated analysis of the request for information that was actually sent out last September. This was a request for information from the public about services and supports for people with Autism Spectrum Disorders, and it was really our first cast at getting information from the public about what important issues in this area come to the

fore.

So, just to review, we received 137 communications, and I actually did a re-analysis of those comments, and what I got out of it was 497 comments. Now, the way we work at CMS is when we receive comments on regulations, we look at what is actually in the body of the comment and go through and start to put the comments into categories.

So I performed a similar activity with this RFI, and there were 21 comments out of the 497 from people who self-identified with an Autism Spectrum Disorder, and initially I had about 25 different categories, and Lee and I sat down together for almost a whole day last week, and we have 18 remaining categories.

I think one of them will probably be eliminated, but if you're looking at this picture, or this paper, the number one category that arose from the comments is concerns about adults with Autism Spectrum

Disorders, and, as you can see, the first category is that people need additional housing.

The second most area of concern that rose to the top was people were concerned about institutionalization of their family member. The next one was that people are concerned about what will happen to their family member when they're gone.

People mentioned less costly housing alternatives, that they need -- that there needs to be a better assessment instrument for adults, and then after that there were smaller concerns, and I won't go through and read them all. I am going to try to highlight today the ones that came to the top, but this area clearly with 12 percent of the comments was right up on the top.

There were actually six areas that hit the top. The next one is an area that Lee and I decided to call Community. The highest comment was that people felt that people with

autism needed better community acceptance and inclusion. Fourteen commentors mentioned that.

Six commentors mentioned that better peer opportunities were needed. Several other people mentioned that better access to services was needed in rural areas, that there needed to be better dissemination of research findings to community settings, and then several commentors mentioned the need for autism centers to provide one-stop services.

And then there were other comments, you know, that had two or three comments underneath that, and, by the way, if anyone is interested in seeing this document, it is available from Dr. Schwechter, and his address will be provided, but it is also in another document that we're going to be talking about today.

The third category that rose to the top was family support, with ten percent

of the comments. Ten commentors indicated a need for more respite and child care. Eleven commentors indicated they needed more family support. Five commentors needed that more crisis care opportunities were necessary, and four commentors indicated that family preservation and spousal counseling was necessary.

The fourth category is, not surprisingly, school services. Fifteen commentors indicated that teacher training and education was very important. Nine commentors indicated there was a need for more adequate or appropriate services in schools, and then three commentors indicated that they had worries about restraint issues in school settings, or there needed to be more funding for school services.

The fifth category is one that we decided to call Providers. Seventeen people indicated that providers need additional training, both care givers, staff, and

professionals.

Another area that rose to the top was better physician training, and then five people indicated that there needed to be better services for people with Asperger's Syndrome in particular.

The sixth category, and this is kind of where we drew the line initially, is one that we decided to call Infrastructure. The first comment was that private insurance needs to cover people with Autism Spectrum Disorders.

The next amount of commentors indicated that there needed to be better training on Autism Spectrum Disorders for care coordinators, and then there were a number of comments that related to infrastructure that don't necessarily relate to each other, for example, parent training center coordination, that the system is crisis-driven, under-funded.

There need to be more telemedicine

options. Medicare and Medicaid need better coordination. It was kind of a hodge-podge of comments that we put under infrastructure, and then --

Mr. Grossman: These are things that are -- that we identified as items that should be -- the reason we put them under infrastructure is because we wanted these items to show the inconsistency in the service delivery, and that's how this infrastructure -- that's how we thought that it should be so that we can somehow coordinate the services across different times in a life span.

Ms. Blackwell: And if anyone thinks that these categories are just dead wrong or that we walked off in the wrong direction, please feel free to interrupt me and, you know, say, because, you know, as I said, I started out -- my first run at this, I had 25 categories, and Lee and I really tried to narrow this down so that we didn't have, you know, quite as many and so we could

see where the chips were falling with this first RFI.

So that's where we drew the first cutoff, with those six, and most of those had about -- it ranged between 12 percent of the comments and nine percent of the comments, and then there was kind of a break where the next group of topic areas seemed to garner about five, six percent of the comments, and the first category at that level is one that we called Employment.

Nineteen commentors indicated that there needed to be more employment and support training. Seven commentors indicated that there needed to be better engagement by community employers.

The next category is one that it kept coming up over and over again, and I actually wasn't quite sure what to do with it, so I kept it in its own place. It was -- and we're calling it Evidence-based Services and Support.

Mr. Grossman: Ellen?

Ms. Blackwell: Yes.

Mr. Grossman: I want to comment just on the employment portion.

Ms. Blackwell: Oh, sure. Go ahead.

Mr. Grossman: Real quickly. That was an area that we thought that we would separate out for now, but we had discussed that employment could obviously be in the number one category, which was related to adult services, but we wanted to somehow break that out, have it separate for now, and we'll let the Subcommittee decide if they want to retain it separately or if they want to move it up into the adult services sector.

Ms. Blackwell: And what do folks think about that? Should we leave employment as a separate category, or should we collapse it into adults with Autism Spectrum Disorders?

Dr. Rice: Well, there seems to be some overlap, so I'm not quite sure how these

are quite different from some of the things that were listed in the adults.

Ms. Singer: I think it's hard. This is Alison. I think it's hard to know how to categorize them until we understand what we're going to be doing with each of the buckets.

Ms. Blackwell: Okay. So, for now, for this discussion, should we just leave them where they are, Alison?

Ms. Singer: Or maybe you can back up. Do you -- do you have an idea for how we're going to handle each of the different buckets? Because that may help us in terms of sorting them.

Ms. Blackwell: Well, these were just the first buckets, and one of the suggestions we're going to talk about today is going into -- is issuing a second RFI now that we have some buckets, so I think when we're going through these it's worth thinking about that, you know, in terms of how we move

forward.

Dr. Huang: You know, Ellen, I'm seeing some kind of possible organizing strategies around this.

Ms. Blackwell: Okay.

Dr. Huang: I see that you have a number of infrastructure issues, and then you have services and that array of services that were required, and it would be different depending on developmental age. And employment seems to me like a critical service piece that would be for transition, age, youth, and adults.

I mean, it depends. I think it depends how we want to organize these buckets, but I'm just seeing something that really reminds me of what we did in mental health in terms of really developing a concept of a system of care that has infrastructure pieces.

And I think I at one point started to mention this to you, Lee, and I've been detailed away from SAMHSA, so I haven't been

able to participate as much, but we do have a major program that is really building a system of care for -- this is focused on children and adolescents and transition age to adult with mental health issues, but so many of what your buckets are looking like are really what we started with when we started this program that's been in existence about 14 years and pretty well funded, but it does have infrastructure issues, which have to do with the payment issues, the workforce training issues, some of the other pieces that you mentioned and then really creating an array of services.

