U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

JOINT TELECONFERENCE OF THE SERVICES AND SAFETY SUBCOMMITTEES

MONDAY, JULY 11, 2011

The Subcommittees convened via teleconference at 8:00 a.m., Ellen Blackwell and Lee Grossman, Co-Chairs of the Services Subcommittee, and Sharon Lewis, Lyn Redwood and Alison Tepper Singer, Co-Chairs of the Safety Subcommittee, presiding.

PARTICIPANTS:

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PROCEEDINGS

8:06 a.m.

Dr. Daniels: Good morning. Good this Dr. Susan Daniels from the NIMH, Executive Secretary of both the IACC Safety and Services Subcommittees.

We are having a joint conference call today of both subcommittees to talk about seclusion and restraint and our upcoming IACC Services workshop and town hall in the fall. I know it is bright and early, I welcome members of the public who may be listening and all of our members who are here, and thank you so much for your patience with the time change due to a conflict in our schedule but, hopefully, everyone got the message through our broad broadcasts of this information.

I would like to get started by doing a roll call of the IACC Services Subcommittee. Ellen Blackwell?

Ms. Blackwell: Here.

Dr. Daniels: Thanks. Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Henry Claypool or an alternate for Henry? Currently, not here. Gail Houle? Currently, not. Sharon Lewis? Christine McKee?

Ms. McKee: Here.

Dr. Daniels: Here, and I heard from Larke Huang, but she will not be able to attend, and Ari Ne'eman that he would not be able to be on the call, and Denise Resnik that she cannot be on the call. Cathy Rice?

Dr. Rice: Here.

Dr. Daniels: Stephen Shore, who is traveling and said that he may phone in at some point. And Bonnie Strickland?

Ms. Kavanagh: This is Laura Kavanagh. I am sitting in for Peter van Dyck.

Dr. Daniels: Wonderful. Hi, Laura. And for the Safety Subcommittee, Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Alison Singer?

Ms. Singer: Here.

Dr. Daniels: And I believe we are through the roll call. So everyone is here.

The first order of business we would like to take care of is approving the minutes. All the members received a copy of the minutes, and I received some corrections by email. Is there anyone else that has any corrections that you need to let me know about? Not hearing any, would somebody move to accept the minutes? Second?

Ms. Redwood: Lyn.

Dr. Daniels: Thank you. All in favor? Any opposed? Any abstaining? So it sounds like the motion carries. So the minutes are accepted, and they will be posted on the web shortly.

Ms. Blackwell: Susan, this is Ellen. I just have a comment about the minutes.

Dr. Daniels: Sure.

Ms. Blackwell: I thought these were a really excellent summary of the meeting that we held on May 19th on seclusion and

restraint, and if members of the public did not have an opportunity to attend the meeting or listen to it, I think that they are an excellent guide to go along with the slides that were posted on the website.

So these are just a really good portrait of seclusion and restraint issues. So thank you for doing such a good job. I intend to distribute them internally here at CMS.

Dr. Daniels: Excellent. So, yes, everything is up on our website -- or the minutes will be up on our website this week, and the slides are all there from all of our presentations, and we really did have just an excellent meeting on seclusion and restraint.

That leads us to the draft letter that the subcommittees have been working on diligently over the past few weeks, and I would like to, at this point, turn the call over to both the Safety Subcommittee and the Services Subcommittee to discuss what you would like to see with this letter.

For members of the public, you can access the letter if you go to the Meetings and Events page for the IACC, and click on Materials. You will see that the draft letter is there, as well as the other materials for today's meeting.

I believe Alison Singer and Ellen Blackwell can help lead it, as well as the other co-chairs of both subcommittees who are present on the call.

Ms. Blackwell: Thanks. Well, I will start out. This is Ellen. I first want to say thank you to everyone for taking the time to read this, with a very short timeline. The actual author is Sharon Lewis, the Commissioner of Disabilities in the Administration on Children and Families.

So Sharon had offered to put forth a first draft, and everybody did a fantastic job sending in their edits, as I said, on a very short timeline. So I tried to take this -- I think it was Thursday night -- and sort of integrate everybody's comments in a way

that I could understand.

I think there was only one comment from the CDC, and that came from Coleen, Cathy. One of your comments was that we included definition of seclusion and restraints, and in the third paragraph I did reference involuntary confinement and restrictions on movement, but I was a little reluctant to start putting formal definitions of seclusion and restraint in here, because they actually differ in different parts of the Medicaid statute and the Medicare statute. So I thought it might be a little bit confusing and maybe not add to the letter, but I certainly understood your comment.

I did have a general summary of seclusion and restraint put in there in paragraph 3.

Dr. Rice: Yes. Ellen, I thought that definitely -- that addressed it.

Ms. Blackwell: Okay, great. Great. That was the reason why I didn't go a little bit further, and I also thought that it

might -- Some of the definitions are so long, as you can see from our meeting materials, that I thought it might get distracting from the message of the letter. But I think this is a great letter, and I really think that, if we present this to the committee on July 19th, I would certainly hope that they could get on board, and we can get this off to the Secretary.

Alison, do you have other comments?

Ms. Singer: Well, first I want to add my thanks to all the members of the Services and Safety Subcommittee, and particularly Sharon who wrote the first draft. Again, I also appreciated that everyone really stepped up in a very short time frame and got their really important comments. I think we have really improved the letter as a result of everyone's input.

I think that one of the things that we struggled with was that, sort of by necessity, these letters, because of protocol

and intergovernmental requirements and issues, the overall tone of the letter is very corporate and formal.

I think one thing that we could talk about is whether you want to add more of a sense of urgency, and try to better reflect the sense of fear that is rampant in the parent community and throughout the advocacy community as a result of inappropriate restraint and seclusion.

I think that is really the only thing that is missing, is really just that sense of terror that we all experience. So I think that would be the first thing: Is everyone on the call comfortable with the tone of the letter overall, really, before we get to the weeds and go through it. What is the general feeling about the tone?

Ms. Lewis: And, Alison, this is Sharon. I just would like to comment to that. I think that, if there are additional anecdotes that we feel like we want to specifically point to that might highlight the

urgency, I don't have a problem with that.

I think that, as we have experienced in the past with some of these letters, for those of us who are members of the administration and working to advise the Secretary, I think the overall tone of the letter is appropriate as a letter going to the Secretary, and to take a tonality that is a balance between the advocacy perspective of the members of the IACC and the Federal members is a hard balance.

So I would just add that perspective, and again I would also like to add my thanks to everyone who jumped in and so quickly provided revisions and ideas and greatly improved upon the draft of the letter. So thank you, everyone, for your work in doing that.

Ms. Blackwell: Alison, this is Ellen. I would concur with Sharon, and I also think that when we present this to the full committee, we have a much better chance if we leave it as is in terms of getting the

committee to approve it, because, of course, the letter has to come from the whole committee. But I was thinking about this issue, and I would suggest that, provided the full committee agrees to the letter, that the advocacy groups on the IACC are not precluded, of course, from writing other letters on seclusion and restraint.

So if anyone on the call who represents another -- an advocacy wants to write a concurrent letter on seclusion and restraint, that also might be a powerful statement.

Dr. Rice: Additionally, the other point that I would just like to make is I would love to see us get to a place where we can include a letter -- I mean a sentence in the letter that indicates that this letter is going to the Secretary with unanimous support from the IACC, and I would like to see that be our goal. I think that that balance is critical to that goal.

Dr. Daniels: This is Susan. That

is something that we certainly can add, if we get the sense that it is unanimous.

Dr. Rice: Once it has gone through the committee.

Dr. Daniels: Once it has gone through the committee.

Dr. Rice: Right.

Ms. Redwood: This is Lyn. I just want to say thank you to Sharon for pulling this together. I think the letter is great, but I also agree with the concerns that Alison expressed.

