U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE

MONDAY, NOVEMBER 29, 2010

The Subcommittee convened via teleconference at 2:00 p.m., Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

PARTICIPANTS:

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

LEE GROSSMAN, *Co-Chair*, Autism Society

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

HENRY CLAYPOOL, Health and Human Services (HHS) Office on Disability

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

JENNIFER JOHNSON, Ed.D., Administration for Children and Families (ACF) (representing Sharon Lewis)

CHRISTINE McKEE, J.D.

PARTICIPANTS (continued):

DENISE RESNIK, Southwest Autism Research and Resource Center (SARRC)

CATHY RICE, Ph.D., Centers for Disease Control and Prevention (CDC) (representing Coleen Boyle, Ph.D.)

STEPHEN SHORE, Ed.D., Autism Spectrum Consulting

BONNIE STRICKLAND, Ph.D, Health Resources and Services Administration (HRSA)(representing Peter van Dyck, M.D., M.P.H.)

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PROCEEDINGS

(2:07 p.m.)

Dr. Daniels: Thank you.

This is Dr. Susan Daniels, Deputy Director of the Office of Autism Research Coordination at NIH. And I'd like to welcome the IACC Services Subcommittee members and remote listeners to this conference call of the IACC Services Subcommittee.

I hope that many of you were able to join us for the informative and stimulating IACC Services Workshop that took place here in the Bethesda area on November 8, 2010.

And I'd like to thank Ellen Blackwell and Lee Grossman, Co-Chairs of the Subcommittee, as well as the rest of the IACC Services Subcommittee for all the hard work they put into making this workshop a success.

For our remote listeners, the slides and videocast from the workshop are posted on the IACC website for anyone who is interested.

And the main topic of today's phone call will be to discuss recommendations stemming from that workshop that the IACC wishes to share with the Secretary of Health and Human Services.

The materials for this call are posted on the IACC website for our remote listeners' access.

And then, I'd like to begin with a roll call before turning the call over to Lee and Ellen. So, Ellen Blackwell, are you here?

Ms. Blackwell: Here.

Dr. Daniels: Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Henry Claypool?

Mr. Claypool: Yes.

Ms. Blackwell: Gail Houle?

Dr. Houle: Yes.

Dr. Daniels: Larke Huang? Maybe not yet, or not right now.

Jennifer Johnson?

Dr. Johnson: Here.

Dr. Daniels: Christine McKee? Not right now.

Ari Ne'eman is not going to be able to join us.

Denise Resnik?

Ms. Resnik: Here.

Dr. Daniels: Cathy Rice?

Dr. Rice: Here.

Dr. Daniels: And I believe Stephen Shore is not going to be able to join us. Stephen, are you here?

Dr. Shore: Yes, I was actually was able to make it.

Dr. Daniels: Oh, wow, great, Stephen. Okay. So Stephen is here.

And then, Bonnie Strickland?

Dr. Strickland: Here.

Dr. Daniels: Here. Wonderful.

So with that, I'd like to turn the call over to Ellen and Lee.

Ms. Blackwell: Okay. Thanks, everyone, This is Ellen. I'm so glad we have

such a good crowd participating today.

As Susan mentioned, this is the second IACC Subcommittee today. There was an meeting this morning on safety. So this afternoon, as Susan mentioned, we'd like to talk for a little bit about what transpired at the November 8th meeting, where we talked about a variety of issues that touch on services.

One of the first items of business we have to dispense with today is the approval of two sets of minutes; one from the August 10, 2010 Services Subcommittee Meeting Teleconference, the other from the September 13, 2010 Services Subcommittee Teleconference.

So, if someone would like to move that we -- hopefully, you've all had a chance to review these minutes. Lee and I did both look at them, and we think they look okay. So if there's no objection -- I mean, Susan, do we need to actually vote on these minutes?

Dr. Daniels: Yes. Please go ahead

and vote.

Ms. Blackwell: Can someone make a motion to approve the minutes?

Dr. Shore: I'll second that motion.

Stephen Shore.

Ms. Blackwell: Are you okay with that, Susan?

Dr. Daniels: Yes. So no objections, everyone is in favor?

Ms. Blackwell: Yes.

Dr. Daniels: So then both sets of the minutes are approved.

Ms. Blackwell: Okay. Great.

So Lee and I have had several opportunities to talk following the meeting. But, Lee, I was thinking that it might be good should we solicit folks' reaction to what happened on November 8th or should we just start digging deep into what we think we want to recommend to the Secretary?

Mr. Grossman: Well, I think it's

probably best to have people share their thoughts, their opinion, their comments on the day. Because we haven't had a chance as a group, as a Subcommittee, to meet to discuss this at all.

So, I wouldn't mind opening up the floor for people who want to comment on what they heard, what they found was significant, and any other comments that they might have.

Ms. Blackwell: Okay. Great.

Mr. Grossman: Anybody want to go first?

Well, if nobody wants to share, then we can go right into the recommendation.

Ms. Resnik: Okay. This is Denise Resnik.

Before we go into the recommendations, can again we talk about process in terms of how we are going to be evaluating the recommendations that are included from the workshop and how we're going to prioritize those, and whether any

additional study is going to be conducted on their impact?

Ms. Blackwell: Denise, this is Ellen.

I think maybe just to back up a little bit. I know some folks have been on this Subcommittee a little bit longer can maybe attached to previous discussions where we have talked about constructing a set or sets of recommendation to Secretary Sebelius that would be focused on services reforms that could be, for the most part I believe, implemented within programs that are under her purview such as, for example, the Medicaid program and perhaps some other agencies that provide services to people with autism.

So, we really haven't discussed a process for developing them, other than we had a set of speakers who put forward their thoughts about certain topics: self-direction, seclusion, restraint, standardized assessment, that we thought when we formulated this agenda

might be the basis of such a set of recommendations. And then this Subcommittee has also talked about, and we can talk about this more later, maybe after we go through the first set, that we had so many issues that were left off of the table at the first meeting that what we might like to do is offer the Secretary a set of additional recommendations if we have a second meeting.

So, I guess it's something that we all need to be mindful of. Do we want to offer one or two sets of recommendations? And do we want to ask the full Committee if it will sponsor a second meeting on services?

So, Lee and I felt that some of these were pretty easy, and we sort of had the bones of some recommendations based on what we heard that day. But does that -- go ahead.

Mr. Grossman: And part of this, Denise and the rest of the Committee, is time to find what we're looking at. Realistically if we're going to get recommendations to the

Secretary this year, as what Dr. Insel had charged us to do, we have to have these prepped and prepared, and then presented to the full IACC Committee on December 14th for that to occur. And that's a mighty charge. It's one that is certainly going to be -- is not easy to obtain. But what Ellen and I have attempted to do with the recommendations that we were going to put forth, and we do want and encourage others to comment on that, to suggest your own and also if there's other suggestions for how better to address the timeframe that we're working under, we want to be open to those suggestions as well.

Ms. Resnik: So let me clarify -- this is Denise -- that the recommendations that we're making are based only on the workshop?

Ms. Blackwell: Yes.

Ms. Resnik: And are there recommendations that will come from the prior work that you did in terms of your outreach,

the community outreach that the Committee undertook, or was that all just to culminate in the workshop?

Ms. Blackwell: I think that we could probably use that as part of the background for the recommendations, Denise. Because what came into this meeting partially did draw from the RFI and the public input that we took at the town hall meetings the summer before last. So, I think that all of that is good background information. But our thinking is that we could develop some very clear and concise recommendations. As Lee said, that's a pretty short timeline between now and December 14th. And because we don't have any other meetings on the docket, I think that we would have to be doing some wordsmithing, between the Services Subcommittee members, between now and our next full meeting.

Mr. Grossman: And I guess to add some context to what you're saying, Denise,

this should not preclude us from making further recommendations to the Secretary at some other time after the first of the year, for example. And I'm hoping that this is just the beginning of a number of recommendations that we'd be bringing forth.

Certainly we've talked about putting on another workshop in August -- excuse me, in April. But if there are recommendations that come forward prior to that, that are based on our prior work, we want to entertain those. And if the full Committee of IACC agrees to it, then we certainly want to bring those to the Secretary as well.

Ms. Resnik: Lee, I really appreciate that clarification. It's most helpful, and I think that's going to be an important message that we convey to the full IACC and to the broader community, that whether it's going to be three phases or three sets of recommendations, that this is our

first set of recommendations based on this recent workshop.

The next set of recommendations may be based on another pool of information, again between all of our respective interests and organizations and efforts in public policy.

I just want to make sure that we leverage the assets of the organization and our respective interests to bring forward good recommendations, you know, helpful recommendations at this time.

So, if the next set of recommendations can be based on other work. And then the third set of recommendations would be based on maybe an April conference.

I just think it's going to be important that we manage expectations for ourselves and for the broader community so they know where they can have a voice and provide input to the process.

Mr. Grossman: Sure.

Ms. Resnik: Okay.

Ms. Blackwell: And Denise, this is Ellen.

One of the other items that is overlaying our thoughts is that the IACC itself is set to sunset next September. So we want to make sure that we, as Lee said, Tom directed us to do this very quickly. But we also are mindful of the fact that because there's some uncertainties surrounding the reauthorization of the Committee itself, that we would like to do something as speedily as possible.

Ms. Resnik: Right. Maybe what we could also suggest, Ellen, is first quarter of 2011, that we could advance a second set of recommendations to the Secretary.