And the idea around this program is to be able to -- people to avoid institutional care, to be able to live, you know, a supported life in the community, you know, with jobs, with schooling, with supported employment or housing, whatever.

So we have this kind of framework for doing this. There's also a big piece on

education and awareness, stigma reduction. That goes into part of what is part of the infrastructure.

Mr. Grossman: Well, Larke, that's very useful to us, because, I mean, the way that Ellen and I had discussed this in putting it into these various buckets was to make this an exercise so that we could get comments from you and everybody else in terms of how they see this falling into place and if there are opportunities that exist in ongoing programs that your agency currently has, how this can fit.

We were also trying to organize this, and you'll see this in the next -- one of the other discussion points that we're going to have following this -- is to organize this as part of what we see our role is in the Services Subcommittee to make recommendations to the full IACC that hopefully would then become recommendations to the Secretary.

So, I guess in response to what

Alison was saying, that's kind of how we were trying to frame this is to make this so it's more logical in terms of what recommendations we would be bringing forward to the entire IACC Committee.

Ms. Blackwell: And I think we also wanted to make sure that we were operating with -- really based on what the public said was most important to it, I mean, so, you know, again, I took a little different run at this than initially what we talked about last year, so it's pretty subjective, so bear with us a little bit.

Mr. Grossman: And one other thing. I just got an email. Stephen Shore just joined us. Do you want to --

Ms. Blackwell: Hi, Stephen.

Dr. Shore: Yes.

Ms. Blackwell: Would you like to introduce yourself?

Dr. Shore: Yes. I'm Stephen Shore. I'm a public member. I am my own

autistic adult and therefore have -- represent my -- represent people with autism so far as services are concerned.

Ms. Blackwell: Great.

Dr. Shore: Currently I'm a professor of special education at Adelphi University.

Ms. Blackwell: Okay. Well, what we're doing now, Stephen, is going over this document that's sort of an initial analysis of the comments that we got in the end of last year.

Dr. Shore: All right.

Ms. Blackwell: And we were talking about -- Lee and I had mentioned that there were sort of six areas that came out on top, not by a lot, and the first is adults.

Dr. Shore: Right.

Ms. Blackwell: The second is community. The third is family support. The fourth is school services. The fifth is providers, and the sixth is infrastructure,

and then we have these other categories: employment, evidenced-based services and supports, health and safety, early diagnosis and treatment, transition to adulthood, and therapies that were sort of the second level that the public said. So there's your transitions, Larke. It falls into that second piece.

Dr. Huang: All right.

Ms. Blackwell: And it really was to me -- it was about five percent of the comments. It was 25 comments out of 497, but if you -- actually, if you look at this document, I think what happened, there were some people that might have only commented about one issue, but it's a really important issue, so, you know, I made sure that even if only one person said something, I included it in these sub, you know, notes so that -- you know, because I'm not sure that this first cast got everything. Only 137 people responded. Obviously, they had a lot to say,

but it did sort of allow us to get these ideas about maybe what the concerns might be.

And then the last categories that came out of this, and these are the ones that were sort of at the bottom, but, again, we thought these were important enough to at least preserve for now for our discussion, were legal issues and guardianship, issues surrounding dental care, issues surrounding medical treatment, and Lee, why don't you talk about the next one? It's vaccines.

Mr. Grossman: Wait, let me get that. Let's see. This is the medical treatment or the --

Ms. Blackwell: The vaccines. I mean, some people --

Mr. Grossman: It kind of cancelled itself out in terms of the responses. There were eight responses. Four said we need more study, and four said to shift away from the vaccines, but because of our comments, it's certainly important to list them.

Ms. Blackwell: However, we think moving forward that we should strike vaccines as a service. It came up, but it's really not a service and support, so, you know, in terms of moving forward with these categories, which we'll talk about a little bit later, we just wanted to perhaps take that one off the table.

The next one is one that I know, Christine, is dear to your heart, assistive technology and augmentative communication. The last one is diet, and then there were just a small number of comments that really did not fit in anywhere and were really not, again, not germane to services and supports, so that took the list up to 100 percent.

So that was our second run at what we got out of this RFI that came back that -- you know, it was open for about four weeks, which is actually kind of a short period for comments to be open, and I'm not sure how well distributed it was. I mean, it's certainly kind of a disappointment to me that only 137

people wrote in, so if we did, you know, elect to move forward with another RFI, I would certainly hope that we could perhaps get better proliferation and better response.

Dr. Rice: I guess my -- this is Cathy Rice. My comment would be about another RFI. Do we really want another general RFI, or would it be a request for the next thing I think we're going to discuss on the agenda, which is the recommendations to the overall IACC? Would it be better to have an RFI asking for specific comment to that document, which attempts to integrate these comments?

Mr. Grossman: Well, yes, and that's what we had -- Ellen and I had also discussed that, and we wanted to get feedback from the subcommittee on that.

Ms. Blackwell: I mean, Cathy, what I think is that I actually think we set ourselves up pretty well for a second RFI if we went out with these 17 categories, or fewer if the committee thinks that that's

appropriate, I mean, but I think that this would be -- I mean, at this point we really do have 17 categories that express themselves.

Dr. Rice: But would the goal then be for whatever the new round of responses would be about using that to then inform this report back to the overall committee?

Ms. Blackwell: Yes.

Dr. Rice: Okay.

Ms. Blackwell: And then, you know, so we took the scattershot approach, and then I guess we could have a more focused approach and say, "We want comments in the following areas: adults, community, infrastructure, schools, family support, providers," or, you know, do we just ask for, I mean, an RFI on the top six, or do we go with all 17? I mean, what approach should we take?

Ms. Singer: I think you would increase your response rate if we were able to communicate exactly how the information collected was going to be used. I think that

was some of the feedback we heard from the initial RFI, which is, "What are we going to do with this other than to sort of sit and talk about it and present it to the IACC?"

So I think, for example, the RFI with regard to the Research Strategic Plan had a very clear mission in that it was to inform the Strategic Plan, so is there some way to incorporate a formal revision of the Services Roadmap into the RFI so that people understand how their participation is going to be used?

Ms. Blackwell: Yes, that actually was exactly what we had planned, Alison. Lee, do you want to talk a little bit about the second document, or should we -- you know, because it seems to be -- to make sense?

Mr. Grossman: Yes. Let me pull that up. Well first of all, maybe we should conclude any other questions or comments that people have on this one that -- first of all, I want to thank Ellen for pouring through all of those comments.

It was just amazing when she plopped down in front of me this breakdown, and I think we can't thank her enough for doing that, and it was a great experience to see how the comments actually laid out. But before we go to the next part, I just want to see what comments people might have at this point, or are we ready to move on?