I am wondering whether or not a way to make the letter a little bit stronger would be to order our action items in priority. One of the things that was sort of the take-home message for me from the meeting was the fact that one of the most effective ways to really address this across all these different agencies was through legislation, and I think everybody at the meeting supported Federal legislation.

That sentence is like at the very

bottom of the second page under "Reduce or eliminate the use of seclusion and restraint in schools." I am wondering if that could be moved up more into the body of the letter, that we support strong Federal legislation in this area.

Also in that same paragraph with regard to the school system, I think it would be important to also add that parents should be notified in any event where seclusion and restraint is employed with their children, and that is missing right now from that paragraph.

Let's see. There are a few other comments, too, with regard to how we might want to sort of reorder the different things that we have in terms of our action items. I think there are one, two, three, four, five -- five of them right now.

I would propose that we move the improved data collection across settings down to the very last paragraph, which would be number five before the closing, and that we move up the reduction or elimination of the

use of seclusion and restraint in schools, up to the second paragraph.

Ms. Blackwell: Lyn, this is Ellen. I guess my comment would be that we have to remember that the letter is to the Secretary of Health and Human Services, and I think that the first bullet is really important, because that bullet applies to programs that are under her purview. That is why I left it up at the top.

The last recommendation is a little bit different, because it really pertains more to what the Secretary of Education might be able to do, but that is why it is lower.

As far as data collection, I can tell you that, speaking from the CMS perspective, that is a very important issue. So I was reluctant. I saw a couple of comments asking to move it down, and I actually was reluctant to do that, because I think it is so important. So that is why I put them in this order or why I left them in a

particular order.

Sharon, I think you actually had data collection first.

Ms. Lewis: Yes, I did, and I am open to -- I mean, I think that both the data collection and the regulations are, based on my recollection of the discussion on the 19th and the notes and my understanding of members' interest, part of the reason that I think that both of those two things are critical and, frankly, high on the action list is exactly as Ellen has stated, which is those are within the jurisdiction of what the Secretary can do.

The legislation related to seclusion and restraint -- and those of you who are with us in the prior meeting may recall there was some conversation about issuing a separate statement specifically in support of legislation, which is something that maybe members of the -- non-Federal members of the committee may want to consider.

Those of us who are representing the administration, as individuals

participating on the committee can support this, but in general have a process that we have to go through when the administration is taking a position on a particular piece of legislation. So this is kind of the split the middle difference in incorporating it into the letter in the way that we did.

So I would agree. The other thing that the committee may want to consider -- and, Susan, I am not sure if this is problematic, but we may want to consider directly cc'ing this letter to Secretary Duncan simultaneous to sending it to Secretary Sebelius, given this jurisdictional issue.

Dr. Daniels: That is something that we can do.

Ms. Redwood: Can I address that, what Ellen just said real quickly? Ellen, with regard to the data collection, I was also wanting to add to that, that we would evaluate the effectiveness of our efforts to reduce seclusion and restraint as part of the improved data collection across settings, and

utilize that sort of as an evaluation tool to see how effective these other measures are.

I also felt like adding where we are talking about collecting improved data collection and reporting of seclusion and restraint, that we include all episodes of seclusion and restraint, because my understanding was some agencies only collect data where seclusion and restraint led to death.

So I think including all in there would be necessary, and to use that data collection as a way to evaluate the effectiveness of these different recommendations across agencies. That is why I thought moving it to the end would be more appropriate.

With regard to the legislation, I was thinking that Dr. Daniels said during the meeting that the IACC could include a statement that would support legislation, and it was well within our authority as an agency to be able to do that, even with Federal

members being on the committee. Did I misinterpret that, Susan?

Dr. Daniels: No. You could make a general statement that you are supportive of Federal coordination through legislation, etcetera, but because we do have Federal members on the committee, they would not likely be able to support specific legislation.

So it is something that can be done, but if many members on the committee are uncomfortable with it --

Ms. Blackwell: Lyn, this is Ellen. I think that is actually in the last bullet. We do say that we support legislation. So it is in here in a way that is probably going to be palatable to everyone on the committee.

Ms. Redwood: I was thinking about moving it up, though, before the actual action items, because that seemed to be the overall take-home message in terms of how we could be most effective. That is why I thought it

should also be included in the first part of the letter.

Ms. Lewis: I guess my question is, if -- I think that, if you are looking at the letter as a useful document for the public and for a reflection of the IACC interest and perspective, I think that that is really important.

If we are looking at the utility of the letter in terms of action items for HHS, as directed by Secretary Sebelius, it is a less effective point, because it is (a) legislation and (b) legislation outside of HHS jurisdiction.

Dr. Rice: This is Cathy. I would second that. I think we have to be clear that, if we are writing to the Secretary of HHS, what can we recommend that can actually -- that she can do.

Maybe under the bringing attention to the issue, as we list having an interagency conference, including Education and Justice, is it possible to include interested members

of Congress in that collaborative conference, because this legislation is going to come out of that. It would be important somehow to engage Congressional members that are interested in this issue in that conference.

Another point in terms of the urgency of the letter and making it hit home: It might be better in that second paragraph to be a little bit more specific about an example, as unfortunate as it is, to make it real. You know, hearing the details about, for instance, the youth that had died and was highlighted in the New York Times, a little bit more detail in terms of making it personal -- you know, what was his name? What was the circumstances -- just to make that a little bit more tangible and real. Those would be my suggestions.

Ms. Blackwell: So you are talking about paragraph 2, Cathy? This is Ellen.

Ms. Lewis: Yes. I think what we are saying -- What I hear you saying, Cathy, is adding to the reference to the New York

Times story the information about the Kerry family.

Dr. Rice: Right.

Ms. Lewis: And making that anecdote more personal. I think that that is fine. I am happy to throw a couple more sentences in there about Michael and Jonathan's story. That was a story that was also highlighted in the GAO report as well and has been a high profile case of all of the difficulties that have been evidenced in the inappropriate use of restraint.

Dr. Rice: Exactly. Seeing that a child was restrained for wiggling in their chair and realizing we are not talking about instances necessarily where this is an extremely aggressive -- this is happening when there are not safety issues involved. Not that even that is justified in many cases, but there are so many clearly unjustified cases, and making one of those examples more poignant would be helpful.

Mr. Grossman: This is Lee. I

wanted to comment on some of the things that Lyn brought up. I think those are all great suggestions, and I appreciation, Susan, your clarification on the IACC's role in supporting legislation, because even though we talked about that at the workshop, I feel much more comfortable about it right now from this clarity.

I think on the legislative part and actually bringing some of the stories to life, we should be putting a call out -- a strong call out for advocacy organizations to get involved in supporting this letter and for them to supply information, because they can take this to the next level.

Particularly, I am sure all of them have multiple examples that they include in a letter of support for what we are doing from the IACC.

I think also, to make this a little bit more urgent and relevant, in the third paragraph, the one that starts out with the GAO has issued multiple reports, etcetera,

we could reference in there that -- reference that and the hearing that took place that did describe in detail many incidences of restraint and seclusion and kind of bring that a little bit to light as well.

I want to make this as strong as possible. When the hearing and the legislations first happened under Chairman Miller at the Autism Society, we got inundated with calls from people that did not support what we were doing, and I want to nip that in the bud coming out of the gate.

There was a lot of misinformation that was out regarding -- and it was primarily directed at schools that take higher end and kids with much greater behavioral issues, and the information that they were getting was that this is going to restrict any of their activities in terms of providing a safe environment for their employees, for the individuals, the other students at the school.

I think this letter is specific enough, but we really need to get the advocacy

groups involved and to push this forward, so that if there is any push-back that comes out from some other groups, that we have a tremendous amount of support for what we are doing that can put that to the side.