Ms. Blackwell: We had actually looked, I think, Susan, is it not correct at dates in April for a second workshop?

Dr. Daniels: Yes. And I'll send out a note that outlines some of the possible

dates to see what works for the Subcommittee. It was really March, April, and May. But now that we're already getting into December, I think that the later dates will be easier to coordinate, in terms of getting the quality of speakers you want and the venues you want.

Ms. Blackwell: And I would also remind the Subcommittee that we have to obtain the permission of the full Committee to hold a second meeting. So that, again, would be something that we would need to broach at the December 14th meeting.

Dr. Daniels: That's correct.

Ms. Resnik: Okay. So this is Denise again.

So just one last thing. So then as we proceed with the conversation now and based on the workshop and the summary that you've created, is there a way that we want to evaluate these recommendations or have some discussion on each, prioritize and make sure that we advance? I mean, I don't know if it's

appropriate to advance all these things. I mean, I think creating some focus and hierarchy of recommendations might be helpful.

Ms. Blackwell: Denise, why don't we take a step back and then just go through what came out of that day and then what is also left on the table, perhaps, for April. We had some great speakers November 8th. We had people talk about what's happening in the current services system. Very wonderful people. Charlie Lakin from the University of Minnesota and then the leaders of, respectively, the State Development on Disabilities Directors and the Executive Director of the State Special Education Directors, followed by presentations on self-direction, universal assessment, seclusion and restraint, direct service work force training, housing, particularly bridge-type housing, temporary housing until people get into more permanent situations, peer support and systems integration.

So those were, in a nutshell, the topics that we tackled on November 8th.

There are a number of other topics that have been raised by the Subcommittee as potential issues that we might want to address at a future meeting. And I will go through those very quickly because we had a long list of things that we also thought might translate into potential recommendations that we couldn't fit into all one day.

Person-centered policy and planning, employment and vocational opportunities and systems. We wanted to look at managed care delivery systems and services for people with autism. We wanted to look at criminal justice system diversion. We wanted to talk a little bit about direct service worker certification through the Department of Labor.

We have not had a lot of discussion about recreational programs for people with autism.

Jennifer, I believe you mentioned diversity issues and cultural competence.

Ari has brought up the topic of having the characteristics of home and community-based service setting.

Unfortunately, we were not able to obtain speakers that day on November 8th to talk to us about the Americans With Disabilities Act and Olmstead activity. But with a further out timeline, as Susan has pointed out, we would like to have folks from the Department of Justice come and talk with us about what is going on there and the sorts of activities that are playing out in the states.

Sharon has brought up repeatedly the issue of family support. And I actually do think we have a recommendation that came out of the November 8th meeting on family support.

Infrastructure, community inclusion and lastly, Department of Defense

programs, which we talk about sometimes at IACC meetings but not in great detail.

Dr. Daniels: This is Susan.

And Ellen, in the lists that we've put up on the web, services research was the last bullet. There was one --

Ms. Blackwell: Yes. Okay. Sorry about that.

Dr. Strickland: This is Bonnie.

I didn't get to the meeting on November the 8th. But what I don't see in this list and in the recommendations that we have and what I don't see in the list, Ellen, that you just talked about was healthcare and continuity. That sort of surprised me given-- I wonder if, you know, (1) Perhaps there was a healthcare-oriented discussion at the meeting. It seems like a missed opportunity not to include a recommendation around healthcare.

Ms. Blackwell: Yes, that's very good, Bonnie. Thank you.

In fact, I just drafted materials

for the bookends for Chapters 5 and 6 of the Strategic Plan, and there is some discussion in the 2010 updated research data on accessing physical healthcare services for people with ASD, in particularly dental, oral healthcare services.

Dr. Strickland: Yes. I think we've got a good evidence base that talks about the disparities in healthcare at all kinds of healthcare, including oral health.

Ms. Blackwell: Yes. And I think it's also important to separate the child group from the adult group because the services they receive can be quite different.

Dr. Strickland: Yes. I agree.

Ms. Blackwell: Okay. That's a great one. Thank you.

Next slide.

So that's a pretty big parking lot list for a second meeting. I think we might even have enough for two meetings, Susan.

Dr. Daniels: We may. So then

you'll have to bring that to the full IACC.

Ms. Blackwell: Yes. Okay. So, Lee, should we just dive into what you and I talked about, what we sort of walked away with?

I know that, as part of the materials for this meeting and as part of his MC duties at the meeting, Lee had a great idea, which was to ask each speaker what he or she thought we should recommend to the Secretary. And we did review this material, and in some cases we found it quite helpful in looking at the topics and the kind of recommendations that we think that Secretary Sebelius might be able to accomplish.

So, Susan, I believe you sent that out as part of the materials for this meeting today?

Dr. Daniels: Yes, that's correct.

And just as a note, OARC was just trying to help in terms of reporting what we heard the speakers say in response to Lee's

question.

Ms. Blackwell: Yes.

Dr. Daniels: And so it's just a starting point for you all to help you start working on your recommendations.

Ms. Blackwell: Right. And it was helpful to us. And I think it will be helpful to us today as we sort of go through the slides that each speaker presented. And then if you haven't had an opportunity, as Susan said, both the slides and the live podcasts are available. There's a link on the IACC website.

I mean, I guess if we go chronologically, the first recommendation that we saw in the materials actually came from Charlie Lakin, who discussed to a lengthy degree the changing composition of the services system in light of what's happening in terms of state fiscal constraints. And I think that that thesis was also supported by what we heard from Nancy Thaler and Bill East.

So what we saw -- you know if you take a look at Charlie's slides, you'll see that he discussed at some length that, as the services system contracts to some degree as the result of these fiscal problems the states are facing right now, especially in their Medicaid programs, people are staying at home longer, especially people -- youth that are being transitioned out of school settings.

So one of the recommendations that Charlie put forth is that there should be a greater focus on evidence-based quality family support services research. So, you know, again, in light of the changing landscape in the service delivery world.

So, that was something that we picked out as a potential recommendation. There are opportunities in the IACC Strategic Plan, I believe in Chapters 5 and 6, that could certainly support such a recommendation.

Lee, do you have anything else to add to that?

Mr. Grossman: No, not at this time.

Mr. Claypool: Ellen, it's Henry Claypool.

Forgive me, I'm reviewing the materials and I don't see something that -- I have a list of draft recommendations for Secretary Sebelius, and then it has a header and then some bullets.

Ms. Blackwell: It would probably be more helpful, Henry, if you actually looked at the slides from the meeting.

Mr. Claypool: Okay.

Ms. Blackwell: That would be my suggestion. Because they're much, much more detailed. These are just suggestions, as Susan said, that people kind of made off-the-cuff.

Mr. Claypool: Well, I'm trying to get to, in the slides I will have specific recommendations then, is that it?

Ms. Blackwell: No. I think in

the slides you'll have data that supports such select ideas that Lee and I have considered bringing forward to the Subcommittee today.

Mr. Claypool: Okay. I have to leave the call at 3:00, but I would really like to review specific recommendations as a member of the Committee.

Ms. Blackwell: We would love to have your input, Henry. Some of these are pretty radical, I think.

Mr. Claypool: Is there going to be a summary that lists specifically what you heard from each of the speakers and what the group is offering up as a recommendation?

Ms. Blackwell: Yes, I hope that we get to that by the end of today's call.

Mr. Claypool: Okay. I'll hang tight and look for that.

Ms. Blackwell: Okay. So, that was the first one that we heard. Obviously, we need to do some tweaking, wordsmithing on that, but that was one that sort of came out

of the introductory session that really talked about family support needs as the services system -- you know, we have fewer people being supported independently in home and community-based settings and probably are looking at people staying at home with their families longer. That seems to be a prediction that all three of our introductory speakers brought up in their crystal ball for the next ten years.

And then when we came to our self-direction presentations, Dr. Conroy and Mike Head from Michigan, we felt that their presentations supported a recommendation to the Secretary that every state must offer a self-directed option within Medicaid, home and community-based services waivers that serve people with intellectual and developmental disabilities, including individual budgets, hiring authority, the hiring of relatives, paid peer support. And again, we need to work on this a little bit more, but that was the

baseline recommendation that we felt came out of that self-direction presentation.

Mr. Grossman: Yes. What you're going to hear throughout this as part of the recommendations that we have, these are the ones that we felt that the Secretary had some power over. And in most cases if we're referring to the states, we are almost entirely talking about Medicare and Medicaid services. So you'll hear that as a recurring theme throughout.

And if anybody wants to comment on that, please do speak up. We kind of leapt around the notion of what the Secretary could actually recommend and have some enforcement power over.

Ms. Blackwell: And if there are folks, some of you guys with other HHS agencies may have other thoughts, for example about self-direction in these presentations that could be accomplished within a recommendation. And we did sort of dig a

little bit into that with some of the latter presentations. Not particularly with the one on self-direction.

So, that's what we got out of that.

Mike Head spoke a lot about how for many years Michigan has required self-directed options in all of its programs. And the thrust of Dr. Conroy's presentation was on the cost effectiveness of self-direction and participant direction. So that's where that came from.

Dr. Johnson: Ellen, this is Jennifer.

I also heard in that presentation that not only should there be better use of self-directed services in a waiver program, but also that it be based on person-centered planning.

Ms. Blackwell: Yes. In fact, that's a really good point, Jennifer. And we had planned to have a speaker on person-

centered planning, and then we kind of had to throw the dice and choose. But that is at the top of the parking lot list.