Dr. Rice: I would just say that the categories you broke them down into are very helpful, and really much more easily digestible, so echo Lee's thanks on doing that.

Ms. Blackwell: Thanks, Cathy. I just felt like I really needed to look at every one of them, and try to understand, and you know, put it in a form where I could, you know, really see what had come to the top.

So as I said, we do this a lot at CMS. We issue a lot of regulations over here, so you know, we're sort of used to looking at comments, and the only other thing I would add

is that, in a future RFI -- Lee and I talked about this a little bit, and I didn't do this with this bunch of comments, because I wasn't sure that it was totally representative.

Typically, we'll find a way to weight comments from large organizations, so in a future RFI, you know, for example, the National Association of State Medicaid Directors, the National Association of Directors of Developmental Disabilities, the Autism Society, say. If one of these organizations write to the IACC and registers comment in an RFI, we typically -- well, here at CMS, at least, we would weight those comments a little more, because we know that they represent many, many more people.

So I didn't do that with these comments, because they were actually sort of falling into place, anyway, but I think in the future that's something that we would definitely want to do in our analysis. Does that make sense to everybody?

Dr. Huang: Yes.

Ms. Blackwell: Okay. Well, you're exactly right, Alison. The second piece that Lee and I talked about was something we had talked about with the Subcommittee before, which is, you know, what do we do with this roadmap, and when we were together we sat down, and we started to go through the roadmap to see, you know, what was still relevant, what wasn't relevant, and you know, how this document fit in, if at all, with what we were hearing from the public.

So the second document that you got today is actually, you know, sort of our first crack at taking a look at what we might do going forward, and this is the document that's stamped all over as draft, which is just -- and this is totally a draft, because we wanted to get some feedback from the Subcommittee about if this is even the right direction that you want to go in.

Mr. Grossman: We were struggling

on what to do next with the roadmap, and we weren't very happy with just that term itself, roadmap, and so we went back to the statute and saw that, for the most part, the IACC and the Subcommittee is --

One of its responsibilities, one of the things that it can do, is to make recommendations, and we felt that that was totally in line with what we wanted to do, and to frame a different document around recommendations to the Committee and then, if approved, then to the Secretary, and that's why we changed the name. We took the roadmap out.

We tried to update it from what was produced in 2005. For example, there was a lot of language in there regarding the New Freedoms Initiative, and you know, not knowing how that's going to progress or how that's going to move forward, some of that language was taken out. It doesn't mean that we can't put it back in.

It was just that we're looking at a new administration and a new time frame, and we probably didn't necessarily need to follow what was in, at least in that regard, in the old roadmap, and then take the information that was provided to us in the RFI and feed that into this draft.

Obviously, there's a lot more work that needs to go into it, and I think that perhaps some of the agencies are doing work right now that would fit very nicely into this and perhaps can -- well, it should be part of the recommendation, as well as anything that they'd like to do to further expand and improve the current programs and initiatives that they are now offering.

Ms. Blackwell: Lee, a couple of years ago, the General Accounting Office came out with a report that really looked at intergovernmental cooperation and coordination, and the report focused predominantly on the FERPA issue with the

Department of Ed, but it also made some specific recommendations with regard to improving the Services and Supports Roadmap.

Has anyone taken a look at that document? I haven't read that document in a couple years, but I remember it had very clear recommendations with regard to ways to improve the roadmap, and I think it called for more specificity.

Mr. Grossman: Well, we did take a good look at that, and much of what we culled out of that went into the Expanding the Promise for Individuals with Autism Act, which was to create -- and as part of that act, which Senators Allard and Clinton had introduced, was for a pilot project so that we could pretty much approve various concepts, and those were some of the systems issues that were identified in that report.

You are right. It was mainly done to address the FERPA issue, which was the issue that was going back and forth between

IACC and the Department of Education, and that was -- I guess the conclusions around FERPA were somewhat less than satisfactory, because it still left a lot for interpretation.

Ms. Blackwell: Susan, would it be possible for you to locate a copy of this GAO report and send it around to the Subcommittee members, just so we could take a look at it?

Dr. Daniels: Sure.

Ms. Blackwell: That would be great.

Dr. Schwechter: This is Azik. I just wanted you to be aware that the draft document that you're referring to, as well as the RFI analysis that you've done, are all available on the IACC website at www.iacc.hhs.gov/subcommittees, and if you go to the meeting materials for the 2/24 meeting, you'll be able to access all these documents.

Ms. Blackwell: That's great.

Thank you.

Mr. Grossman: Is that GAO report

part of the Subcommittee documents now?

Ms. Blackwell: Well, it's probably up on the GAO website, Lee. It should be easy to get a hold of for anybody. I mean, all those reports are public. I just don't know what the number is, or the date of issue.

Mr. Grossman: I'm looking for it right now. If I find it, I'll send it around.

Ms. Blackwell: Okay. Well, so what we did was we took a stab at writing this new document, which would be an updated roadmap, and really this is just bare bones. This is -- Lee liked the idea of calling it ASD Services and Supports Recommendations, and on the first page we state our mission statement, which is To assess and improve services and supports for people with ASD, and our vision statement, which is, All people with ASD have the services and supports they need and desire throughout the life span to lead productive lives in the community and reach their fullest potential.

And then the next thing we did was we referred to the last two chapters of the Strategic Plan that the IACC issued in January, which specifically referred to services. Well, one is, Where can I turn for services and what does the future hold? And then we noted the aspirational goals that go along with those, too.

Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for preventing the disabilities associated with ASD, and communities will implement high quality evidence-based and cost-effective services and supports across the life span for people with ASD. Those are the two aspirational goals that go with those latter chapters.

We looked at the core values that overlay the Strategic Plan and the cross-cutting themes, which I'm sure by now we're all very familiar with, and then we put in

President Obama and Vice President Biden's four-part plan that's been posted on the WhiteHouse.gov website that talks about their plan for people with disabilities.

The latter part of that plan specifically refers to a category called autism, and I think it's important to note that a lot of these goals are specifically directed at services and supports, so we thought that would be a nice addition to this, you know, first, really, first basic draft.

Then we have a historical piece, you know, on the roadmap where we do talk about the fact that it was built around the performance measures that are included in the New Freedom Initiative, which of course is built around the Olmstead Decision, which I'm pretty sure everybody's familiar with by now.

We just weren't sure if these six categories were what we should be using as the basis for these recommendations, but we did feel like it's really important to, you know,

at least mention the New Freedom Initiative and Olmstead, because, you know, these programs and the Olmstead Decision are still driving a lot of activities in this country regarding keeping people in and helping people stay in home- and community-based settings.

The other thing that we included in this document was something that Ronald McPherson liked, which was a little model that talked about how important it is that people with ASD have access to all community services, community services for people with disabilities, and community services that are aimed at people with Autism Spectrum Disorders.