Dr. Rice: Lee, could you say a little bit more about what some of the concerns were in terms of push-back, and if there are things --

Mr. Grossman: Yes. As I said, these were generally from schools or agencies that took the kids that, for lack of a better term, nobody else would take, because they had severe behavioral issues. The information that they were receiving was that this was going to restrict -- that what was being proposed in the legislation was going to restrict their ability to restrain a child when there was imminent harm to either the child or an employee or other student.

That explicitly was not in the legislation, but the word was out contrary to that. They had organized pretty well, I

thought, because we were getting letters, emails, and calls, probably 30 over the course of a few days, or more that were against what we were doing in supporting the legislation.

So I would expect them to be organized again, but yet there is nothing that has been in the legislation and nothing that I think that we would be supporting that would deny an agency from protecting its employees and individuals or other students, when necessary.

Ms. Lewis: And, actually, one of the important pieces of data that, if we decided that we needed to cite at some point, was we don't have a tremendous amount of data in the school setting related to staff injuries, but the one study that has been done in New York that was actually supported by the Teachers Union in New York indicates that, in environments in which staff are utilizing restraint frequently, staff injury rates go up substantially, and that there is a direct correlation between the use of physical

intervention and staff injury.

Dr. Rice: This is Cathy again. This brings up a good point. As I reread the letter again, one primary bullet, I think, I would recommend that we add is a focus on establishing alternatives in the standard of care that is based on positive behavior supports and training as a key component, certainly within HHS's purview whenever there are possibilities of having requirements or supporting training or whether it is also supporting research in terms of best practices, and these studies in terms of getting that information out there.

It is implied in the letter, and it is stated, but it is not really an action item, to make sure that we understand what works best, that it is disseminated, and that people have the tools and supports and technical assistance to actually implement those alternatives.

Ms. Lewis: This is Sharon again. I guess -- Larke, are you on the call?

Dr. Daniels: Larke wasn't able to join us, unfortunately.

Ms. Lewis: Because I think that one of the things that, in terms of a specific action item, if we were to write something like that in, I think it is a great idea. I guess the question is do we encourage the -- and do we build this out in terms of development of collaborative guidance, because SAMHSA has done a substantial amount of work in terms of, and has a full initiative around, the development of alternatives to seclusion and restraint, and this has been a key initiative that they have worked on since 2003.

I guess one of the -- and I am not the expert here, but it seems to me that we would want to encourage Federal agencies to work collaboratively with SAMHSA and look at what are the both data collections as well as technical assistance and training needs across multiple settings that are not currently addressed through the SAMHSA initiative.

Dr. Rice: Yes, that sounds reasonable to me. Clearly, there are great resources, but they are not out there being utilized, accessed, and across settings as well.

Ms. Lewis: Yes. I mean, if you note in the letter, we did reference -- and maybe we need to provide more explanation, but we did reference, for example, under "bring attention to the issue" SAMHSA's Six Core Strategies, which again is a curricula and key component in a framework that was developed through the mental health directors with SAMHSA support that has been shown to be effective in mental health settings -- so perhaps building out on that.

On the flip side of it, a level of specificity in terms of development of recommendations along those lines for the Secretary -- I think we want to talk about the need for the agencies to collaborate, without proscribing specifically how they need to do it, because I am not sure that we are the

right experts to tell them how to do it.

Dr. Rice: Right. That makes sense. So I think going through and highlighting that component in terms of any collaboration, and making sure that each step has the follow-through of increasing access, increasing technical skills of the people on the ground for each of these recommendations in whatever way, the best way for that particular setting, needs to do that.

Ms. Lewis: So do you think it is adequate to flesh out the "develop collaborative guidance" bullet point or do you think it is critical that we add another component that specifically creates an action item?

Dr. Rice: Personally, I think a specific action item for training and technical assistance, and even if that is expanding and collaborating and disseminating and following up, that is good, but highlight that as a key component, to me, I think, is important. But certainly, we will defer to

whatever the rest of the committee thinks.

Ms. Blackwell: Cathy, it is Ellen. I actually think I would rather see it under the present bullet. I just think that is more appropriate, knowing all the work that SAMHSA has done. I think that it would fit in better there. I don't want us to get too cluttered with recommendations and have it start to detract from what the Secretary can actually do.

Ms. Lewis: Would it be helpful to take the point that says "develop collaborative guidance" and change that to "develop collaborative guidance and improve interagency technical assistance" or something like that, and then flesh out that bullet point a little bit more?

Dr. Rice: Yes, that sounds reasonable to me.

Ms. Lewis: Okay.

Ms. Blackwell: Other concerns? Sounds like you got a winner, Sharon.

Ms. Lewis: Great. I am happy to

-- I have taken a few notes, and I am hoping, Susan, you have some good notes as well, and we can incorporate these changes to the letter and send it back out to everyone.

Dr. Daniels: Yes, we can do that. Does anyone else have comments on the letter?

Ms. Singer: I just have a little technical comment. At the bottom of the second paragraph, the clause "During the period April 2010-January 2011," where that clause is, is actually modifying the period of identification, which I don't think it is intended to do. It should really be modifying that that is the time period over which the media stories hit. So we just need to move that to the end of the sentence.

Dr. Daniels: Okay.

Ms. McKee: This is Christine. I want to echo Lyn's comment about parental notification, if we can add something into the paragraph.

Ms. Lewis: This is Sharon. How about this? Actually, what I had drafted was

at the end of that paragraph after requiring that seclusion and restraint only be imposed by trained staff, and then add the phrase "and ensure that family members are immediately notified of each seclusion and restraint incident."

Ms. McKee: Wonderful. Thank you.

Ms. Redwood: Were we also going to add something to improving data collection that would allow us to evaluate our efforts to reduce episodes of seclusion and restraint?

Dr. Rice: So at the end of the first sentence, "to identify opportunities to improve data collection and reporting of seclusion and restraint incident across settings, including the evaluation of such data and outcomes."

Ms. Redwood: That sounds great. Could you also include all episodes of seclusion and restraint?

Dr. Rice: Sure.

Ms. Redwood: So we are not just collecting data on death.

Dr. Rice: Yes.

Ms. Blackwell: Could we say that? This is Ellen. I am a little -- I mean, we can make that recommendation, but I would be more comfortable with something like a wider array of -- because I think there are the Federal agencies involved like CMS will have to look at what it is actually practical to collect. There is a real burden of data collection here, but I don't know exactly how to say that.

Ms. Redwood: Doesn't SAMHSA collect all of episodes?

Ms. Blackwell: No. We collect the data here at CMS. We collect hospital data, and we collect data in psychiatric residential treatment facilities for children, and also in ICS, but it differs according to the setting.

Ms. Singer: I would actually go further and say I think that is a key point to highlight, because I think that is -- In this, that is the one piece of data that makes

people say are you kidding me. The fact that data is only recorded if a person dies is shocking.

Just like with the -- When we did the wandering letter, I think that the shocking fact was AMBER alerts don't cover children with autism. Here, one of the shocking facts that came out of the workshop was data are only collected if a person dies.

So I would even say -- I would explain that point more in the letter and say, currently, financial considerations or whatever the issue is make it impossible to collect data unless the person dies, and ask for more resources so that we can collect all of the data.

Ms. Lewis: How about if we add a sentence in between the first and second sentence, and I am doing this without having written it down. So I am sure it will need to be wordsmithed, but along the lines of current data collection requirements focus on incidences of death, and the committee is

concerned about the frequency of the utilization of these interventions and, as such, would like to see additional incident reporting consistent with the ability of entities to report such information, given the burdens -- or something like that.

That is a little bureaucratic-speak, but you know what I am saying, some way to come up with a sentence that basically acknowledges that there is (a) a lot of variability in terms of what data is being collected in different settings, because on the flip side of it, actually, the new -- Ironically, despite the inability to regulate seclusion and restraint in the schools, the new Office of Civil Rights data collection, which will have its first data available this year, -- that was implemented administratively with a regulatory change almost two years ago -- will provide a fair accounting of the number of incidents in the schools across the country, not just in circumstances where an individual is injured or killed.