I totally agree with you that it would be very important to make sure that person centeredness is included in the wording of that recommendation.

Dr. Johnson: You know, I don't know where this fits into our conversation, but some of what we're talking about are recommendations regarding policy, but then there's always implications, that go along with policy recommendations. And one thing that we have learned when it comes to self-directed services and persons that are planning this, that not always people with developmental and other disabilities know -- they might understand the concept of self-directed services, but then actually applying those skills can be a challenge. And the same for maybe the service providers are failing members; that, again, they might understand

the concept but how you actually apply them in practice is another issue.

I don't know if we can get at that in what we're recommending. But it seems like we should have something that addresses the need for implementation of these ideas.

Ms. Blackwell: So to me, in my world, that translates as an emphasis on a strong support broker focus.

Dr. Johnson: Yes.

Ms. Blackwell: Does that--

Dr. Johnson: Yes. And it might be just wording it in such a way that it brings in this notion that, yes, we can promote the concept but there also needs to be a part of this that includes or addresses the implementation piece.

Ms. Blackwell: Yes, absolutely. Because we know that that is the weakness, in many places, that families feel like they're not able to take this on because they don't have the support or the support broker

function is not fully developed or supported. So, I agree with you. I think that's really, really important because that would certainly open self-direction up to more families that just feel like they can't do it because they don't know how or et cetera.

Dr. Johnson: Right. Yes. Again, I don't know the extent to which we can get to this, but also how the person-centered emphasis is done and done in a way that really is, I guess, reflective of a person's life. And sometimes it ends up that the person is sitting in the middle of a group where they're being advised by a group of people on what they should plan for their lives. And, you know that's not always, I guess, a realistic or -- the way people live their lives. And so I don't if there's a part of it that we can get out in terms of how this is carried out in practice.

Ms. Blackwell: I actually think that there are several states that are doing

really good work in this area. And they should be top of the list to come in to a second workshop. Because I think that that would be a different recommendation about how to do person-centered planning at a systems level.

Dr. Johnson: Yes. Okay.

Ms. Blackwell: To me -- I mean, I totally hear you. It's really important. But I mean, I think we can give it a nod in this self-directed one, and that is really important. But I wouldn't want to sort of gloss over it because it is so important. I hope that we can focus on it if the full Committee allows us to do a second meeting.

Dr. Johnson: Sounds good.

Ms. Blackwell: But I really like your idea about making sure that that strong support broker function is integrated into self-direction.

So, any other comments about the presentation that we heard from Mike and Jim?

Okay. Our next presentation was on standardized assessments and we heard from Don Clintsman, who was the Assistant Director of the Washington State Developmental Disabilities Division. And, as Don spoke about, Washington State has adopted a tool generally called the CARE Tool in most of its home and community-based waiver programs. But Don spoke specifically about the challenges of adapting that tool to the developmentally disabled population. And he did a really good job, I think, of talking about the benefits of universal/standardized assessment. So Lee and I talked about, perhaps, recommending to the Secretary that states adopt standardized assessment procedures in their Medicaid home and community-based services waivers that serve people with intellectual and developmental disabilities to collect common data, promote consistency, determine effectiveness, inform state policymakers of budgeting needs.

If you look at Don's presentation, I think there are quite a few of promising wording that we can pull out of that to support such a recommendation.

So, do folks have comments about standardized assessment?

Dr. Strickland: Ellen, this is Bonnie.

I don't know the tool, but I'm still thinking back on how to provide a little bit more visibility for healthcare specifically in here. But this might be a good place to talk about standardized assessment across domains. And I'm assuming the CARE Tool does talk about -- does cover healthcare.

Ms. Blackwell: I think it does, Bonnie. He actually did not get into it a whole lot, because everybody was running on such a tight schedule. But if you take a look at his slides --

Dr. Strickland: I'm looking at

them now.

Ms. Blackwell: Yes. There's a supporting document for acuity that includes ADLs, mobility, interpersonal acuity, medical acuity, behavioral protective supervision.

Dr. Strickland: I particularly like that support assessment. It looks like a puzzle piece. So maybe -- well, we can wordsmith a little bit. But I would like to find some places in these recommendations where it's very clear that when we talk about systems, we're including the healthcare system as well. Maybe that comes in the preamble or at the end.

Ms. Blackwell: Right.

Mr. Grossman: Yes. Those are good comments.

Dr. Johnson: This is Jennifer.

I was going to suggest something similar. I thought it was a really neat model as he outlined it, and it seems pretty clearcut that they were based on different

standards that, from what I could tell, seemed to be pretty good standards.

And what would be even more beneficial is to integrate this with other systems so that it addresses some of the access issues in terms of navigating the service system itself. So if there's not only ways to standardize the assessment process for Medicaid services, but for other types of services, I think that would be really beneficial, using this as a model.

Dr. Strickland: Yes. I agree with that.

Ms. Blackwell: Can you give us some examples, Jennifer?

Dr. Johnson: Well, of other service systems that might --

Ms. Blackwell: Yes.

Dr. Johnson: Well, I'm thinking that there's some of our grantees that are working on this in terms of a single point of entry, and they have online applications that

people can complete. And it is a fairly universal tool for people to access services.

I don't know if it's sophisticated in terms of this one using the standards that it uses. But there are efforts to integrate different systems in terms of determining eligibility.

I know our office -- I mean our administration, ACF, is working on that and has integration with their information systems for determining eligibility for services with other information services systems for the same purpose.

So, I again don't know if you're asking for specific examples of actual services that might be integrated into this assessment tool or for models that are out there that do this.

Ms. Blackwell: No. I think we could probably fiddle with the wording to talk about what the goal of integrating such a tool -- you know what I mean?

Dr. Johnson: Yes.

Ms. Blackwell: Yes.

Dr. Johnson: And I think there are going to be different service systems that people are going to access depending on where they are in life; it may be employment services, it may be health services, it may be social services. So if you wanted to speak broadly in those categories you could, or again offer some specific examples of where is this happening.

Ms. Blackwell: Okay. That sounds like a great idea.

Harry, are you still with us?

Mr. Claypool: Yes.

Ms. Blackwell: Do you have any thoughts on the standardized universal assessment topic?

Mr. Claypool: I think it fits in with a broader aim of some of the work around Medicaid services. I think it's very specific.

I think there's a core assessment that could be shared across population, and that might have some functional element to it. But I'm not sure what this recommendation would match up with compared to what we might see coming out of a mental health arena versus an aging arena or another developmental disabilities area.

Ms. Blackwell: In fact, I think that Don discussed that maybe peripherally at the beginning of his talk, that the CARE Tool that was developed for the older adult population in the state, when the DD Division went to look at using it, they found that it didn't meet all of their needs. So they sort of stuck to the ABCs of it, but they had to tweak it quite a bit to get it to match the needs of this particular group.

Mr. Claypool: And I think that's probably a better way to define the assessment is that it has some basis in assessing the individual's functional abilities in certain

domains. But it might not, in the end, be labeled a universal functional assessment, because I think in some ways that creates confusion that you would be applying it to other populations as well.

Ms. Blackwell: Yes. Yes. He was pretty clear that their assessment tool just looked at people with developmental disabilities.

Okay. Any other thoughts from the Subcommittee?

Dr. Johnson: Ellen, this is Jennifer again.

I think the other thing that I concluded from his presentation that I thought was interesting about this system, was that it identifies individual needs. And so you're planning based on what the individual actually needs, rather than just approaching it in a more generic way, which I think can happen. So, I think that does something important to highlight in what ends up being recommended.

Ms. Blackwell: Yes. And I'm not sure if it came out in his presentation, but when I spoke -- I spoke several times with his supervisor, the DD Director in Washington, and the tool itself, which we did not see a lot of, is very much focused on people's strengths.

So it was my understanding that when they first implemented tool, the case managers were so used to looking at people's deficits that it was very hard for them and families almost reacted in sort of a negative way. Because their approach was that this is something the person can do, that pretty much everything is something a person can do. So, it really changed the whole dynamic and the thinking behind case management, which up until that point was sort of based on a person's deficits and their needs rather than their capabilities and their needs.

Dr. Johnson: And have it individualized --

Ms. Blackwell: Yes.

Dr. Johnson: -- by services.

Ms. Blackwell: I actually have another presentation that this team gave in the past that digs in a little bit deeper. Because again, we cut Don short. But it's quite fascinating. It really changed the dynamics of their system and made everything so much more positive. And it made families think differently about their disabled family member.

Dr. Strickland: This is Bonnie.

I have just one wordsmith here, and it pertains to this conversation. I think I would call this category standardized tools or standardized approach for person-centered planning, or something like that. Because standardized assessment doesn't really get to that personal piece, you know what I mean? You don't really get the sense that we're talking about person-centered -- standardized ways to do person-centered planning.

Ms. Blackwell: We usually call it individual plan in Medicaid, Bonnie. IP.

Dr. Strickland: Well, however we call it, I mean I suggest changing "standardized assessment" to add another word or two to make it clear that we're really talking about person-centered, or whatever you just said through standardized assessment.

Ms. Blackwell: Okay. We can definitely work with that.

Dr. Rice: And this is Cathy. Another component seems to be the coordination emphasizing that we're also talking about not just person-centered, but it's person-centered because it includes coordination across setting the agency's needs, which may be implicit for those of us that know what person-centered planning is but may not be unless you're really familiar with what that means.