Then we talked a little bit about the ASD, and just for you guys, we put in these mock-up charts of what we talked about earlier. We called them, we called the first six Emergent Priorities, or excuse me, we called them Priority Categories.

Then we had Emergent Priorities,

and then the latter ones we called Other Categories of Interest, and after that we kind of went, okay, you know, we've got these what are now, I think, 17 areas of concern or interest that were identified by the public, and in the previous roadmap we had identified areas, and then each had attached to it a goal, a challenge, you know, and then a list of the challenges associated with that goal, and then what our recommendation is.

So in this draft document that you see today, we just took the top six categories, and Lee suggested maybe putting one goal, you know, one recommendation, with each of the top six categories, and we don't know if that's the way to go or not, so that's where we're really interested in getting some feedback from the committee, you know, and also in terms of whether or not, you know, we should definitely issue a second RFI to, you know, try to focus us a little better. So I think that's where most of the discussion

should go today. Lee, can you add anything to that?

Mr. Grossman: No, I think that was a very good synopsis. We really do want feedback from the Committee, Subcommittee, because this is really where the rubber meets the road.

This is what we believe is our primary responsibility, to make recommendations to the full IACC, and here's our opportunity to come forward with a document that's very meaningful around the information that we've received to date, and try to build this out in very strong recommendations that would go to the Secretary.

And I just sent out that GAO report to some of you, and I didn't have the full Subcommittee email address, so if somebody could get that to everybody else, that would be -- that would be great.

Ms. Singer: I think one thing that

was very useful when we did the Strategic Plan for research was really trying to work within the structure of what do we know, what do we need, and what are the specific objectives, and I think using that framework, we didn't feel that we had to be locked into the same number of specific objectives for each category, because we were treating -- we were addressing each category through the what do we know, what do we need?

But not every category is going to have the same number of goals or objectives, and I think you sort of pigeon-hole yourself when you say, well, we're going to try to distill it down to one. I think there's another way to do that, and did you guys think at all about using the framework of, what do we know, what do we need, and what are the specific objectives, and trying to look at that framework so that it would mirror, in some way, the research plan?

I'm just -- I keep coming back to

this, because I think it's really critical. Even though the law does not specific require a Services and Supports Strategic Plan the way it does a Research Strategic Plan, there's nothing in the law that precludes that, from doing a document that has the same weight and heft.

Ms. Blackwell: I don't disagree with you, Alison. In fact, that's why I brought the Strategic Plan into this first draft, because, you know, we spent, as we all know, hours and hours and days on that plan, and I think it's really good, and has a really good framework.

So you know, I do think it's a great idea to try to link the work we did in the Strategic Plan with this other document, you know, so that is a very good suggestion, and I agree with you that I don't want to be limited in terms of, you know, where we go with this.

I do think it should be something

that we can accomplish, and I think that's one of the problems with the roadmap, that there's a lot of stuff in there, and what can we really accomplish? And when we make recommendations, they should be things that are realistic. Does that make -- you know?

Ms. Singer: And they should be expressed in ways that are measurable --

Ms. Blackwell: Yes.

Ms. Singer: -- so that two years from now, we can come back, and we can do an update, and we can look at our progress the way we're going to do with the Strategic Plan.

I mean, I would almost like us to impose the same requirements on this document that are on the research plan, in that it has to be measurable, and there has to be accountability, and it has to be annually updated, and I don't see anything in the law that prevents us from taking that on.

Mr. Grossman: And you're absolutely correct, and I'm glad that you're

speaking out on that, as well. That is absolutely the way that we've interpreted it. If it's something that the full committee agrees to, then yes, we can give similar weight to the other activities of the IACC, and I certainly have a strong bias in that direction that that is something that we try to achieve.

Ms. Blackwell: So I think it would be good, Alison, to incorporate that sort of feedback into the way the RFI is written, as well, you know, so that we -- you know, people -- I think we need to think about it more, but it would be -- you know, we'd have to -- I don't know. We need to think about it more.

Ms. McKee: I think if we were going to sit down and draft up specific goals, and I absolutely agree with what everyone has said - this is Christine - that we present that in the RFI, as well.

As I talk to parents about the RFI and why they weren't responding to it, they

questioned what we were doing with the information, exactly what Alison said, you know, what is this going to change? And I'd talk about the roadmap and its lofty goals, but they want to see, you know, it on the ground. How is this going to change the education of my child?

That's who I hang out with, people who have school-aged children. You know, how is this going to improve the training and the programs? How is this going to help them see that we need to make progress with these children, you know, not leave them at the levels they're currently at, you know, really force them to start to make progress and measure that progress?

So I think taking the roadmap of, you know, overall lofty goals, but then sit down and specifically, what can we do? What can we do in a year? How can we start getting some actual research programs going on services and supports that are narrowly

tailored to start to make baby steps into providing and improving the supports and services available to people? So did any of that make sense?

Ms. Blackwell: Yes.

Ms. McKee: It was kind of rambling, but I'm on board with going full-out with a what do we know, what do we need type of program, and setting this up for services and supports, absolutely.

Mr. Grossman: Well, I -- can we throw this back to the staff, then, to see what is it that we need to do to start really making this a more robust and meaningful document?

Dr. Daniels: So you need to make a decision on how you're going to proceed and vote on what your steps are going to be, and then once you have a document in place, you can take it to the full IACC and get their approval.

Mr. Grossman: Okay. Well I guess

my -- I think there's a few more steps in between there, because for us to be able to really put together a meaningful document is going to require bringing in other folks, and a series of meetings and numerous activities before it's at the point that I think that it would be really there for the full IACC to truly consider what it is that we're proposing. Are there suggestions on how we go about doing that?

Ms. Blackwell: Well Lee, I think you can probably -- I wasn't really involved in the previous Services Subcommittee, but I think Lee can attest to the fact that at one point, the Subcommittee convened an expert working group, you know, sort of like what we do with the Strategic Plan, and brought in folks to, you know, help us figure out where we should be going, so I guess that's one thing that we could do, and we'd have to think about ways that we could solicit expert input.

You know, I know that cost is a

concern. I mean, we have a limited amount of administrative dollars available from NIMH to do this work, so we'd have to be all thinking about ways to do this that are cost effective. I'm sure you would support that, Susan.

Dr. Daniels: Yes, and this summer -- the Planning Subcommittee hasn't met yet, but there is a possibility that the full IACC will be having a series of conference days that will be devoted to certain chapters, or to all of the chapters of the Strategic Plan, and services and supports is a part of the Strategic Plan, so you may be able to take advantage of some of that activity to feed into your activity.

Ms. Singer: When are we doing that?