So I think a sentence acknowledging that differences in the data collection, that in some circumstances only death data is being collected, and the committee's interest in improving the overall understanding of the number of incidents is probably a reasonable route.

Ellen, would you feel comfortable with that?

Ms. Blackwell: Yes. That sounds fine to me. Thank you.

Ms. Redwood: And I think also, just the fact that the incidences will be recorded may make people think twice about using seclusion and restraint.

Ms. Blackwell: Absolutely. That was part of the thinking behind the discussions related to the school legislation, is that -- and part of what SAMHSA has been able to demonstrate with the Six Core Strategies is that, frankly, an understanding and attention and attitudinal shift in training of staff make a substantial

difference especially when the individuals understand that there is going to be data collected on these incidents.

Dr. Koroshetz: Well, I felt that -- Who collects the data from nursing homes where any use of restraints is reported? Is it state board of health?

Ms. Blackwell: Actually, we do, Walter, indirectly because we govern the serving and certification function in nursing facilities across the United States.

Ms. Redwood: And that includes hospitals as well, Ellen?

Ms. Blackwell: Hospitals, skilled nursing facilities, nursing facilities, psych facilities for children under 21. I think that the missing link is here, which is that we do not collect information in home and community based settings, which are really beginning are now dominating, certainly, the residential route for people with disabilities in this country, and that is a really important point in the first bullet.

Ms. Singer: This is Alison. So, Sharon, I heard you reading out some of the changes that you were making. Are you able to send us out a new draft before --

Ms. Lewis: Yes. What I would like to do is I will send this to the Chairs and Susan, and you guys can double-check it and make sure that I haven't missed anything and, Susan, please incorporate anything else that I may have missed. Then, hopefully, the Co-Chairs of both subcommittees could review and send it back out to all the members. Does that make sense?

Dr. Daniels: That sounds good. Anything else?

Dr. Daniels: Thank you all for your hard work on this and, Sharon, especially for putting together that first draft, and everyone for making your thoughtful comments. It sounds like we are going to be able to really roll a lot of these things into the letter without overly lengthening it, but really strengthening the message of the

letter. So this will be great, and it should be all ready for next week's meeting for the full committee to see it.

So as soon as I receive it from Sharon, then we will circulate it within the Chairs and make all the different edits, and then send it back out to the Subcommittee.

The Subcommittee members, when you look at it, after you have seen it, if you could just let me know that you approve of the letter as it is or if you have additional suggestions, to let me know.

Hopefully, what I would like to see is that most of the Subcommittee will be in agreement on this version of the letter that is going forward. So if you have any additional concerns, it would be great to raise them now on the call, but otherwise, hopefully, with all these additions that you have suggested, we will be able to move forward to next week.

Ms. Blackwell: Thanks, everyone.

Dr. Daniels: Thank you.

Well, the next order of business on our call today would be to discuss the IACC Services Workshop and Town Hall meeting. That will take place this fall on September 15th and 16th, and Lee and Ellen have been working on putting together some ideas for this workshop. I would like to turn this over to them to talk with you all about suggestions.

Safety Subcommittee members, you are welcome to stay on the call, if you would like, but if you need to move on to other business, you can go ahead and do that, too.

Thanks. So, Ellen and Lee.

Ms. Blackwell: This is Ellen. I thought it might be useful to us to harken back for a moment to the first Services Workshop that was held on November 8th, and the materials for this workshop also are up on the IACC website, but we might just want to quickly review what we talked about in November.

Our introductory session, we had Nancy Thaler, who is with the National

Association of State Directors of Developmental Disability Services; Bill East of the National Association of State Directors of Special Education; and Charlie Lakin from the University of Minnesota, talk about where services are today and where we want them to be in 10 years.

We had Mike Head, formerly from the State of Michigan, and Jim Conroy talk about self direction. We had Don Clintsman from the State of -- Washington State talk about standardized assessment of people with developmental disabilities and what the State of Washington has done.

We had Kevin Ann Huckshorn talk about seclusion and restraint in institutional settings. We had Carrie Blakeway who does a lot of work for us here at CMS. She is the Lewin Group, and Erika Robbins who is the State of Ohio's "Money Follows the Person" Director talk about direct service workforce training.

We had Sheldon Wheeler and Joe

Wykowski -- Sheldon is with the State of Maine. Joe is with a group called Community Vision in Oregon -- talk about housing options for people with disabilities in the community.

We had a panel on peer supports with Jim Sinclair, Lisa Crabtree from Towson University, and Julie LaBerge who has established some programs for children with autism in Wisconsin. Jim is a self-advocate.

Then lastly, we had John Martin, the Ohio Developmental Disabilities Director, talk about what Ohio has done to integrate the various systems in state that serve people with autism.

So that is what we did in November, and we actually had quite a long bucket list of topics that we did not get to, and I believe that Susan sent that out as an attachment to today's meeting.

There are also a number of speakers that we have suggested on and off that I know that we would like to have at

larger meetings, but I think would fit nicely into this fall workshop.

One of them is Tom Perez or Sam Bagenstos with the United States Department of Justice. Many of you are aware of the aggressive and successful efforts that the Department of Justice has recently -- more recently engaged in to support the Americans With Disabilities Act and the Supreme Court's Olmstead decision. So I know that I would definitely like to have someone from DOJ on the agenda for the workshop.

Also, I know that Sharon has asked for Michael Wehmeyer from the University of Kansas to come and talk. So I think that we should make sure that we get Michael on the list.

Then we have these bullets that came out today along with today's list that we can talk about, but I would definitely say that those are my top two suggestions for the workshop.

Susan, do we have a date?

Dr. Daniels: Yes. September 15th and 16th, 2011. I believe it is at the Bethesda North Marriott. That is right near the NIMH offices.

Ms. Blackwell: So we have two days?

Dr. Daniels: I think the 15th is a full day, and I think the 16th is a half-day, but I would have to check.

Ms. Blackwell: Okay.

Mr. Grossman: This is Lee. I believe that we were trying to also incorporate a town hall meeting.

Dr. Daniels: Right, which is why I put the half-day there, not that you have to have the town hall on that day, but then you could still have a full day of meeting with a few hours for a town hall, if you would like to do it that way, and you could put the town hall anywhere in it.

You could start off with a town hall, have it in the middle or have it at the end.

Mr. Grossman: Could the town hall be in the evening?

Dr. Daniels: Well, the town hall in the evening. I think that normally we book these venues for something like nine to five. So I don't know. I would have to find out. If you wanted to do it going into the evening -- You mean, instead of having it go into the 15th, like have it all on the 16th but run into the evening and have a session after dinner?

Mr. Grossman: Well, I guess what I was thinking in that regard was that, if it is held in the evening, then the ability for family members to participate is much greater.

Dr. Daniels: Oh, okay.

Mr. Grossman: They are not coming, taking the time off from work, etcetera, and also I was being a little bit maybe overzealous, thinking that if we have a day and a half of workshops to discuss specifically service needs, I wanted to take advantage of that entire time, and then have

the town hall as a part of that but somewhat separate so it doesn't distract from, if we do have a day and a half total for a workshop to use that entire time slot for the workshop.

Dr. Daniels: That might be possible. I would have to check on the reservation and see if we have space or if we can get space. So would you be talking about both dinner -- I assume that people will want to eat at some point, and how it be having a town hall if we don't have dinner.

Mr. Grossman: I guess --

Dr. Daniels: We would break at five, have dinner for an hour or something, and then come back for the town hall?

Mr. Grossman: Well, I am just brainstorming at this point. It is the first I have thought about it, because I kind of missed the fact that we were going to put a town hall meeting in there as well.