Ms. Blackwell: Another thing, and I'm not sure if this came out in Don's

presentation, I think that some degree it did, but the state found that this reliable way of assessing people was very helpful in terms of forecasting budgeting needs for the legislature. So instead of just asking for a bulk amount of money, they could actually go in and say we know exactly what we need based on this process. And it was a much more reliable way of asking for money and resulted in better results for them once they had it in place.

Dr. Rice: It makes perfect sense.

Ms. Blackwell: Yes, it really does.

And that, I have to say, and Harry unless you're aware of more states that are doing standardized assessment with this group, I had trouble finding a state that has really integrated such a process into its case management function.

Mr. Claypool: No, I think you've got pretty much the state-of-the-art. And

when you're talking with Washington, they're one of the leaders in assessment instruments.

Ms. Blackwell: Yes. So, he was very good.

And again, for those of you that are interested, I think I do have another presentation from them. But I thought Don did a very good job.

So next on the docket we had Kevin Ann Huckshorn from Delaware. And there are quite a few slides from Kevin. She really whipped through these, but she did a fantastic job. And I know that Larke and Sharon, and perhaps you, Harry, are also familiar with Kevin. She is a passionate proponent of the prevention of seclusion and restraint in all settings, community settings, institutional settings, school settings. And she really gave a great presentation on an overview of what's going on in seclusion and restraint.

And I actually think that the bullet point that you included as her

recommendation, Susan, is pretty good. I think, again, we probably need to wordsmith it a little bit but as Kevin said, this was her answer when, Lee, you asked her what her recommendation should be, to significantly reduce the use of seclusion and restraint. And then -- let me take a look at my notes. But I think that one of the things -- oh, what we wanted to do was specify settings, institutional settings, community settings, school settings.

And then she talked a little bit about the six core strategies that have been developed in concert with our SAMHSA partners.

And Lee mentioned perhaps that there could be a way to work with ADD to develop training strategies, to develop and disseminate training strategies to support the reduction of seclusion and restraint.

Mr. Grossman: Ellen, this is Lee.

Ellen, there were a number of suggestions that we had discussed. Do you

have those written down there? Because I think --

Ms. Blackwell: What my scribbling notes say are:

States must significantly reduce the use of seclusion and restraint in all Medicaid/Medicare -- you know, again, these were jotted notes. In Medicaid & Medicare programs within the next three years including school settings, community settings, institutional settings. And then I think you mentioned possibly a side recommendation to the Secretary of Education.

Mr. Grossman: That the Secretary would work with the Secretary of Education -- yes. That Secretary Sebelius would work with the Secretary of Education for the school-based programs.

Ms. Blackwell: As some of you know, there's legislation in the Congress floating around that pertains, I believe, exclusively to schools. And, of course, there

was a GAO report from a couple of years ago that looked at seclusion and restraint in school settings. Unfortunately, a lot of the individuals cited in that GAO report were identified as people who have autism spectrum disorder.

Mr. Grossman: I think we had added in the recommendation that there'd be an immediate response from the Secretary saying that the goal was to eliminate restraint and seclusion. And then this next part was the timeline of three years where we would work towards to that.

We also thought that this would be cross-cutting through mentally -- not CMS, but SAMHSA, HRSA, ADD would be involved in the training and the education that would be necessary to implement this.

We probably didn't think through all the agencies that could do this, so feel free to add to it.

Dr. Johnson: This is Jennifer. I

think it makes sense to have the recommendation around work between the two departments.

I also know that Education has invested quite a bit in positive behavioral support in schools. And actually our agency has extended that to a certain extent into the early childhood arena. And so I think the work that ACS is doing related to that would be good to incorporate into this. And I think bringing in the idea of positive behavioral supports is important here too if we're going to identify specific strategies that might be used in different systems for addressing behavioral issues.

Mr. Grossman: Yes, Jennifer--

Dr. Johnson: Or we just are more generic in terms of mentioning any specific strategies.

Mr. Grossman: Well, I think, Jennifer, your point about specifically noting positive behavioral supports is something that

we should put in the recommendation. And maybe add some verbiage that it might be limited just to that. But I think that it's important to note the behavioral positive supports. It's well worth calling that out specifically.

Dr. Johnson: I think Gail's on line, isn't she?

Dr. Houle: Yes. Yes, I am.

Dr. Johnson: So I don't know if you have anything to say about that?

Dr. Houle: Well, yes, we do support positive behavioral support implementation and training, and have for a number of years and have several centers that do that. And it ranges. It's preschool through age 21, actually, with the focus mainly on school-age children, but some work in early intervention as well.

And the results of it, according to evaluations that we have, have been very successful in terms of behavior management

and positive behavior management and reinforcement.

So, I mean, I think that's a great thing to include as one of the strategies.

I'm looking through Kevin Ann's slides right now. And also there seem to be other recommendations that she has that would round out the whole system. So, I agree with adding that and I think we need to really even go beyond that.

Ms. Blackwell: Yes, I agree, Gail. This is Ellen.

She really puts the focus on staff education and training as one critical piece. And again, we didn't really word through this completely yet. We wanted to talk to the Subcommittee about it. But her presentation is pretty detailed, so I would think that we could come up with something, between our group and what Kevin presented.

Dr. Houle: Right. You know, I am sorry that I had missed it because it looks

like it was a fantastic presentation.

Ms. Blackwell: You don't have to miss it. You can watch it on --

Dr. Houle: Yes, I can, I will. And, you know, changing the larger context within which the individual is either educated or works in, or whatever environment, is very, very important. And PBS is one way to do that, positive behavioral support.

Ms. Blackwell: And this was, by the way, I thought a truly outstanding presentation and well worth taking the time to go back and look at what Kevin Ann had to say.

Dr. Houle: Definitely will. Yes.

I'm going to have to leave for a few minutes and then I'll be back. So if you call me in the next few minutes, I may not answer. But I'll be back.

Ms. Blackwell: Okay. Okay.

Anything else on seclusion and restraint?

I mean, again, I think that we

need to play with the language here as far as the recommendation goes. But we felt like we had enough from Kevin to put something in there.

Dr. Johnson: This is Jennifer.

In terms of wordsmithing it, seclusion and restraint is obviously a focus and a real concern. And that is what was through the presentation, a result of an oscillation of many issues that would lead you to seclusion and restraint. So it might be wordsmithing in a way to talk about how a broader system might address, in a more proactive way generally, behavioral issues to better support people with ASD and other disabilities to prevent behavioral issues, or something to that effect. So, I don't know if that's the approach to take in this, or if you want to exactly call out seclusion and restraint as the issue. So this system talks around how that might be worded.

Ms. Blackwell: Lee, how do you

feel about that?

Mr. Grossman: Well, yes. I think when Ellen and I were discussing this and putting this in the perspective of all the recommendations that we were putting together and presenting to you today, this one seemed like it had the most legs, that it could be the one that is, perhaps, the most doable in the shortest amount of time. So anything that we can add to strengthen this, to push it forward, certainly let's get it in there. Let's get it in there in this recommendation.

Ms. Blackwell: I'm not sure if John Martin said this during his presentation at the end of the day, but he did share with me that the State of Ohio has done a lot of work on restraint and seclusion. And the Governor has actually prohibited prone restraint in all state-funded programs. So, I think that's a good example of what has been done on a state level, or at least one example in terms of seclusion and restraint.

So, we can probably work with that to try to come up with something and then share it with the Subcommittee, I guess via email.

Our next presentation -- is it okay if I move on or does anybody else have anything about seclusion and restraint?

Our next presentation, a very excellent presentation on training of the direct services workforce. We heard from Carrie Blakeway from The Lewin Group and also Erika Robbins who happens to be the state's Money Follows the Person Demonstration Director. She's also the Assistant Deputy Director of the Office of Ohio Health Plans.

And if you take a look -- I mean, I think Carrie, again, did a pretty good job of talking about what could be done in this arena. And Lee and I talked about, if you look at her first suggestions, I think, again, we need to mull this over a little bit, but there are a couple directions we could go.

One is, we could recommend that Medicaid subsidize direct service worker training as an optional home and community-based service.

And then there's the second piece which could reward -- and again, we have to give it some thought. Is there a way to reward states that are using personnel who have additional training? Could they be provided with a higher federal match, as Carrie has suggested, or, you know, what's the incentive to states to provide their workers with additional training?

So I think she -- they had some pretty good ideas in their presentation that really look at:

(1) Can Medicaid pay for training of workers, and;

(2) Is there some sort of a tiered reimbursement strategy for workers who are trained?

And I think they made a pretty

good case that, in the long run, this sort of investment at baseline results in cost savings further down the line in terms of -- especially in terms of retention of direct service workers.

Comments about their presentation and our thoughts?

Dr. Johnson: This is Jennifer again.

I thought this presentation really mirrored conversations in the early care and education field because they really deal with a lot of the same issues. There's no formal mechanism to support training, but there's a great need for training and there's huge recruitment and retention issues.

And a lot of states have implemented the career ladder type model to support recruitment and retention in training. And I think that was an idea that they talked about in their presentation. I think incorporating that into the recommendations,

if that's possible to do, would be really helpful. And again, looking at the early care and education field might be a model for the system.

Ms. Blackwell: Okay. Other thoughts about direct service worker training? I mean this would certainly be something in the Medicaid program. I think Lee and I, and others perhaps here at CMS, would have to give some thought as to how to structure this. And, Henry, you might want to think about it too, and Jennifer, how this could be worded. And again, there are other people at CMS who could certainly be helpful in crafting a recommendation.