Dr. Daniels: The Planning Subcommittee meeting has not been set yet, but it's in the process of being set up for March 17, and so I know some of you are on that subcommittee, which was formed at the last

IACC meeting on February 4.

Ms. Blackwell: That's the Strategic Planning Subcommittee, in case anyone is confused. We have two subcommittees, this subcommittee and then the Strategic Planning Subcommittee.

So what Susan is proposing is a potential opportunity to, when we convene over the update to the Strategic Plan, since two of the chapters are devoted to services, maybe bringing in some experts to talk with us about, you know, where we are with the development of those documents, you know, when we get together over the summer for a day, or a half a day, or whatever period of time is allotted to services.

Dr. Daniels: Right, so that's one possibility, and it really depends on the decisions of the Strategic Planning Subcommittee as to how that will be structured, but it might be an opportunity to get more work done through one meeting.

Ms. Blackwell: And there are electronic opportunities, you know, to solicit comment, as well. I mean, I don't know, I guess, Lee, you and I would have to think a little bit more about how we would do that.

Dr. Daniels: Certainly webinars are quite cost-effective. If we had a speaker or a number of speakers that have slide presentations that could be up on the webinar that could speak through webinar, that would also be a cost-effective way to get information, and then you all could deliberate on that information after the presentations were done.

Ms. Blackwell: Lee, when you had the expert working group, how did that work? What happened? How did people get together?

Mr. Grossman: Well, there was -- we -- about 25 experts from around the country in many, many different services, disciplines, and SAMHSA and HRSA took the lead on pulling it together, but we had also CMS and

Department of Education there, and we had a day, two-day -- a two-day very, very hardworking two-day seminar, and then we met again for another -- I think it was a day and a half, and much of the work, I think, was done by HRSA and SAMHSA, though, on the sidelines in terms of the writing.

And they had -- one of the important aspects of it, they brought in an independent person who coordinated all the activities. It was Beth Roy.

I don't know if people know Beth Roy, but she's with a private agency in this area that had a contract with NIH, as well as others, other agencies to do -- to coordinate strategic planning efforts, so she was very important in it, but it was very good. I don't know if Cathy Rice was -- were you involved in that?

Dr. Rice: Yes, I was, and I think you pretty much described what happened, and I think what really helped it go forward was

the coordination of Beth Roy to really pull it together, and that she did do a lot of the writing, as well, I think.

And at that meeting, too, I mean, it was real structured in terms of taking the heading areas and coming up with the specific kind of, let's get into more details about what objectives we're talking about into the primary topic areas that are being developed, so you know, somewhat like how the -- I'm mixing up the -- were they workgroups or workshops, but when the expert groups were convened for the IACC research plan last year of, you know, splitting people out into different topic areas, and having people while they're there, present, actually write out the objectives, and then coming back to the group to clarify them, clean them up, and then from there have the list of objectives by each topic area that then went out for the public comment. I think for the last service round, I don't remember that the public comment was

such a big part of it. It was just more of the working group process.

Ms. Singer: I thought that worked very well, that process for the research plan. They were long, hard days, but at the end of the day, we came away with real product.

Dr. Rice: Yes, I agree.

Ms. Blackwell: So we're on the right track with an updated document, and we need more help, and I'm just trying to think. We need to think about how this RFI, if we issue one, would be structured, or if we do issue an RFI, should we issue it after we convene these experts, potentially in the summer, or before?

Dr. Rice: I mean, I would vote after, because I kind of feel like there's some fatigue that happens if we just keep asking for these general comments without a real specific objective, and that gives people something to react to and us to actually, you know, refine the objectives that are put

together, and you know, and then if the public comment shows that there are areas that are just not addressed in what the workgroups came up with, then that's important, too, but it gives them more, something more specific to respond to.

Ms. Singer: I think that -- I think that, again, paralleling the process for the research plan, we did the RFI. Then the RFI informed the workshops, and then we didn't do another RFI until after we had a draft, so the people were actually responding to a document that wasn't as open ended.

Ms. Blackwell: Yes, I agree. That's why we took a run at something, but we just weren't exactly sure what -- you know, we had the bones here, but we didn't -- we really needed to get input from you guys.

Ms. Singer: I think it was a lot for you to take on, also, and I think if the document is based on input from multiple stakeholders who participated in a day-long

workshop, I think it'll be -- it'll be more reflective of broader opinions, and you'll get more diversity of commenting when you put out an RFI.

Ms. Blackwell: Well, and also if we make more of an effort to structure it congruent with the Strategic Plan. You know, it won't look the way it looks today, so --

Ms. Singer: It would also be good if there was some way for it to link back specifically to the chapter in the Strategic Plan that focuses on services and supports so that, you know, the IACC looked as if it were coordinated with regard to the need, not only to have more research with regard to services and supports, but also to then translate that research via this new document into practical services that people can --

Ms. Blackwell: Well, and I think it's also important to link it to the Administration's statement on autism. I mean, this is what we have now, so if we, you know,

if we know that this is the way the Administration is moving, that we should try to, you know, keep it on that footing, as well.

Mr. Grossman: Right, and I think that that's a very critical part to this, and because of -- there is a lot of efforts going on in the disability community right now to look at different systems, and how to change them, and various models. We're involved in a number of coalitions with other disability organizations that have active discussions going on around that, and then there's other national professional organizations that are doing the same.

So I think that, you know, letting this sit for a little bit and having us chew on this for the next few weeks won't be -- really won't be delaying this. I think it'll be much more fleshed out during that period, so that we'll have more direction, particularly from the Administration, or those

that are talking to them, in how we can proceed, and I'd rather have that type of guidance and advice before we go off willy-nilly doing what we think would be right and then find out, perhaps, that it's the wrong approach.

Ms. Blackwell: Well, you know, as you all know, we don't have a Secretary of Health and Human Services right now, and the IACC is, with the exception of the Department of Education, primarily composed of HHS agencies, so you know, there's a little bit of a leadership void right now that hopefully will be filled soon, but you know, as Lee pointed out, it might be nice to just sort of sit on this until we get a little more direction or information.

Dr. Rice: Well, another way of looking at it is that, if we have something ready and specific, we might be able to help the direction that is then given out.

Ms. Blackwell: That's true, Cathy.

Well, I mean, and we do have something. I mean, we have the statement that talks about public awareness for supports and services, the improvement of lifelong services, for treatments, intervention, and services. It mentions adults.

We have a discussion about improving federal and state programs for ASD. We have a specific reference to universal screening at age two, and then we have, you know, a statement that says, disabilities will be identified early enough for children and families to get the services and supports that they need.

So there is this really large focus not just on autism but clearly on screening and then services and supports, and that, to me, that speaks to a direction, so I don't disagree with you that it would be really nice to get moving and have something, you know, ready, especially when the Secretary does come to work.

Dr. Rice: Right.