I would want to think about this a little bit, and also communicate with Ellen on that. We would be asking the Services

Subcommittee people for a lot of their time also in that one day, a full day of workshop and then an evening of town hall meeting. For me, that is okay, but it may not be for everybody.

Dr. Daniels: Okay. So we can consider that. In the meantime, I can check on our end about whether we would be able to find space in that convention center for having the town hall in the evening potentially, but we can discuss amongst ourselves to try to decide on how that might work best for all the committee members and members of the public we would like to invite.

Ms. Singer: This is Alison. One of the outcomes, I think, from the previous Services Workshop was that it was very heavily weighted toward the public sector with regard to services delivery. I would hope that this time, when we are thinking about whom to invite as speakers, we could try to broaden the reach to include more of the private sector providers.

A lot of them are parent groups. I think one thing we saw was maybe 10-15 years ago parents were the ones who started schools, and now in many cases parents are the ones who are starting these new service delivery. I think there is a lot of best practice that can be shared.

So I am going to just recommend Denise Resnik. She did an amazing presentation about the service delivery projects that are going on at SARRC, at the UJA Federation Autism Conference in May.

I think, by and large, people walked away from that saying, wow, we got to get one of those here. So I am just going to throw her name out and say it would be great to have that presentation again in a much more public and visible environment like this one will be.

Ms. Blackwell: This is Ellen. Should we go through the bullets and talk about them a little bit? Alison, I guess the only thing I can say in response to your

comment is that I think we were looking at systems reform.

So I think, back in November at least, we were trying to focus on what recommendations could be made to the Secretary in terms of systems reform.

Ms. Singer: But I think ideas for systems reform grow out of some of the experiences that are being --

Ms. Blackwell: Oh, absolutely.

Ms. Singer: I think that a lot of good ones did come out from the presentations that were made through public sector projects, but I think one thing that we just missed, maybe for lack of time, at the last event was hearing from some of the private sector projects. I would like to just try to not miss those again.

Ms. Blackwell: Is there anyone else who would like to suggest a particular speaker? Lee, should we go through these and see where interest lies?

Dr. Daniels: Ellen, this is

Susan. I got an email from Cathy Rice. She had to leave the call.

Ms. Blackwell: Yes, I have it.

Dr. Daniels: So you will mention that one as well?

Ms. Blackwell: Yes. Cathy has suggested that we look at access across the lifespan in terms of coordination of services, and we could certainly try to find -- I am just thinking as a Medicaid person here -- a state perhaps that has done a really good job of coordinating the various pieces of the services puzzle from education to the developmental disabilities network, to vocational rehabilitation; because that certainly comes up repeatedly as an issue -- you know, fractured coordination.

Mr. Grossman: Right. It was a goal of our first workshop to have that represented. It is difficult to find that being done on a statewide level, which is unfortunate.

I think John Martin talked

somewhat about it, the coordination that they have among all their various agencies.

Ms. Blackwell: He did. I don't know if we are going to find anyone -- any state that is doing a great job in this arena right now.

Mr. Grossman: Right. I agree with Cathy's suggestion about addressing lifespan services or supports, and finding someplace that is actually doing that. I have been actually reaching out to some friends that I have in Europe, and they may know of some regions there that are doing it, and I will again put a call out to them and see what they are doing in that regard.

We have been struggling to find anybody in the U.S. that is doing what we all want, and that is the comprehensive, seamless system of care across a lifespan in the U.S. It is just not there.

Ms. Blackwell: As far as the first bullet, person-centered policy and planning, I actually think that is Mike

Wehmeyer. So I think that is one that -- and Mike is the country's leading expert on self-determination. So that is -- I think we could probably put a checkmark next to that.

I think we could probably all agree that we would really like to hear from Tom Perez or Sam or maybe Mason about DOJ efforts. Every day brings something really new and exciting. So that, certainly, would be a highlight and a big draw, and it might even be useful to try to put the town hall together with the presentation from DOJ. I have to think about that a little more, but I would just be thrilled if we could have those individuals with us.

As far as employment and vocational opportunities, does anyone have -- Again, I have to think about this more, but does anyone have thoughts about that? We have -- Maybe have someone from the Department of Labor come and talk?

Mr. Grossman: Well, there are some private sector groups who are doing a

very, very good job on this, one of which is ACHIEVA in Allegheny County and the Pittsburgh, Pennsylvania, area.

ACHIEVA is an Arc, I guess, chapter, for lack of a better term, and they employ about 700-plus people with disabilities, and many of them have autism, competitively in various open competition types of employment. There is supportive employment.

So that is one group that has been doing a fantastic job. I know of two agencies in North Carolina that are doing very good work, a couple in New Jersey. So it is just a matter of -- and these are private agencies that are doing these on a pretty large scale.

They are running hundreds of people through their programs. So I think that we can probably bring somebody from those groups in to talk about what they are doing.

Ms. Blackwell: So maybe we could have a panel with them and someone from the

Department of Labor to talk about the direct service certification program, Lee?

Mr. Grossman: Yes. You know, I am wondering if -- It would be nice to have somebody from the Department of Labor from there, but certainly most of their clients are more -- are getting more of state assistance or Federal assistance, your agency. So the Department of Labor would be nice, but I think CMS would be even a better representative on that panel.

Ms. Blackwell: Well, I agree. In fact, we are in the midst of working on some efforts to strengthen our guidance on employment and vocational opportunities. So maybe this would be a good time to have someone come from CMS to make a presentation on that work. So I can certainly look into that. I think that it is pretty exciting. I am not sure if it is ready for prime time yet, but I will find out.

Regard managed care delivery systems, I think this is a really important

one, as state budgets constrict even further. We have more and more states coming to us here at CMS wanting to integrate managed care delivery systems into their home and community based services programs.

It is a huge, big deal. We have some states like Arizona that have always used managed care delivery systems to delivery their HCBS, but for the most part, home and community based services in the United States have been delivered through a fee for service system.

So I think that it is really important to understand how managed care delivery systems can be used effectively for people with developmental disabilities, especially as we have states clamoring to start moving in this direction.

We have one state, Pennsylvania, that has a very small program for adults with autism using a managed care delivery system, but I think it also might be useful to have someone come in from a state and talk about

what they have done to make sure that they have kept their programs vital and up to quality snuff as far as when they move to managed care, which is generally using a capitated payment methodology to delivery, for people with autism, a very complex, high level set of services.

So I would really like to see this on the agenda. It is very timely.

Mr. Grossman: Would it be helpful to have somebody from the insurance industry there, the medical insurance industry, like an Aetna or a United Healthcare, because I think that they are all trying to deal with this issue.

Ms. Blackwell: I don't know. That is a thought.

Mr. Grossman: And I also have --

Ms. Blackwell: It is a different set of services. It is physical health care services and not the kind of home and community based support; for example, respite care, residential habilitation, the sort of

community services that we haven't seen in the past move into these systems. But, yes, that is a thought.

Mr. Grossman: What about Kaiser? Even though you are really dealing with a pediatric population, they have done a fairly good job with their autism program in northern California in terms of managing care, and they have great statistics on what they have been doing there as well.

Ms. Blackwell: Well, Care Optima is another one. Recently -- I don't know how many of you are familiar with this landscape, California -- the Centers for Medicare and Medicaid Services approved a very large Section 11.15 demonstration in the state of California that mandates older adults and people with disabilities into managed care physical health delivery systems.

It does not presently include home and community based services, but maybe this is the time to -- You know, California is always a good state to look at, because it is

so big, and it involves so many people, but Arizona, I think, is another great example where we have a lot of providers providing to people with disabilities over the long haul.

So maybe we could think about that, Lee.

Mr. Grossman: Okay. On the next one, criminal justice diversion, that is such a big, huge topic, I almost feel like that we probably should take it off for the workshop, just because it is so big, and it could be a day and a half in itself.