But I thought they did a good job putting out there the issue and some solutions.

Mr. Grossman: This is Lee.

Yes. Jennifer and/or others, one of the things that I didn't get from the direct service workforce training portion, and

maybe I was just missing it, was this idea of building capacity. And do you think that what the recommendations were and, Jennifer, what you just talk about is enough to address that issue or should we put something more into the recommendation?

Dr. Johnson: In terms of developing the capacity of the workforce?

Mr. Grossman: Yes. Bringing more people into the workforce. Obviously what you were talking about was retaining them, giving them proper training. But one of the things that is the impediment at the beginning is just that there's no real incentive for people to get involved in this type of work.

Dr. Johnson: Again, I think generally or personally I understood that to be a part of the presentation. So, maybe it wasn't made explicitly clear.

And I think the second bullet here on strengthening partnerships between DHHS and the Department --

Mr. Grossman: Yes.

Dr. Johnson: -- I mean that's one way of building incentives and addressing capacity issues.

I think capacity is something that will be an issue throughout somebody's career whether they're just entering the field or if they've been in the field for a year or two, or five or ten. So you're going to have a need for training and there's going to be a need for that service to be available and somebody to provide that training.

So, I guess again, I thought that was part of the discussion, but like you said it might not have been expressly addressed.

Ms. Blackwell: This is Ellen.

Yes, I was going to say the same thing, Jennifer. I think that they sort of got to that when they talked about the apprenticeship program with DOL. But, you know again if we're basing our recommendations -- I mean, I think that we might be able to

get to something through that number two.

Dr. Johnson: Yes. And I don't know if it's worth mentioning in here in the recommendations, but our University Center in Minnesota has that College of Direct Support, which you all probably are familiar with. But that is a training resource and serves as a model for many states.

Ms. Blackwell: Yes. So it could be used, for example, as a training qualification that could come through Medicaid.

Dr. Johnson: Yes.

Ms. Blackwell: Yes. I thought exactly the same thing.

Dr. Johnson: Right. Or maybe part of a career ladder program or something like that.

Ms. Blackwell: Yes. I think there's enough there where we can come up with a recommendation. But the main problem for states with that apprenticeship program, as I

think both of our speakers pointed out, is that the providers have to pay for it.

Dr. Johnson: Right.

Ms. Blackwell: So, they're not looking at the long view. They're not taking the long view right now. Everyone seems to be taking a short view. So if there are ways for HHS to support that in taking the long view, it might start to turn that ship around. It's a big ship.

Dr. Johnson: Yes.

Ms. Blackwell: So that's a thought, something new to find mechanism to pay for training to support providers.

And also, by the same token, that could support training in self-directed programs which is also absent. In fact, in some ways even more absent.

Dr. Johnson: Yes. And I have a note here from their presentation, and I don't know if it's something that they do or that they're suggesting, but I have tie pay rate to

the number of specializations. And I think they have something in here about that workers can go and get more specializations and the more that they have, the higher pay rate they're given.

Ms. Blackwell: Yes.

Dr. Johnson: And so that may be another way to have incentives to fill capacity.

Ms. Blackwell: Yes. And states have ways of doing that now. I mean, they can certainly tier provider rates based on a certain set of qualifications. But it's a little bit unusual unless there's a big gap in whatever it is.

For example, an LPN or RN, you know you don't see it so much in terms of the direct service worker pay rates.

Dr. Johnson: No. Well, and it might be worthwhile to bring in the argument that was made at the beginning of the session about the fact that more people are living in

home and community-based setting, and therefore there's a greater demand and a growing demand for the direct care workforce that is working in the community.

Ms. Blackwell: Oh, I think we could definitely put something in, you know in a short historical section about the -- I mean, maybe what we could do is construct each recommendation with a background paragraph and then the recommendation.

Dr. Johnson: Yes.

Ms. Blackwell: Okay. Well, this is a good discussion.

Next on the docket we had Sheldon Wheeler from Maine. Again, a passionate discussion of housing options or the lack of housing options for people who are not served through the system, particularly that are waiting long periods of time for housing choice vouchers followed by Joe Wykowski who talked a lot about what happens, as did Sheldon by the way, once people get into their

own homes. And I think that Sheldon certainly made a pretty good case for cost savings associated with having a home.

The materials that you see actually is a different -- Sheldon spoke -- he had talking points, but the presentation that came with this is something that he gave at another meeting, and it really focuses on the cost savings associated with the invisible health care costs, the take away when you put a person in a home it's pretty staggering the savings that accrue almost immediately when a person has a home.

So, after listening to Sheldon and Joe, Lee and I talked a little bit about exploring ways to pay for housing assistance, temporary housing assistance services in home and community-based services waivers and potentially in the Money Follows the Person Demonstration, both of which fall under the aegis of CMS.

Thoughts about that? Again, I

think this is a pretty groundbreaking suggestions. Because traditionally Medicaid is prohibited from paying, quote, room and board, unquote. So we're talking about today are temporary housing assistant services. And in my mind that would be housing that, like for example, bridge housing until a housing choice voucher could be obtained or some other sort of residence could be obtained.

Does anyone have any objection to making such a recommendation?

Dr. Strickland: No. I think it's a wonderful recommendation.

Ms. Blackwell: Great. Okay. Great. Okay. Great. Thank you, Bonnie. Yes, I think so too. So I think that Sheldon and Joe both just really made a strong case for housing as we know here at CMS is one of the problems. And, Jennifer, as you know that people face in trying to access home and community-based settings. A lot of people who subsist only on Social Security incomes, $674

a month, find it extremely challenging to turn that into rent -- and I'll just use our words, room and board. And it is extremely challenging as we move towards self directed models because -- I mean, again if that's a person's entire income, it really eats up a lot of it.

So, this sort of temporary housing assistance service could I think really makes a difference.

Dr. Strickland: You know what occurs me, and this is thinking more about the report and the way it gets presented to the Secretary.

In terms of the basis for these recommendations, sort of the evidence base and the compelling reasons to do it, not just because it's the right thing to do but because there's real not only cost savings, but benefit to the individual to do it a different way. So, do you see sort of a preamble to each one of these sections of recommendations?

Ms. Blackwell: You know, that's what I was thinking, Bonnie. And I think that our speakers actually gave us a lot to work with.

Dr. Strickland: Yes, I do too. I do too. So it just wouldn't be a memo with these recommendations. It would be sort of these sections, and I do like these sort of groupings. But it seems like it begs for some, two or three really concise statements that are compelling for why it's a good idea to do it this way.

Ms. Blackwell: Yes, I agree. That's kind of how I was seeing in my head. You know, we actually drafted a preamble to a recommendations document last year, and then we got hijacked by the 2010 Strategic Plan, which was significantly rewritten in the services in adult section. But we the Services Subcommittee had already started drafting kind of a beginning to the recommendations which I think perhaps might be

used as sort of that main introduction. And then I really like this idea, a compelling history to support the recommendation right before the recommendation.

Ms. Resnik: This is Denise.

You might want to also add the desired impact. So if you have the compelling case for why we're making the recommendation, so the background and what it is and then what are desired impacts.

Ms. Blackwell: Okay.

Mr. Grossman: That's a good idea.

Ms. Blackwell: Yes. Okay. So I thought those two they did a pretty good job. You know, housing the most well known problem that we hear about. So, I thought they did a great job.

It was very difficult to find state programs. I could only find two, Maine and Illinois. And Sheldon's program is sort of operating on a shoestring. But, again, I think this is an area where if you put some

investment at the front, I think Maine has proved that you get back at the backend. So, that could be the impact for example with that one, Denise.

Ms. Resnik: Right.

And also, which has been part of discussions that we've had, Ellen, and that is further ways to engage the private sector in developing housing as well. So if funding were available. I mean, we need everybody at the table on this housing concern. And true public, private nonprofit collaborations I think are what's going to make the difference.

Ms. Blackwell: Yes.

Ms. Resnik: And so I think any public policy that helps bring those groups together could be most valuable.

Ms. Blackwell: Okay. I know you're very familiar with this housing issue.

Okay. So that's groups.

Dr. Johnson: Ellen, I'm sorry. This is Jennifer.

Ms. Blackwell: Yes. Yes. Go ahead.

Dr. Johnson: Just a couple of thoughts I had on the housing topic.

Ms. Blackwell: Go ahead, please.

Dr. Johnson: Is there I guess anything that relevant to these recommendations related to the HHS and HUD Initiative? I'm just wondering if we should better understand what that workgroup is doing and how it might impact these recommendations.

Ms. Blackwell: Henry, do you have thoughts about that?

Dr. Daniels: I think Henry had to leave the call.

Ms. Blackwell: Oh. he did. Okay. Well we can loop back around with him, Jennifer.

Dr. Johnson: Yes.

Ms. Blackwell: I think in some ways, you know at the end of the day the person is looking for a housing choice

voucher.

Dr. Johnson: Yes.

Ms. Blackwell: So I think what we were envisioning here is a bridge to voucher.

Dr. Johnson: Right.

Ms. Blackwell: So, I don't know if it interfere with the vouchers. I actually think it supports the vouchers in that it offers a temporary way to transition people who may or may not be leaving institution, or who may just be on the waiting list for a -- I'm sorry. I keep wanting to say Section 8. I'm dating myself here. But a housing choice voucher.