Ms. Blackwell: And that was the reason, one reason, at least, why we felt there was a need to, you know, definitely get our Strategic Plan on the ground. So, you know, possibly the same principles could drive these recommendations.

Dr. Rice: Right, so it seems like kind of the idea that was thrown out before about going forward with, you know, trying to assemble the work groups to get real specific objectives in that framework that Alison mentioned, what do we know. What do we need to know, and specific objectives and then having that laid out for public response, you know, seems like that would be informative to --

We're not going to come up with anything so off-the-chart that whatever the new HHS Secretary is wanting to do, that these are just going to be just totally off the mark. They could be informative, and

hopefully we could inform that process as to what's needed, because we've had this multiple-format way of soliciting this feedback and getting expert and consumer input.

Ms. Blackwell: So, Susan, do we have a date possibly, you know, at least a month or mid-month for this meeting in mind?

Dr. Daniels: Sorry, I was looking at my email on my Blackberry. What was your question?

Ms. Blackwell: Do we know -- I mean, I know that you mentioned the Strategic Planning Subcommittee needs to meet, but do we have a general idea of when this meeting might take place, in what month or what time of that month?

Dr. Daniels: We are working on trying to get a date. It's mainly around trying to get a date that's going to work for people that need to be there, and so we were working around Dr. Insel's calendar first, and

we're also doing, you know, trying to put together some ideas for this meeting, and then March 17 is the date that we're looking at, but it hasn't been announced.

Ms. Blackwell: Well, this is for the Strategic Planning Subcommittee. I mean, I think you were talking about the meeting in the summer where the Subcommittee has more in-depth input.

Dr. Daniels: Right. That's all going to be discussed at the March 17 meeting. I guess it's a little bit preliminary that I'm giving you --

Ms. Blackwell: Okay, so some time this summer. I'm just trying to think ahead, so what we might want to be thinking about is --

Dr. Daniels: They may not decide to do that. That was one of the proposals of ways that they might be able to update the plan. They might decide not to do that at all.

Ms. Blackwell: Well, I think that one thing that we Subcommittee members might want to do is to, perhaps, submit or be thinking about the names of people that we would like to participate, at least give us input in whatever format it comes. You know, we should be thinking of who could be helpful to us in terms of, you know, further refining these recommendations.

I mean, there was a group of people that worked on the roadmap. They're listed on the roadmap. I don't know if those are the right people. I can certainly think of some others that would be very helpful to us, but should we each, you know, try to come up with the names of at least two people who we think we'd like to solicit in terms of their input?

Dr. Daniels: I think that that would be a good idea, because it may be used for the strategic planning meeting, or if you end up deciding to have a separate meeting of

your own, you could use the names for that, so I don't think it would hurt you either way to come up with a list of the people that you would like input from.

Ms. Blackwell: Okay. So could everybody be thinking of -- I mean, I don't know. Lee, how many people do you think we should each -- I'm sure there will be some overlap, but should we each come up with the names of at least two people that we think could be helpful in this effort?

Mr. Grossman: I would say two to three. I mean, I can come up with dozens, but --

Dr. Shore: Yes, me, too.

Ms. Blackwell: Okay.

Mr. Grossman: Well, Stephen, you would be on my list.

Ms. Blackwell: Well, Stephen is already on the Committee, so we're not counting him.

Mr. Grossman: Okay, so I think,

you know, two to three is realistic, and --

Ms. Blackwell: Okay. So that's a job for Subcommittee members, to be thinking about who could help us inform these efforts, and, Lee, maybe a job for us is that we need to, you know, refine this document, go back to what we presented to the Subcommittee today, and then take their comments in mind and try to make it look a little bit more -- a little bit more congruent with the Strategic Plan.

Dr. Daniels: Ellen, would it make -- this is Susan. Would it make sense for you all to come up with a plan for how you would like to go about producing your new document, what type of RFI or meeting or whatever that you want to have, and present that at May 4, and that would give you time in between?

During that period, the Strategic Planning Subcommittee will meet, and they'll come up with a plan of how they're going to do their work, and maybe you could put it all together before May 4 and then present it on

May 4 to the full Committee for their approval.

Ms. Blackwell: Okay. Lee, could you -- I'm just trying to think of how this would work, Susan. We need a master plan. Yes, that's a good idea. That could certainly be something that we would present on May 4. I mean, we were planning to make a presentation to the full Committee anyway on our activities, but, you know, I do think we need to take a stab at least getting this document to look a little bit more like what we talked about today.

Dr. Daniels: Right, and if you had a time line for when -- if you decide that you want to convene your own meeting or if you want to piggyback on other activities in the summer, if by the time -- I know that you're on the Strategic Planning Subcommittee, and Alison and some others may also be on that Subcommittee, that you could all coordinate and decide which activities you might be able

to do in common and which things would have to be separate and come up with a time line for what's going to suit this document and present it on May 4.

Ms. Blackwell: Well --

Ms. Singer: It would be great for us to have a joint meeting of the two Subcommittees with regard to the session and Strategic Plan on services and supports.

Ms. Blackwell: That's not a bad idea, Alison, if we're going to be there, anyway, I mean.

Dr. Daniels: If you have a joint subcommittee meeting, though, you would be -- that would basically be a full committee meeting, because you'd be over quorum.

Ms. Blackwell: What if we do it at a different time or day and we're meeting separately, Susan? We're not -- we're not together in the room as a -- I mean, we reconvene as the Services Subcommittee.

Dr. Daniels: But you're talking

about having a joint --

Ms. Blackwell: No, I think -- I mean, I don't know if -- Alison may have misspoke, and don't let me -- I'm just -- I'm saying we could meet at the same time as the Strategic Planning Subcommittee but as the Services Subcommittee.

Dr. Daniels: In person?

Ms. Blackwell: Well, if we're going -- I think Alison is saying if we're going to be there together anyway, why not try to do both during the same time period.

Dr. Daniels: Back-to-back?

Ms. Blackwell: Yes.

Dr. Daniels: So if the Planning Subcommittee meeting is a half a day, then have the other half day be Services Subcommittee meeting?

Ms. Blackwell: Yes. Is that what you meant, Alison?

Ms. Singer: No. I was actually suggesting that the Strategic Planning

Subcommittee and the Services Subcommittee hold a joint meeting to talk about the services and supports section of the Strategic Plan and the Services Strategic Plan.

Ms. Blackwell: I think the problem with that that Susan is trying to express is if there are too many of us in the room -- and this is a FACA rule, okay -- we become the IACC. Is that right, Susan?

Dr. Daniels: Right, so, I mean, you might as well, if you want to do that, just have your Subcommittee come to the full IACC and present at that meeting, and you've got a -- you've got May 4 and July 29 that are coming up that are currently scheduled for full IACC meetings.