Ms. Blackwell: Well, you know what? I actually found a town in Massachusetts, the town of Taunton, Massachusetts, which has many years ago established sort of a little boutique program that could be replicated on a national level.

They have presented at other conferences. It is pretty amazing what they have done. So I don't disagree, but I think that it might be nice to have them come in and talk about what they did, because it is great.

We could use something positive. Right?

Mr. Grossman: Yes.

Ms. Blackwell: Here we have a jurisdiction that actually developed its own model that is working really successfully with very little money, and certainly has helped a lot of people with autism and other mental disorders stay out and keep out of their criminal justice system.

That was the one that I thought we might want to hear about. It is difficult to find areas where something like this is happening, as Lee has pointed out.

Mr. Grossman: And it is just so big. It is just such a big issue. There is such a huge part of this. Anyway, yes, we can look at that, what Taunton is doing.

Ms. Blackwell: I think we already talked about Department of Labor in the context of employment and vocation, but this topic about recreational programs -- this comes up a little bit in the scientific literature, and it certainly comes up in

community settings, but I don't think we have ever addressed recreational programs for people with autism and other developmental disabilities in the IACC.

Does anyone have thoughts about having a presentation about how people with autism are integrated into recreational programs in communities?

Mr. Grossman: There certainly are a number of groups that we could talk to that could present on that subject, though.

Ms. Blackwell: It came up -- I don't know if you remember, but when we did our request for information, I think that this was one of the ones that came up, not at the top, but it did come up a lot, because it has a lot to do with integration of people into their communities.

Okay, so we probably should talk further about that.

The diversity issues and cultural competence: I actually cannot remember who put this on the agenda. Does anyone on the

phone have thoughts about this one?

Dr. Daniels: Ellen, this is Susan. I think it might have been Jennifer Johnson, but I am not sure.

Ms. Blackwell: Is Sharon still on the line? Okay, because I am not quite sure where to go with that one. I guess we could ask Sharon if she has thoughts on that topic.

The next one, home and community based services characteristics: I know that this was one that Ari had asked to talk about. It is a very sensitive subject right here at CMS. We just closed a Notice of Proposed Rulemaking on this topic, and we have received a multitude of comments on it.

So I would have to say that at this point I am really not sure that, unless we talked about what is on the books now and what the Notice of Proposed Rulemaking says, anyone from CMS could go further than that. But I do think it is a really important topic. It comes up here all the time, certainly not just in the context of people with autism, but

people with all disabilities.

So we could have someone from CMS talk about the NPRM and the guidance that we have issued thus far, but we really can't go any further than that. How do people on the call feel about -- I know that this is really important to Ari, and I know that several of the advocacy groups that are part of the IACC have sent in comments on the NPRM.

Does anyone have thoughts about this? I certainly can't say when CMS would issue a proposed rule. We just closed the comments and, boy, we have a lot to go through. Lee, do you have thoughts about this issue?

Mr. Grossman: I personally don't.

Ms. Blackwell: It is a very important issue.

Mr. Grossman: Right. I know people that do that are private sector folks. I can reach out to a few of them to see if they would be interested in commenting on it and talking about it.

Ms. Blackwell: Yes. It is very important.

Mr. Grossman: Yes, oh, yes.

Ms. Blackwell: So maybe we should keep it on the agenda, and then just play with how we want to approach it.

Mr. Grossman: Right.

Ms. Blackwell: Knowing that there are sensitivities about the fact that CMS is working on a rule in the post-comment period.

Mr. Grossman: Would groups such as CARF or CQL that do accreditation -- would they be somebody that you would like to hear about?

Ms. Blackwell: I would have to -- Actually, I would have to go and look at the comments maybe and see. I know that a lot of advocacy groups -- NASDDDS has offered comments, and then I know that there are a lot of self-advocacy groups that got together. There were some very sensitive comments about this. So maybe we need to just dig a little deeper here.

Mr. Grossman: Okay.

Ms. Blackwell: We talked about DOJ. Does anyone have any objections to DOJ coming in, because I think that would just be fantastic myself?

Dr. Daniels: Ellen, this is Susan. The last time we talked about trying to invite Tom Perez, we were talking about doing it as a keynote type thing. Would you want to do that again to see if we could get him to be the first speaker of the day or --

Ms. Blackwell: Sure. I think that would be great, and as we discussed earlier, maybe we could have him come in and then have a town hall meeting right after that.

Dr. Daniels: So that can be something in mind. I know that it seemed like the subcommittee was really very excited about the idea of having him come. So that is one we could start working on right away to see if we can get on his calendar.

Ms. Blackwell: Right, and I

understand Lee's point about having the town hall in the meeting, so more people could participate. I just have to think about that a little more, because I think you have a point, Susan. It would be tough to run a whole day and then have a meeting, but I'm sure lots of us would be willing to do it if we felt like it would accommodate more people participating. But I don't know how we would tie that into DOJ speaking in the morning.

Dr. Daniels: Yes, and the date. Sometimes with folks on this level, it is kind of hard to get them at the end of the day.

Ms. Blackwell: It is really hard, yes. So maybe we could put the town hall meeting -- But maybe we could put the town hall meeting after the keynote speaker.

Dr. Daniels: Yes, you could.

Ms. Blackwell: Maybe that is the -- Lee, how do you feel about that?

Mr. Grossman: We should talk a little bit more about that. I definitely want to maximize the impact of the town hall

meeting. It is always good when we can schedule it at a time when people can participate. But, yes, it would be a long day for everybody.

Ms. Blackwell: And I think that a lot of people attending the town hall would really love to hear what Justice is doing. You know, maybe that would attract more people right there.

Okay, the next bullet talks about family support. Again, this may have come from ACF. I can't recall at the moment, actually. Thoughts, anyone? Okay.

Infrastructure: I think, as we talked about, this was something that John Martin talked about at our last meeting, but it is a really important subject. I am not quite sure what approach we would want to take. Lee, do you have more thoughts about infrastructure?

Mr. Grossman: Well, I look at family support and infrastructure, person centered policy and planning, employment and

vocational opportunities kind of managed care, etcetera, kind of all sitting in the same basket, actually. You could put the next one in there, community inclusion.

You know, what we were saying before about comprehensive and seamless lifespan services -- that is really what infrastructure is, the way that I had interpreted it. If we find somebody that can really address how somebody is successfully doing lifespan services and support, that addresses the infrastructure issue.

Ms. Blackwell: Okay. We will see if we can find someone who is actually doing that successfully. Suggestions would be great. I will ask around here at CMS.

Mr. Grossman: Yes, I will look -- As I said, I will reach out to some of the people I have been communicating with recently and see what I can find.

Ms. Blackwell: Okay. The next item: We have talked several times about having a Department of Defense representative

come in to talk about the early intervention programs that they are running. How do people in the group feel about that? We have not heard from them ever, so far as I can recall.

Way back in the early days of the IACC, someone may have come to present. I don't remember that I was there, but I think that is what I heard.

Mr. Grossman: DoD -- I am trying to remember. There has been a lot of discussion about what they do with TRICARE, and they actually have probably the best overall benefit package of any managed care system out there in terms of autism.

So, yes, it would be good to hear what they have to say and where they are going with that. I know there has been a lot of debate and controversy around it: Is it being adequate or not. But they are providing early intervention services, and it is something that they have approved.

So, yes, it would be great to hear how they are doing it and what their success

is. I haven't followed it that closely. I am not aware of any studies that have come out of that, showing what their outcomes are or any of their data. I don't know if that exists, but if it does, it would be wonderful to hear what their success rate is and even anecdotally what it is that they are seeing are their results.

Ms. Blackwell: Well, we can certainly ask and see if they are willing to participate.

Emergency preparedness: This is a really important issue. There are some states that have done a really good job of putting emergency preparedness systems into place, some better than others, but it is a very important topic. How do people feel about having this on the agenda?

Mr. Grossman: Is Cathy still on -- Cathy Rice?