In many communities the waits for these vouchers, as Sheldon said, are ten years.

Dr. Johnson: Right. Yes.

Ms. Blackwell: So one of the things that we might want to talk about for a second is these are temporary housing assistance services that we're proposing.

What does the Subcommittee think temporary means? Because I gave that some thought, but I'd like to hear what other folks think. Because we are talking about waiting lists, as I said, I think between five and ten years in many places. So what's temporary?

Dr. Johnson: Are you asking what's temporary in terms of length of time?

Ms. Blackwell: Yes. If we make a recommendation, do we actually say 12 months, 24 months? Do we put a cap on the length of time that the temporary housing assistance services could be offered?

Dr. Johnson: I'm not a real expert on housing issues to that degree. But it seems like at least a year, or possibly two would be appropriate from what I know.

Ms. Blackwell: Yes, I would have to agree. I would say 12 to 24 months is reasonable.

Dr. Johnson: And, you know I think maybe incorporating in something related

to universal design or something to that effect. Because we've talked a little bit about the need for a person's living environment to be accessible and to support their needs. And so I think if we can incorporate that concept into one of these recommendations where they have housing that would be important.

Ms. Blackwell: I think maybe what we could do here is also make -- we need to go back and review Joe's presentations and maybe there's a way to extract some of what Joe presented and put that in here too.

Dr. Johnson: And I would think a lot of it would be environmental adaptation when we're thinking about people with autism spectrum, but that be too narrow too.

Ms. Blackwell: I mean, I have to be honest with you. In many home and community-based waivers, I mean CMS has no issue with covering environmental adaptations. Again, services and waivers are what states

request. So in most of the IDD waivers, I generally do see an environmental mental adaptation service or environmental modifications service. States frequently cap the amount, or they put a lifetime limit on it, which actually can be an impediment in some cases if the person doesn't own their own home or if they're not permanently placed. Because they may have to move and then need a modification made later. But I think that that is a separate issue. But that is something that Medicaid already covers, temporary housing assistance services is not something that Medicaid covers. So they're two different things, but we could certainly look at what Joe presented and maybe find a way to make a nod to any kind of environmental adaptations that are necessary.

Dr. Johnson: And that might be it, just making a nod or a reference to it.

Ms. Blackwell: Yes.

Dr. Johnson: Yes.

Ms. Blackwell: Because there is a need. I mean, you know right off the top of my head plexiglass versus glass. You know, there is a need, especially for this group of people.

Any other thoughts about this recommendation?

And of course, we can make these recommendations to the Secretary, but we don't know what the Secretary will do with them. So, you know, it'll be interesting to see.

So our next group, this was an interesting group. Talked about peer support. And I'm not sure exactly what our recommendation would be, so we would like to hear from the Subcommittee thoughts about what this group presented. And we had person, a self advocate. We had Lisa Crabtree. Dr. Crabtree is from a university here in Maryland that's put together a peer support program that mostly assists high functioning adults with autism spectrum disorder who are enrolled

in college matching them with other peers who have autism and peers who don't have autism and setting up all sorts of activities.

Lisa did a great job talking about the genesis of this center. It's only been around for a couple of years.

And then our third presenter was from a school district in Wisconsin that actually created the germ and the blossoming of a program that operated in schools targeted to children with autism spectrum disorder. So there was a lot in that presentation. And I know that I have a little trouble focusing on what the recommendation would be. So, I think this is an area where we could some help.

There's nothing in the Medicaid program now that prohibits a state from creating a program that could serve adults or children with autism with peer supports. We actually approved this service under the Medicaid State Plan, and we approve it in home community-based waivers. You know, I just am

feeling a little -- I don't know. Not too clear about what a recommendation would be. So this is an area where I would like to hear, and Lee would like to hear comments.

Ms. Resnik: This is Denise.

I'm not sure what form the public policy recommendations would take. As I acknowledged at the meeting, as there are a number of programs that speaks to the peer support. And they make a lot of sense for lots of reasons from, I mean social integration and awareness, building skills. But I'm at a loss for what from a public policy recommendation we would do.

I mean, our program is funded, it's philanthropic. But are we looking for funding for these types of programs or --

Ms. Blackwell: Well, I think again we're looking at things that the Secretary could engage her agencies in. And the only other thing I could think of, Denise, is having just spent a lot of time looking at

the Strategic Plan, or the IACC's Strategic Plan that there's very little scientific research on peer support. So that might be an area. And I don't believe that we have that integrated into our IACC Strategic Plan.

You know, I was thinking last week that maybe that's an area that the Committee could talk about as a -- actually, I think when I drafted -- I drafted some information last week for the full Committee that has not been distributed yet, but I didn't specifically talk about peer support. I think I looked more at engaging people with autism in research activities.

But, you know, we mentioned possibly requiring SAMSHA, HRSA and ADD to assign funding to support models of peer support for people with ASD.

Dr. Johnson: Yes. This is Jennifer.

I was thinking that it is speaking about adult services. That maybe looking at

models of peer support in the delivery of home and community-based services and supporting themselves direct serviced and person-centered planning, you know that concept might be brought in there.

And then part of this may be another partnership with Education.

Dr. Shore: Right.

Ms. Blackwell: Yes.

Dr. Johnson: And also looking at age span issues specific to agencies working within ACF and its early childhood programs and looking at peer support and how it might be supported through some of the early childhood programs in ACF. This also might be an arena for SAMHSA, there might be interest around that.

Ms. Blackwell: Okay. That's a great idea. I think, Gail, have you come back yet.

Dr. Houle: Yes. Yes, I have.

Ms. Blackwell: Good. Okay.

Great.

Mr. Grossman: Perfect timing.

Dr. Houle: We could talk about evaluating the existing programs and expanding the programs that provide successful outcomes, outcome data in peer support models.

And also then with that, I mean looking ten years down the road, hopefully we would have data and evaluated models and we would be also looking at if they did come out to have successful outcomes, the dissemination and sustainability of these successful models of peer support.

So if we're talking particularly about that area of peer support, per se, the area of peer support is really kind of a narrow area, but an important area.

Mr. Grossman: So, maybe you and Jennifer and Larke work together to craft a recommendation, does that sound reasonable?

Ms. McKee: Ellen, this is Christine.

Ms. Blackwell: Yes, hi.

Ms. McKee: I've actually been on -- I know, I was in listen only mode because I didn't have the right code.

But, kind of on the issue of peer support and kind of growing the next generation of providers, I think that this is especially important for our children who are in segregated classroom.

We have all this great research from Sam Odom and David Mandell and everyone about peer modeling. But I think somehow there can be a recommendation either to the Secretary of HHS or back to Secretary Education, we have requirements about all these restrictive environment. But can we bring the peer models into the classroom for the children who cannot sit in a regular education setting? And I think this also helps grow your next generation of providers; your doctors, your dentists. You know, they're going to be the kids sitting in the

classroom next to the kids today. And I think you grow that interest by providing inclusive settings, and a lot more can be done in the schools than is being done for the children who are in self-contained classrooms, as they like to call them, or autism classrooms who every other student in the classroom has autism.

So, I think that there can be a recommendation for peer support based on the research, and then more can be done in this area.

Ms. Blackwell: And I think I have to say that I think that Jim Sinclair really put forth a case to include people with autism in the development of these type programs, and we would want to make sure that we got that into this recommendation.

Ms. McKee: Absolutely.

Ms. Blackwell: Okay. So is that something that you guys could work on; Jennifer, Larke -- or Larke's not with us, but

I guess we can assign her work, Gail? Anyone else? Christine, it sounds like you might be able to help them, too.

Ms. McKee: Absolutely.

Ms. Blackwell: Okay. Great.

Dr. Houle: So the task, Ellen, is that you'd like us to draft possible recommendation?

Ms. Blackwell: Yes. We have to draft that first paragraph we talked about, the compelling history and then a recommendation itself, and then potentially an impact statement.

Dr. Houle: Okay. I think I was off the call when you said that.

Ms. Blackwell: Oh, yes, you were. I'm sorry. Okay. Does that help?

Dr. Houle: A compelling history and what else?

Ms. Blackwell: Compelling history, the recommendation itself. And remember, Secretary Sebelius can only

recommend to Secretary Duncan.

Dr. Houle: Yes, yes.

Ms. Blackwell: Right. And then Denise suggested just a predictor/impact statement of the recommendation itself.

Ms. Resnik: And this one, I think again, in terms of the lifetime it's from the early childhood education throughout the education curriculum and then in community life and residential. So, I think this one has applications for all ages.

Dr. Houle: I think it does too. I wouldn't want to see it just limited to preschooler or school age. Because I think we can cross agencies if we make this into a life span idea or recommendation.

Ms. Blackwell: And you can certainly integrate into this the fact that, as I said, Medicaid has the option in the State Plan to pay for peer support under the Rehabilitative Services Service. And also in home and community-based waivers we may have

one or two that include peer support as a home and community-based service.

In the past peer support in the waivers and in the state's -- well to some degree in home and community-based service systems limited it to people who are at institutional level of care. But because of a change made through the Affordable Care Act, you know there are ways to create, I believe, peer support programs for people who are not at institutional level of care that exists throughout the Medicaid State Plan.

So, I don't see anything prohibiting these programs in Medicaid. It's just that this would be an optional service in the adult world for states.