Ms. Blackwell: I like Alison's idea of using the March meeting to have a back-to-back. I mean, I don't see any reason why we can't convene as a Services Subcommittee meeting if we're all getting together anyway separately from the other

subcommittee. Does that -- Lee, am I making sense here?

Mr. Grossman: I think so.

Ms. Blackwell: We can only convene as one or the other, and if there are too many of us -- I forget how many it is. It might be eight.

Dr. Daniels: Right, but you also have a March 26 meeting, so you have -- you'd want to meet on March 17 and then again on March 26?

Ms. Blackwell: Well, we do have a March 26 meeting, but I think the bulk of it is going to be taken up by the Department of Defense. However, we do have some flexibility in time, so we might be able to do both. That's a good point.

Mr. Grossman: And I can't be there on the 17th, not that that should be a big consideration, but --

Dr. Daniels: And that is not set in stone at all yet. We're still in the

planning stages. I only said something about it because it seems like these two activities are going to coincide in some way, and so I thought it would be useful to mention it, but it hasn't been planned yet. If it turns out that the Subcommittee members can't meet on that date, then it'll have to be a different date, and we'll have to keep looking on the calendars to see what we can find.

Ms. Blackwell: Well, I think your suggestion is good, Susan. We already have a block of time, a pretty big block of time in Washington on the 26th, so maybe what we could try to do is have a meeting to talk about this, you know, the time line and our plan when we're face-to-face in Washington on March 26 and also listen to Captain DeMartino.

Dr. Daniels: So you have five -- five hours? Four hours.

Ms. Blackwell: I think that sounds doable. Do folks agree with that? And we've had that on the calendar for a while, so it

should be clear.

Mr. Grossman: Sounds good to me.

Ms. Blackwell: Okay.

Dr. Daniels: From 12:00 to 5:00, and we've got the building booked from 12:00 to 5:00. You could have all of that time if you need that much to discuss this.

Ms. Blackwell: Okay, and we haven't discussed the time with Captain DeMartino, but my inclination is to believe that he'll be at the end of the meeting, so that might work out really well. We could start out with this discussion and then, you know, have him come nearer the end of the day.

Dr. Daniels: Okay. That should work, and in the meantime, if the Strategic Planning Subcommittee is able to meet on March 17, then you will have that input from those of you who are on that committee. If it doesn't meet that date, then, you know, that will be the way it is.

Ms. Blackwell: Okay. I have to --

I mean, I know, Susan, they're always at the top of your mind, but we can't meet as the Services Subcommittee. If there are more than two of us, it's a meeting, and we have to publish notice in the Federal Register, so the day that we meet as the Strategic Plan Subcommittee, we are the Strategic Plan Subcommittee.

Dr. Daniels: Right.

Ms. Blackwell: Right.

Dr. Daniels: Right.

Ms. Blackwell: So, now, Lee and I can talk any time, because there are only two of us, so I don't see any reason why we can't, you know, take this first run and start talking about maybe how to make it more in concert with the Strategic Plan. I think that's something we should all be thinking about, actually, and suggestions are welcome, you know, because I did certainly take it in at the top of my mind, when I just took a run at this draft, you know, because the roadmap

just seemed like it was a little bit outdated, and I wanted to play off things that the larger committee had done more recently.

Dr. Daniels: Right, and in between, if you needed teleconferences, that's very easy to set up. You could have a telephone call to talk about things but circulate documents by email.

Ms. Blackwell: Okay.

Dr. Daniels: Have a phone call.

Ms. Blackwell: Okay. Can more of us, more than two of us talk on a phone call, Susan?

Dr. Daniels: I believe so. You could get a call-in number.

Ms. Blackwell: Right.

Dr. Daniels: It would have to be public, and we would have to have adequate notice to put it in the Federal Register, but we could organize teleconferences.

Ms. Blackwell: Okay. Okay. So sort of let me sum up what I think we're

getting today, which is we want to take this recommendations document and, you know, try to -- Lee and I will try to bring it a little bit more in line with the Strategic Plan, and then we will meet on the 26th in Washington.

I mean, perhaps before then, we'll be able to send the Subcommittee something else to look at, and we will all be submitting the names of two or three folks that we, you know, think might be people who could help us in terms of refocusing and shining up this document even more, and then when we get together on the 26th we'll talk about that, and so Lee and I in the meantime will try to develop a little bit of a time line.

You know, we'll start thinking about the time line for the May 4 meeting, as well, and then we know that we'll be meeting sometime around March 17. Several of us will be seeing each other at the Strategic Planning Subcommittee. Does that sound right?

Dr. Daniels: With the Strategic

Planning Subcommittee, it also might end up being a webinar, if we end up not being able to do it as face-to-face. The preference is to do face-to-face if possible, but it may not be possible.

Ms. Blackwell: Okay. Have I missed anything? And you guys will circulate the GAO report that Lee sent.

Mr. Grossman: They already did.

Ms. Blackwell: Okay.

Dr. Schwechter: Ellen?

Ms. Blackwell: Yes?

Dr. Schwechter: The GAO report is also available on the IACC website, as well, under the Subcommittee page.

Ms. Blackwell: Oh, great. Okay, thank you, Azik. That was quick work. And then I think another thing we need to talk about today is, you know, we know we have the March meeting, but we don't have any other meetings planned, so we need to -- because, as Susan has mentioned, we need a published

notice in the Federal Register every time we get together, we need to talk about when we're going to meet after March and when -- Susan, could you remind us when the full IACC meets? I know we meet in May and July.

Dr. Daniels: May and July.

Ms. Blackwell: May and July, okay.

Dr. Daniels: October 23.

Ms. Blackwell: November, okay.

Dr. Daniels: So it's May 4, July 29, October 23.

Ms. Blackwell: November 23?

Dr. Daniels: October 23.

Ms. Blackwell: October 23. I'm sorry. I couldn't hear you.

Dr. Daniels: And with the July 29 meeting, that's on the calendar right now, although the full Committee could elect not to have that meeting if they decide that there is too much stuff going on in the summer, because there may be other meetings planned over the summer, so that's up to them, but that's on

the calendar right now.

Mr. Grossman: I'll be out of the country.

Ms. Singer: The whole summer? Mr.

Grossman: The 29th of July. Ms.

Blackwell: Another thing that Lee and I talked about that I know Lee plans to raise this at the larger meeting in May is that we have talked about this at the full IACC before is the town hall meeting issue, and Lee has offered several times to hold a town hall meeting to solicit public comment during his annual meeting, which happens to be outside Chicago in, I think, the beginning of July, the middle of July, Lee?

Mr. Grossman: Actually, it's the 20th, the week of the 20th, 22nd to the 25th of July.

Ms. Blackwell: Okay.

Mr. Grossman: Which is why I've got to get out of the country after that conference.