Ms. Blackwell: Cathy had to leave at nine.

Mr. Grossman: Oh, that is right.

That is right. I don't know where they are now, but in the past, certainly around the time of Katrina or post-Katrina, CDC had worked very closely with Homeland Security and FEMA about getting together an emergency preparedness planning around -- for people with disabilities, and I don't know where that project has gone.

Dr. Koroshetz: And the major group that deals with that is Assistant Secretary for Preparedness and Readiness, ASPR. They are the ones that have contingency plans around hurricanes, natural disasters and things, set up medical tents.

There was, actually, a session about emergency preparedness for children that was held at NIH, oh, maybe about four months ago. I was there for maybe half of it. I don't recall a session on children with disabilities, but --

Ms. Blackwell: There are some states, Walter, that have done a pretty good job putting state based plans in place to

protect people, especially people who are participating in home and community based waivers.

So maybe we could get a state. Florida, I know, has done a lot. I think, at least in the context of this group, we are concerned with people with autism and disabilities. We could ask Sharon and Ray maybe if they have other ideas, but I have seen a couple of presentations from states that are pretty incredible.

I guess the only other one -- I mean, I think we are kind of done with wandering. We have already taken action on that subject.

The Affordable Care Act included a program called the National Background Check Program that is pretty interesting, and we have recently awarded a grant to states. So I was thinking that we might want to add that to the agenda, too, the National Background Program. It has to do with looking at backgrounds of individuals mostly seeking to

work with older adults, but it could certainly be construed to some individuals who have autism who are older adults.

So I would put that on the bucket list, too, because it is the first time that we have really had a national program that requires background checks. I would add that to our older agenda, something that has come since we made this list. Other thoughts?

Ms. McKee: Ellen, this is Christine. I am trying to think about what our take-away is at the end of the day. Kind of as we go through this list, it seems like maybe we are going for glimmers of hope in a bad economy or something. I am not really sure.

I think what Alison said early on maybe making sure that we include some smaller programs that could really use the limelight, so that the ideas get out there a little bit. I am not sure what is cohesive, what holds all this together, and then what we are going to do with it at the end of the day.

We have a great setting for the fall. So it can help with our update to our various documents that we have to get turned out in January. I don't know. I wanted to make sure that we have something that binds this all together, and then Lee is always so good at coming up with the question at the end for the speaker; you know, what can we as the IACC do with this information.

So I guess I want to keep that in the back of our heads as we plan, and narrow down our list for this event.

Ms. Blackwell: Yes, I agree. That is a really good point. I think that at our first meeting our plan was that we would write a letter to the Secretary making recommendations, but I like your idea of also integrating it into our documents that we normally publish.

Susan, do you have thoughts on that? I guess it could get integrated into the strategic plan as our update.

Dr. Daniels: I believe that the

meeting that you had in November, that many of the ideas that came out of that were incorporated into the strategic plan in the next session. So those things have been done. They have been integrated in kind of specific types of statements.

We don't have a set-aside part of the strategic plan to recount meetings, and I don't think that I would recommend doing that, because it could really clutter up the strategic plan.

One can always issue a report after a meeting, if you want to have a meeting report that really goes into what occurred at the meeting. We could do a meeting summary of some kind.

Ms. Blackwell: I think a lot of what we do, as you said, Christine, is educating the public about issues that are really important.

Ms. Singer: Well, this is Alison. I think, especially given that there is going to be a town hall component for this meeting,

we are going to be getting more parents and more members of the public, hopefully.

It would be good if there could be a piece of this that was a little less policy and a little bit more sort of sort of news you can use. So something like what makes a program good? You know, what are the evaluation criteria that CMS uses to evaluate how good a particular program is, because I think that is something that parents would want to use as well when they are evaluating a program.

So I think, if it is possible to get to that level of detail, then the meeting itself has value, has a valued outcome, in and of itself. You don't have to then put something in the strategic plan. You have left people with actionable information.

Ms. Blackwell: Yes, I hear you, Alison. I guess I am trying to think about it from a policy perspective. We don't really evaluate state programs other than in terms of their quality, whether or not they meet our

quality requirements.

Ms. Singer: Well, what are your quality requirements? I think, as parents, we evaluate programs based on what we think of their quality, and it would be nice to know what yours are, the requirements by which CMS evaluates a program.

Ms. Blackwell: Yes, sure. We can talk about that. That is pretty easy. We have well integrated quality requirements in our home and community based waiver programs, but that is separate from the kinds of requirements that states have for physical health.

We have six quality requirements. If a state operates a home and community based waiver, we tell them that they have to report to us mid-term in the waiver cycle on those. I think the most important one is health and safety, frankly.

I am not sure how concerned people might be about whether or not waiver participants are all evaluated for level of

care, but we do look at how states -- I mean, the most important one, in my mind, is how states keep people healthy and safe in our programs. I'm not sure how it ties into restraint and seclusion.

Ms. Singer: It would certainly be interesting, at least to me, to know what the criteria are, and then it would be interesting to see the data. How well are the programs measuring up to those quality standards.

Ms. Blackwell: Sure. We have a quality person here who does home and community based services quality. So I would love to -- I mean, that would be great. We could have her come in and talk about quality in home and community based services. It is very interesting. So that is a great idea.

I always recommend that everyone look at the CMS website. There is a map. If you push the Medicaid button, you can actually see the home and community based waivers that CMS has approved that many individuals with autism may be enrolled in.

I always say, go back and read the waiver, because that is the document that drives these services at the ground level, and a lot of parents and advocates don't always think like that, because they are working with the case manager, and they are being told something from a state developmental disabilities agency, but at the end of the day it is really Medicaid that runs those programs, and the waiver is what grounds them.

Ms. Singer: So maybe we need like an intro class. We need a "Understanding The Waiver."

Ms. Blackwell: I haven't done that for a long time, but yes. I think that would be great.

Ms. Singer: I think there are people who don't even know what you mean when you talk about the waiver program.

Ms. Blackwell: Yes, it is very complicated. I totally agree with you. So, yes, we could do that. I think that would be fantastic. Waivers have names. When you even

use the word waiver, what does that mean? It means that the Secretary waived institutional rules.

Ms. Singer: Right.

Ms. Blackwell: There are all different kinds of waivers. There are these Section 11.15 waivers that are now providing home and community based services. When we talked about managed care delivery systems, well, that is different from a Section 19.15(c) waiver that might provide home and community based services, which is different from a Section 19.15(i) state plan services, which could also provide home and community based services.

It is complicated, but how can you really advocate if you don't understand where your family member's services are coming from or what the rules are? It is sort of like rules for an IEP. Most people learn those, because they have years of getting used to them, but to be thrown into the adult system and then have a whole different set of rules -

- I agree, it is very complicated and very difficult. So that is a great idea.

So we could talk about home and community based services waivers and the quality structure. Great.

Dr. Daniels: Ellen, this is Susan. I have heard HCBS come up now in a few different places. Do you think that you could group some of the home and community based services stuff together into kind of a section for the meeting?

Ms. Blackwell: Yes, sure.

Dr. Daniels: Something you would like to do? And do you all see any themes emerging from what we have already discussed? Is anybody getting some ideas for how this might fit together, and maybe even titles that you might want for the workshop?

Ms. Blackwell: Well, I sort of see it as helping people remain in their communities. Isn't that what Olmstead is about, and ADA and looking at characteristics of what does home and community based mean,

and criminal justice diversion? Isn't all of this about helping people be integrated into community life? Lee, what do you think?

Mr. Grossman: Yes, I agree with having the integration to the community as an important goal. Along with that, though, there would need to be a stronger emphasis on maximizing opportunities and potential of individuals, and that is really where the lifespan services and support come in.

They all may lead to greater inclusion, but we also want people with disabilities to achieve as much as they possibly can.