So, in our world I sort of struggled with it a little bit because it is certainly something a state could do, but we don't tell our states what to do, well for the most part at CMS. So, anyway, that's my contribution to the peer support one.

Dr. Houle: Well, Ellen, we're in the same position in that it would be a recommended practice as opposed to any kind of mandated practice for Education. We can't mandate at this point in time with our statute that a school or school district must use peer support.

Ms. Blackwell: Right. So I was thinking of it more as the way you characterized it, Gail, as a research activity to evaluate the existing programs and then, hopefully, get some outcome data.

Dr. Houle: I think that would be important as well if we could do some short term and some long term outcomes we could incorporate some of the things that Christine had mentioned in there that would be highly positive outcomes, which would be a direction for those who were involved in the peer programs providing a possible career path or direction.

Ms. Blackwell: That would be

great. I think it speaks rains to say that we could only find one peer support program directed at people with autism in the United States, and I believe there's one college program in the United States.

Dr. Houle: For adult programs?

Ms. Blackwell: Yes. It's not like there's a plethora of these programs out there to look at. We're just at the beginning of seeing what can be done, which is in some ways exciting.

Dr. Houle: Sure. There are other peer programs that weren't presented there. There's one at Marshall University, for instance. There's several around. They just probably are not advertised or as well known, and they're definitely very small and in the early stages.

Ms. Blackwell: Yes.

Ms. Resnik: I have to make a plug here in Arizona. I mean all of our -- nearly all of our program at SARRC are peer supported

and integrated. And we've got hundreds of kids involved, and teens involved in peer supported programs, and we do have data on some of these programs.

Dr. Johnson: Well, and I think the point was made about, again, inclusion as a way of understanding peer support and its impact. So we can reference it as well.

And I don't know the extent to which that's really been applied within the HHS early childhood programs. And that may be something that could be specifically addressed.

Ms. Blackwell: Okay. So, we had one speaker after this. He's very dynamic, John Martin, the Director of the Developmental Disabilities arm of the State of Ohio. And John's very dynamic. I don't know if any of you had a chance to look at his presentation. He was at the end of the day, and it was a very busy day.

Lee, you asked John at the end

what were the most important things. And one of the things that he mentioned that I kind of latched on to is the idea, and CMS has already discussed this in public to some degree, you know trying to support states in their ability to create a single home and community-based waiver for various reasons; administrative simplicity and perhaps to focus more on individual needs. And, again, I think that would be supported by this idea of better assessment processes. But that was one of the ideas that John talked about, integrating multiple home and community-based waivers to promote flexibility, incentivize inclusion, et cetera. So, that was one thing that I took away from his presentations but others may have other thought about what John had to say.

Lee, did you have any other thoughts about John's talk.

Mr. Grossman: Well, I'd say I had a lot of thoughts about John had to say. Because it was one of the best examples I've

seen at any level of cooperation among different agencies. And that was an extremely informed method. I think we started off the day talking about what the future would look like where the silos are broken down and agencies are cooperating creating a seamless and comprehensive system of care.

And to me that's what John was talking about.

Ellen and I had discussed what that would look at the federal level, and how the Secretary could facilitate that. And that is probably among our heaviest lifts on the federal side to make that occur, but it seems as though it's something that's a necessity.

The recommendation -- there's perhaps a lot of recommendations that can come out of this. And one of the things if we were to follow John Martin's model is to have one singular agency on the federal level, agency really look at all of the autism services, or in this case I can you expand it to the ID/DD

community as well. But I don't know if that is something we would undertake at this point.

Ms. Blackwell: He did talk about that at the end. I was tired, but I vaguely remember hearing him talk about maybe having a point person in HHS or --

Mr. Grossman: Yes.

Ms. Blackwell: Does anyone else recall how he made that proposal?

Dr. Johnson: This is Jennifer.

I was not able to stay for that part of the presentation, but there was discussion of that at the beginning as well. Just identifying that as an issue.

Ms. Blackwell: Yes. So how would that translate into a recommendation?

Dr. Johnson: What I heard in the morning part was that there needs to be some mechanism for the DD -- I guess it's two parts.

There needs to be a mechanism for the DD state agencies to have a way to

interact with the Federal Government. And then, I guess this boarder issue of, you know the central point of contact, I guess. They could be one in the same, I guess.

Ms. Blackwell: Yes, that's kind of what I thought too, Jennifer.

Dr. Johnson: But maybe it's a centralization of DD, other disabilities issues.

Ms. Blackwell: I don't know if we're in the right place to make a recommendation about DD issues or if we have to stick to autism issues.

Mr. Grossman: Well, I guess it's a question that we'd have to consider. From my standpoint if it's looking at what's in the best interest of the autism community, I think involving the greater DD community in a single point of service I think would be to our best interest.

If we try to carve a placement for ourselves, I just think that -- I just believe

that that's going to be hard to sustain. Because other, particularly in the ID and DD communities are going to want to have a place there as well. And most of our issues, service related issues are the same. I think there's some strength in numbers. But including the greater DD community as part of this effort, and I'm not really seeing what the argument would be just to limit it to autism only.

Ms. Blackwell: Jennifer, can you help us out here? If the request is for an entity or individual, or office at the federal level, how would that compliment or conflict with ADD?

Dr. Johnson: You know, I think it would probably more compliment than conflict with ADD. And I think that we also have to consider the Office of Disability and their role to work across federal agencies.

Ms. Blackwell: Yes, I agree.

Dr. Johnson: I mean, we might

have to get Henry's input on this. But, of course, we take an across disability perspective and so we consider many different types of disabilities to fall under developmental disabilities.

Ms. Blackwell: Yes.

Dr. Johnson: That isn't an issue for us at all.

Ms. Blackwell: Right.

Dr. Rice: And this is Cathy. I don't know if the recommendation is so much to create a new entity or to assign or have a coordinating role for the entities that already exist. You know, that could be a possibility as well. Because I think creating a new entity is going to be a real hard sell right now, and that there are excellent organizations out there. But we don't have the broader disability service coordination role like we do with Department of Education for educational services, for instance.

So, coordinating and integrating,

you know we are talking about autism, but these recommendations also recognize that there is overlap with the needs from other disabilities or from other communities such as individuals with mental health issues. So maybe our recommendations are more about coordination when possible across other entities for efficiency of use, but that there's a hole in terms of the DD coordination, and autism in particular.

Ms. Blackwell: Yes.

Dr. Johnson: And I think it may be a matter of maybe bolstering current office roles to have more about roles and maybe some connection or communication with the state on some of the issues where this currently doesn't exist. And that's where I think the Office of Disability will have some perspective on that, because I think they're supposed to, to a certain extent have that coordinating role. But maybe there just needs to be some language in the recommendation to

better utilize them in that role.

Mr. Grossman: Yes. How do we move forward on this, because I think is an extremely important issue. And since, hopefully, at the end of all of this we'll have the Secretary's ear, what is the best way to approach this? Do we assign the lead to this to ADD or to the Office of Disabilities? It seems as though SAMHSA and HRSA and CMS and even CDC will have a role to play in this.

Ms. Blackwell: Right. Yes.

Mr. Grossman: I'm probably missing some other agencies. At HHS, certainly. I think HUD and Department of Labor and certainly the Department of Education definitely would need to be at the table if we would make it broader than HHS, which it probably should be.

Ms. Blackwell: Susan, do you have any thoughts about that, you know having worked coordinating this Committee for a few years now?

Dr. Daniels: No. I think that Jennifer and Henry, and possibly others who are interested could try to come up with some language about what you feel the coordinating role is. Although right now it sounds like from your discussions it's kind of nebulous as to what exactly you want; whether you would want to have simply have increased coordination between offices that already exist or if you're asking for the creation of a new entity, or a new point person or something to enhance that coordination, or if you're asking for another committee to be formed or something like that. So, you may need to continue discussing a little bit what exactly you really want. Unless you want to make it something that's broad that can be interpreted by the Secretary in multiple ways.

Dr. Johnson: This is Jennifer.

I think Cathy makes a good point that probably recommending something new is not the most feasible. So I think the idea of

looking at what we currently have, but getting a better understanding of, again, the Office of Disability and what their responsibilities are and what their capacity is. And maybe it's a recommendation around their capacity or the capacity of perhaps some other federal agencies to address this whole issue of there being better coordination at the federal level on some of these issues that effect not only people with autism spectrum disorder but with other disabilities.

Mr. Grossman: Yes.

Dr. Johnson: I think, Lee, you mentioned the idea of possibly other federal agencies and maybe the way to get it done is to have a committee that is a cross agencies committee, or across department.

Mr. Grossman: Cross department, right.

Dr. Johnson: Yes.

Dr. Daniels: Ellen, this is Susan.

There are some developmental disabilities type coordinating committees out there. And the ICDR and the one that is through your agency, Jennifer, that one person that contacted me recently.

Dr. Johnson: Oh, right. The President --

Dr. Daniels: The Presidential Committee. So there are a couple of existing committees and whether they could take on some sort of role in this respect might be something work looking into.

Dr. Johnson: Right.

Dr. Daniels: So I could send out some information about the two coordinating committees I know about that address disability issues.

Ms. Blackwell: That would be great, Susan. And then maybe we could sort of loop back around with you, Jennifer and Henry, to come up with something if we need something. You know, this is very important

to Lee, and I think it so important, but I'm not quite sure what it is.

Dr. Johnson: Right. We certainly hear it from our community as well.