Ms. Blackwell: Well, there is an opportunity, I mean, Lee, you know, to talk -- to convene a town hall meeting.

Mr. Grossman: There's a number of opportunities. ASA and Easter Seals are having 30 town hall meetings around the country devoted to discussions of life span services and quality of life issues, and so those are ongoing. Those are being scheduled, so those are opportunities to dovetail that with any activities that the IACC Services Subcommittee might want to do in terms of a town hall meeting.

We always have town hall meetings of some nature at our conference, which is in July, and that's a very large venue. There's, you know, potentially 2,000 people that would be there, not to say that all of them would be in a town hall meeting, but certainly, since the main thrust of our conference is around services and supports, it probably would be one of the most -- or certainly the greatest

venue to get input.

Sixty percent of our participants are professionals or our attendees are professionals, so you're not only going to be hearing it from families, but you're going to be hearing it from the actual people that are delivering the services.

I'm just throwing that out because, I mean, these things are already being scheduled, and it's easy to just put them in there, and it's of relatively little expense to the IACC, since the venues are already being -- are already being expensed by others.

Ms. Blackwell: Well, Lee had brought it up as an opportunity for either the Services Subcommittee to have a town hall meeting or, Lee, again, I don't want to speak for you, but I think you were going to take it up with the full IACC at the May meeting and make that offer, as well, so, you know, I just wanted to raise that there is an opportunity

for either the full IACC to -- and that doesn't mean the full members, because, as I said earlier, more than two of us, it's a meeting, so, you know, in July there is this opportunity for the Services Subcommittee to have a town hall meeting or for the IACC to have a town hall meeting.

Mr. Grossman: Right.

Dr. Daniels: Right, and so if the Services -- this is Susan. If the Services Subcommittee decides that they want to propose that to the full IACC, I would recommend bringing that to them on May 4 or, if needed, before, by email and asking them for their approval to host something, but you might want to have an idea of what you're hoping to get out of that if you're hoping to actually record some of that information in some way and structure it and how that works with your RFI.

Is the town hall meeting there to collect information for the report, and if so,

how are you going to do that and get the information together and get it into the same format as what you get from the RFI, and do you need both?

Ms. Blackwell: Yes. Okay, so that's another item that we -- that I know Lee wanted to bring up.

Mr. Grossman: Right, and I think you brought up some good points. We need to have some objectives out of that, and that's something Ellen and I can think through a little bit more, and we'll have that at the March 26 meeting to discuss.

Dr. Daniels: Sounds good.

Ms. Blackwell: Okay. Is there anything that we've forgotten to talk about today or any other issues? I think it's always good to go around and have folks talk a little bit about their agency activities, and I know we didn't do that earlier, but we have a little bit of time. So is there anything that's at the top of anybody's -- I

mean, should we kind of go around and say what's going on at our agencies, the agency folks? I don't hear anybody piping up.

Here at CMS, we have a -- we have a task order that's focused on autism for which I am the project officer, and it's actually very exciting. It's pretty much underway.

We don't have a report from our contractor yet, but the contractor is looking at the strength of the evidence behind services and supports for people with Autism Spectrum Disorders, and they're doing a really great job so far. They're very excited.

David Mandell has the children and youth piece of it, and Brenda Miles from the University of Kansas has the adult piece, and so I'll be very interested to hear a little bit about the work the Defense Department is doing in the area of early intervention services and how that fits in with the work we're doing here on a little bit broader

level. So that's CMS in a nutshell. We're very busy right now.

As you all heard me say earlier, you know, this fiscal climate has had a dramatic impact on states. We're not quite sure how the American -- how the stimulus package will play out in each of our states since the law was just recently passed, and all of us are working very hard on that, and our state is trying to react, and we also -- you know, the President signed into law -- in fact, it was the day of our last IACC meeting -- the SCHIP Bill, the Children's Health Insurance Program Bill, so we've been handed a very -- another very large piece of legislation to implement over here, and we are very busy. So that's CMS.

Dr. Rice: Okay. Well, I'll speak for CDC. In terms of ongoing activities that are not as relevant for this committee but just are continuing on are efforts in terms of monitoring and characterizing the population

of children affected with autism, as well as our case cohort study we have looking at potential risk factors for autism in young children. So those are ongoing.

Our primary prevention activity is more in terms of improving early identification with the Learn the Signs, Act Early Program, and there are multiple not necessarily town hall meetings, but they're more of trying to coordinate service providers around different regions of the country, so we have these ongoing Act Early summits happening to try to get existing service providers to coordinate better in terms of early identification and service provision.

If anyone is interested in those, you can find announcements for those meetings at the AUCD website, the Association for University Centers for Disability, so the AUCD website has information about those Act Early summits, and similar to what Ellen said, certainly we are in the midst of budget issues

like any government and private agency these days, but standing by to try to react to and put input into any stimulus funding that might be able to get filtered out to states and programs doing research in autism. So that's where we are with CDC right now.

Ms. Blackwell: Larke, are you still on the line? We might have lost Larke. Is there anybody else who'd like to kind of give an update, or are we done?

Dr. Johnson: This is Jennifer Johnson with ADD and ACF.

Ms. Blackwell: Hey, Jennifer. Welcome to your first Services Subcommittee meeting.

Dr. Johnson: Thank you. We don't have anything necessarily specific to Autism Spectrum Disorders, but as many of you know, we are a recipient of significant funds under the ARRA, and so we are working within ACF to suggest topical areas for grants that they may be funding, and so we are trying to

incorporate issues related to Autism Spectrum Disorders and services for such individuals within the funding areas. So we'll see what happens. It's all quickly evolving as we speak, so that's where we are with that.

Ms. Blackwell: Okay. Lee, do you have anything else to add?

Mr. Grossman: Nothing right now. Just thank everyone for their participation on the call. Thank you, Ellen, again for the amazing work you did with reviewing all the comments on the RFI. I still remain amazed that you were able to do that.

Ms. Blackwell: Well, a member of Lee's staff, Margi Colson, was kind enough to help us make the graphs that you see in that draft document today, so I should also thank Margi for doing that.

All right. Well, listen, folks can always send us emails and comments, and we are happy to get them, so if you have any additional comments about these draft

documents, please feel free to send them to us. You know, we really appreciate your input, and we feel like, today, I think we got some direction about where we need to go, so that's great. Thank you.

Dr. Daniels: Oh, and with members of the public, if they have any comments on any of those documents which are under the meeting materials for the Services Subcommittee meeting today, if they have any comments they can send them to IACC Public Inquiries at IACCPublicInquiries@mail.nih.gov.

Ms. Blackwell: Okay. Thank you. All right. Everybody have a great day.

(Whereupon, the foregoing matter was concluded at 10:29 a.m.)