So I keep harking back to that, because it is really the crux, I think, of what we are trying to do, is to create a strong lifespan support services and support mechanism, and if you look at our list, it is very -- It is piecemeal.

It all comes together, if we can all pull it together, and they are all important aspects of what we are trying to

create ultimately. Somewhere along the line, though -- and that has been my frustration with the first workshop and this one -- is that when does this all become part of a systematic system that is truly working.

Again, I will go out, and I will try and see what I can find, because it is not in the U.S. I might have to locate some people that are familiar with what other countries are doing, because we are definitely not seeing it in the U.S.

Ms. Singer: I don't know if I agree with that, Lee. I think we are starting to see it. I think we are not seeing it from the public sector, but I think we are starting to see it from the private sector, and that is why I keep coming back to this program from SARRC.

They offer services across the lifespan, from the time your child is diagnosed, and now they have residential communities that they are building, and they have job programs, and they have -- you know,

it is interesting. It is not system-wide yet, but it is the seed, and it is happening. People are really interested in it.

So I would love to see somewhere if we could include that, but I was listening to what both you guys were saying and trying to come up with a title, and I came up with "Maximizing Opportunities for Community Inclusion Across the Lifespan."

Ms. Blackwell: Great. Okay. So we will work on this more. Maybe we could work with our other co-chairs as we move forward, Susan, to finalize.

Dr. Daniels: Sure. You know, as you have been discussing this, something that came to mind that has come up a few times in other meetings is supported employment. I don't know if that would fit in with some of your maximizing opportunities, but whether you would want some presentations in that area.

Ms. Blackwell: Yes. I think I talked earlier about the fact that we are working on some guidance here at CMS. I

vaguely remember talking about that, and checking to see if maybe we could get someone to present on what we have on the books now and where we are going, because we do have some guidance in the works.

Dr. Daniels: Maybe Larke might be able to add something to that with SAMHSA's perspective on that.

Ms. Blackwell: Maybe, but I think what we got here is pretty good. Most supported employment programs are coming --or they are Medicaid funded for individuals who are participating in home and community based waivers.

So we have some guidance in the waiver instructions now, but we are getting ready to supplement that with stronger guidance about what we believe is appropriate. For example, shelter workshops may not be appropriate. In fact, our guidance already says shelter workshops are not appropriate. So we do have -- Maybe we could get someone from CMS, the person who has been working on

this, to talk a little bit about what we do think is appropriate for people with developmental disabilities.

Ms. Singer: But, again, I am going to say that for this workshop, which is going to have the town hall incorporated, has more community involvement.

I would go back and say we need to talk about what does that word mean? What does that term mean? What is a sheltered workshop, and how does it differ from --

Ms. Blackwell: Right. Yes, I think that she could do that, Alison.

Ms. Singer: And I think we need more "whys" -- you know, not just this is that, and so we have issued guidance. I think we need -- Parents need to understand what it is, why it is not as good, and what makes a different program better.

I know the government doesn't like to do that, but I think that is where we need to be with this particular workshop. We need to really be in the weeds and say this is what

makes a program good, and this is what makes a program bad.

Ms. McKee: Yes, and Ellen, I was in that education and employment breakout group from the White House event, and there were some interesting people, nonprofit people, doing some interesting things with employment.

I will have to go and pull my list of participants and see if I can come up with some names, but just some really innovative things, a very small scale but interesting things.

Ms. Blackwell: Is that Christine?

Ms. McKee: Yes, it is Christine. I will pull some names and see what we can come up with.

Ms. Blackwell: Or maybe pair the government piece with people who are doing the sort of innovative things that we like here at CMS.

Ms. McKee: Right.

Ms. Blackwell: Sounds like we

have enough thoughts. Any other thoughts? I think we need to think about this a little bit, and then start playing with it.

Dr. Daniels: Yes. So if Ellen and Lee kind of want to work on putting some of that together, what I am hearing you say is that maybe you could have some government speakers paired with private sector speakers who are actually on the ground doing things, and then have the sessions kind of organized that way, so that you have both kind of policy perspective and the practical perspective, and Alison talked about having kind of 101 type maybe intros to give some introductory information about what these things are, designing them, and maybe what some of the pros and cons are of different things before maybe having other presentations.

Is that what you were saying? Does that sound accurate?

Ms. Singer: Yes.

Dr. Daniels: Okay. I think that is really a good basis to go on, and I think,

Ellen and Lee, if you want to start putting some of that together, and I can help you, then we can send it back out to the subcommittee and have people throw forward some -- If everybody on the subcommittee can be thinking of names, and you can even start sending them to us as you think of them, people that might fit into some of what we have talked about today. That would be really helpful.

Ms. Blackwell: Yes, and actually, I hate to say it, but if we are looking at September 15th and 16th, we don't have a lot of time. So we do need to -- because we have to ask people to participate. So, again, we need to be doing things really fast.

So, Lee, you and I will have to work together, and then I thought it worked really well with the seclusion and restraint letter. It actually did work pretty well by email, having people send things in. So that was an effective strategy that we can use for this as well.

Dr. Daniels: Right. And in terms of private organizations that are doing things, if any of you that are on the phone can think of some private organizations that would be good to present on these topics, please send them our way.

Ms. Blackwell: Right, and then we could even send a bulletin out to the subcommittee asking for suggestions as well.

Dr. Daniels: Yes.

Ms. Blackwell: Okay. So our next meeting, Susan, is July 19th.

Dr. Daniels: Yes. The full committee will be meeting on July 19th, and so we will have some time for subcommittee presentations.

As far as I know, it is not a very long time, but I think that you have been very organized in terms of the work that you have done on the letter. So, hopefully, there would be some productive discussion, but perhaps not a lot of dramatic revisions might be necessary, which might mean that you might

not need as much time.

Then with the workshop, if we can begin working on it now, but just give the full committee an update and invite them to also send in any speaker suggestions, etcetera, that they may have. We can do that.

We also can have other updates from the subcommittees at that meeting. I believe that CMS wants to give an update on ICD-9.

Ms. Blackwell: Oh, good.

Dr. Daniels: And wandering issues, and Alison was going to give an update on the IAN Survey. So if there are other items that you can think of for the subcommittees that you want to make sure are mentioned, please send them to me and to the chairs of that subcommittee, so that we can make sure that those are listed. I might not formally list them on the agenda, but at least we will know that we are supposed to go through those.

For the chairs, if you want to

prepare a short slide set with at least just a few bullets of what you are going to be talking about, that would be great.

Ms. Singer: This is Alison. On the wandering survey, I think what my suggestion was -- I am happy to do it myself, but my suggestion was to have Paul Law from the IAN project give the presentation, because he knows the nuts and bolts. Was he not available, and that is why I am doing it?

Dr. Daniels: Oh, I misunderstood that you wanted him invited. So he has not been invited. I can check with him and see if he is available or not on the 19th.

Ms. Singer: Okay, and if not, I will do it.

Dr. Daniels: That sounds good. So we will check with him. I will cc you, and then we will see if we can get him and, if we can't, then if you wouldn't mind doing an update for the committee, that would be great.

Ms. Singer: No, I am happy to, but I think he is the guy for that.

Dr. Daniels: Okay.

Ms. Blackwell: Okay, great. I think that is it for the Services Subcommittee for today. Lee, do you have anything else?

Mr. Grossman: No, just to thank everybody for participating from the two subcommittees and everybody that was listening in. It is great to have your involvement.

Ms. Blackwell: And I am really pleased with the seclusion and restraint letter. I think we have a winner. So that is a really important piece of moving forward. So, thanks everybody.

Dr. Daniels: Thank you, everyone, for your hard work and today's productive call. So I think we are all set for July 19th, unless anyone has any last minute items to bring up. Hearing none, I can say that this call is adjourned. Thank you.

(Whereupon, at 9:48 a.m., the Subcommittes adjourned.)