Ms. Blackwell: Yes, I know. And John was very strong, I mean it's reflected not just in his presentation but also in what he had to say.

Mr. Grossman: Susan, this is Lee. And can you help me out here? I see that we're quickly running up to 4:00. Do we have to end at 4:00, or can we go on, or --

Dr. Daniels: You may go on if you all feel that you'd like to.

Mr. Grossman: Okay.

Dr. Daniels: So if you could go around and just see how people feel about that. And if everyone feels comfortable with continuing, you can.

So, is there anybody that's opposed to continuing the call past 4:00?

Ms. Resnik: This is Denise. And

I'm not going to be able to.

Dr. Strickland: This is Bonnie. I won't either. I have a conference call at 4:00.

Ms. Blackwell: I think that we're close to the end. We didn't have any speakers after John, okay?

Lee, should we work with Henry and Jennifer to try to comment on this one a little bit?

Mr. Grossman: Oh, yes. Yes.

Ms. Blackwell: Okay. Well, we can do that offline. And then I guess our plan would be to, you know different people have different assignments. In terms of getting them back in, I would suggest as soon as possible. Today's Monday, maybe by the end of the week. And Lee and I can work together this week to try to start drafting some of what we've talked about today, and then get it quickly out to the Subcommittee so that you can start sending comments in.

And then it sounded at the beginning of the call as if everyone definitely wanted to recommend to the full Subcommittee in December that we have a spring workshop. Do we need to recommend more than one? I'm a little bit nervous about the Committee saying you can have two more workshops between now and September. I actually think that's unlikely, but if the Subcommittee wants to make that recommendation, we can.

I mean, I think if we say we want one more meeting, we have a good chance of getting a yes.

Dr. Johnson: Yes, I think one is reasonable.

Ms. Blackwell: Okay.

Dr. Houle: There's an awful lot to cover because, Ellen, the list you read out earlier, all of them could be a one day workshop.

Ms. Blackwell: I know. But, you

know I think we got a lot in on November 8th. So, you know people understood the allotted time, for the most part, and they got the job done. So if we stick with that line with our next group, maybe we can squash in as much as possible. And then maybe try to rank the most important issues at a future Services Subcommittee meeting.

You know, as far as our next meeting goes, you know again we have to rush this through. This will be going through it looks like before -- you know, so we could get it done as Tom asked before the end of the year. But typically we have presentations at these meetings. Is there anyone in particular that the group would like to hear from at a Services Subcommittee meeting? And I will also say that all of us have the opportunity to also request presentations at the full IACC meeting on Services. And generally we have been having a presentation on services at those meetings as well.

But one of the tactics we had used in the past was have presentations at our Services Subcommittee meetings.

I think if we're planning another meeting in April, our next meeting might be focused on meeting planning.

Mr. Grossman: Yes.

Dr. Rice: This is Cathy.

The only thing that I can think of is when, Susan, you mentioned that there are other disability councils.

Dr. Daniels: Yes.

Dr. Rice: Is there any benefit of having a speaker from one of those other councils to come and talk to us about what they've done in terms of recommendations, whether to the Secretary or to whoever they report to? I don't know of those coordinating councils have that type of role or have done anything.

Dr. Daniels: I'm sure they'd be happy to give a presentation. However,

waiting for them to come and give you a presentation in terms of this set of recommendations would really slow you down.

Dr. Rice: Oh, yes. No. I just meant in terms of --

Dr. Daniels: In general, yes, you could always invite them to present at a future meeting.

Ms. Blackwell: That's a great idea, Cathy.

Dr. Daniels: To find out more about what they're doing.

Dr. Rice: Yes. Especially I think in the future if we are -- you know, we are autism specific, but if we're seeing what's best for people is better coordination, then maybe that's at least a start to see where we have overlap and what has worked and hasn't worked for them, and how can that inform our next steps.

Dr. Daniels: That's a good idea.

So if I'm hearing correctly, it

sounds like you want to by the end of this week have a draft of these recommendations that Ellen and Lee are willing to work on. And that you would like to use the format of having a background paragraph, recommendations and each recommendation to come with an impact statement which would be something short but describes what the expected impact is of each recommendation.

Do you think as a Subcommittee you feel like you can get together a draft that's really approved by everybody in your Subcommittee in order for it to be presented on December 14th for real consideration? It would need to be back to OARC by the 8th, which is a week and a half from now.

It sounded like you were working on quite meaty things that might require some deliberation, or did you feel pretty comfortable with what was said and think that it's going to be a pretty quick turnaround on everything?

Ms. Blackwell: This is Ellen.

I don't know, that's my answer. Lee, what do you think?

Mr. Grossman: Well, we've got a lot of hard work in front of us, so we just have to start tackling it.

Ms. Blackwell: Susan, when is our next meeting after December?

Dr. Daniels: You don't have one scheduled yet, so --

Ms. Blackwell: No, no, not the Services Subcommittee, the full Committee.

Dr. Daniels: January the 18th will be the day that we, hopefully, will be reviewing the Strategic Plan. And so the December 14th, January 18th meetings will be really devoted to the Strategic Plan and the Services Subcommittee will have a 30 minute slot on the December 14th date to talk about their issues. But I don't know if that would be enough time for the full Committee to truly consider the breadth of some of the

recommendation you've been talking about. I mean, you could maybe present an initial draft and then show it to them again on the 18th after you've had more time to work on it.

Ms. Blackwell: Yes, that sounds more realistic.

Mr. Grossman: Yes, that's fine.

Dr. Daniels: And if you showed it to them again on the 18th and there was some final tweaks to make, you know you have the choice of whether you would want to make it go with the Strategic Plan or separately, which I don't think necessarily be with the Strategic Plan at the same time is necessarily a great benefit. You might want to have it as a separate item because this is not an item that's required by law, which the Strategic Plan is.

Ms. Blackwell: I'm kind of liking January.

Mr. Grossman: Yes. I think we --

Dr. Daniels: I don't like us to

be completely stressed because you have a lot of work to do. Many of you are working on the Strategic Plan chapters, et cetera, right now too. So, just trying to be mindful of your schedules and that you have other things to do as well. But, as quickly as you want to work on it, we're willing to help you.

Ms. Blackwell: And when would we meet again, Susan? Do we have anything on the calendar right now?

Dr. Daniels: We don't. And so sometime after January 18th.

Ms. Blackwell: Okay. So we can set up a meeting after and send it around to the ground.

Dr. Daniels: Yes.

Ms. Blackwell: And until then we'll just keep working by email.

Mr. Grossman: Right. Well, I appreciate the work of the Subcommittee today. We got a lot farther than I really thought we would today.

Excuse me, I guess I have to apologize. I was really pushing the envelope for us to get this done in December, knowing that that was going to be extremely hard. But I think we accomplished a lot today. And January, which it looks like we'll be able to get the recommendations in. And I think we'll be a little bit more thoughtful than we would if we rushed it in the next few weeks. And it'll be a better product. And I really admire everybody who stepped up to the plate to help us on this.

Ms. Blackwell: Yes. I second that. And I also think that we need to give a shout out to our great presenters on the 8th who came in with some fantastic presentation and energy and enthusiasm. And really gave us an excellent day.

Dr. Shore: Well, this is Stephen.

I second that. A lot of the work that's being done.

Ms. Blackwell: Thanks, Stephen.

It was really, really a good day.

Dr. Shore: Yes, it was.

Ms. Blackwell: And I believe these are issues that cross the disabilities spectrum. I don't think any of these are autism issues. These are huge issues. So I thought that we had a wonderful group of people.

Ms. Resnik: This is Denise.

Is there anyway for us to learn more about what Secretary Sebelius will do with these recommendations, our process; anything that could help us to better prepare to make sure that what we do recommend gets the kind of attention and notice? Of course, we'd all like it too. I'm interested in, once again, process and what happens after we all worked so hard on these recommendations.

Dr. Daniels: Denise, this is Susan.

I don't think that there is a set process for how a department receives and acts

on those recommendations. They, obviously will be very interested in the work of this Committee. They know that this is a very active Committee. And you heard from the Secretary herself how interested she is in these issues. And so I'm sure that they will be taken into consideration and thoughtfully processed. But we don't really know exactly how the recommendations would be implemented.

Ms. Resnik: And I appreciate that, Susan. I know that she is committed. I think more I was thinking of what would be most helpful in terms of the way that we're presenting and the format, the background. I'm just wanting to probe a little bit once we land on her doorstep what happens.

Dr. Daniels: In my experience working with government documents, the more concise and clear they can be, the easier it is for departments and agencies to understand what it is that might need to be done, and also leaving adequate room for a number of

different solutions to be applied rather than necessarily being super specific unless you know that you have the one key answer to a particular question. I think that those are some general guidelines.

Ms. Resnik: That's helpful. Thank you.

Ms. Blackwell: So this was a great meeting. And we'll just forge on forward.

And, you know our thanks to everyone who participated. I know some people are not with us anymore.

And thank you, Susan, for supporting our Subcommittee.

Dr. Daniels: Well, thank you, Ellen and Lee, and to the whole Subcommittee. We had a great conference a few weeks ago and I think this is a really productive meeting.

I'll send out a memo tomorrow to recap what we did today and spell out the action items and help put that in perspective

with the time frame.

Ms. Blackwell: Okay.

Dr. Daniels: Thank you, everyone, for your participation.

Ms. Blackwell: Thanks. Bye.

(Whereupon, at 4:06 p.m., the meeting was adjourned.)