U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE ON SAFETY

WEDNESDAY, MARCH 16, 2011

The Subcommittee convened via teleconference at 9:00 a.m., Sharon Lewis, Lyn Redwood and Alison Tepper Singer, Co-Chairs, presiding.

PARTICIPANTS:

SHARON LEWIS, *Co-Chair*, Administration for Children and Families (ACF)

LYN REDWOOD, R.N., M.S.N., *Co-Chair*, Coalition for SafeMinds

ALISON TEPPER SINGER, M.B.A., *Co-Chair*, Autism Science Foundation (ASF)

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

COLEEN BOYLE, Ph.D., Centers for Disease Control and Prevention (CDC)

LEE GROSSMAN, Autism Society

PARTICIPANTS (continued):

ARI NE'EMAN, Autistic Self Advocacy Network (ASAN)

PETER VAN DYCK, M.D., M.P.H., Health Resources and Services Administration (HRSA)

TABLE OF CONTENTS

PROCEEDINGS

9:07 a.m.

Dr. Daniels: Thank you. Hi, this is Susan Daniels from the NIH Office of Autism Research Coordination, and I'd like to welcome members of the public and IACC members to this call.

So this is a call of the IACC Subcommittee on Safety, and we have a number of interesting agenda items to discuss this morning.

I'd like to start with a roll call of the members of the committee, so, our three co-chairs, Sharon Lewis --

Ms. Lewis: I'm here.

Dr. Daniels: Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Alison Tepper Singer?

Ms. Singer: I'm here.

Dr. Daniels: Coleen Boyle?

Coleen, are you on, or can you hear? If you're having trouble, you may want to try dialing in again.

Dr. Boyle: Can you hear me?

Dr. Daniels: Yes, I can hear you.

Dr. Boyle: Okay, I'm here.

Dr. Daniels: Great. Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Ari Ne'eman?

Mr. Ne'eman: Here.

Dr. Daniels: And Peter van Dyck? I wasn't sure if Dr. van Dyck was going to be able to join us.

So I'd like to first take us through the approval of the minutes from January 12th. Do any Committee members have any comments on these minutes, any corrections?

Ms. Redwood: I thought they looked fine, and I make a motion to approve.

Ms. Singer: I second.

Dr. Daniels: All in favor?

(Chorus of ayes.)

Dr. Daniels: Anyone opposed? Okay, the motion carries, and we will accept the minutes as provided for you, and those will be posted on the web shortly.

And at this time, I would like to turn the meeting over to Lyn Redwood to begin the discussion of our different agenda items.

Ms. Redwood: The next item on the agenda is update on the letter to the Secretary. Susan, could you walk me through that?

Dr. Daniels: Sure. So, I just wanted to give you an update on this letter to the Secretary. At the last full IACC meeting, the majority of the committee voted to send a letter to the secretary, and after the meeting was over, we had some email back and forth just to make some minor adjustments that were discussed in that committee meeting, and the letter was finalized and sent on February 9th.

And it has been received in HHS, and I assume that a response will be coming fairly soon. They do have a particular time frame in which they need to send a response. So I'm sure that by the next full IACC meeting, you will have received the response to this letter.

So I don't know if anyone has any other questions about it, but we have assured that it has been received.

Ms. Singer: So, the next IACC meeting, we should have the response prior to April 11th?

Dr. Daniels: I believe so. I think that the time frame for response to one of these letters is within that, so I think you'll have it before then. You know, I can't control that, but I assume that that will happen.

Ms. Redwood: Susan, should we follow up in any way, just to get an idea and let them know we have an upcoming meeting, and

it would be wonderful to have a response from the subcommittee?

Dr. Daniels: I don't think it's necessary, because they're required to respond within a certain number of days, and that's going to fall well within the time before the meeting.

However, if we're a week before the meeting and we have not received a response, I can always send a note up and see if they're forthcoming with a response. So I'll be happy to do that, to give myself a reminder to check up on them if they haven't responded by then.

Ms. Singer: Is the response a matter of public record? Does she respond -- I mean, does the response go to you, Susan, or is it posted, or how does she respond?

Dr. Daniels: It will come to my office, and so once I receive it, although technically, the letter from the Secretary is not a FACA material because this committee has

been involved with this, of course, we will provide it to you, and it will be provided to the public, too, so they can see what that letter looks like. And eventually, I'm going to have a special place to put this letter of the response on our website. But for right now, it's available. Anyone who's in the public who wants to see the original letter that went up to the Secretary, it's included in the meeting materials for this meeting, and it's posted on the web, so you can easily access it. And if anybody else needed a copy, they can always send an email to our office.

And so, we certainly will let the full IACC know as soon as a response comes in, and then at the April 11th meeting in the business section, we will discuss the response that I'm sure will have come by then.

Ms. Redwood: Does anybody else have any questions regarding a letter to the secretary?

If not, we'll move on to agenda

item number two, which is an update on the ICD-9 meeting, the next steps.

Dr. Boyle: This is Coleen. I can't hear Lyn at all. And I don't know, Lyn, if you're on a speaker phone? I can hear everybody else very well.

Ms. Redwood: Is this better?

Dr. Boyle: Much better, thank you.

Ms. Redwood: Okay. I'm sorry. That's interesting. I was on a land line versus my cell phone, so my cell phone actually is better.

Dr. Boyle: It's perfect. Yes.

Ms. Redwood: Okay. The next item on the agenda is an update on the ICD-9 meeting and next steps, by Dr. Boyle.

Dr. Boyle: Sure. I'd be happy to -- thank you, that's why I wanted to hear you, so, thanks.

(Laughter.)

Now, as you all know, we've

developed a wandering code proposal to address the data in these -- really, the paucity of data in response to concerns about safety that were raised at the September IACC meeting, as well as our discussion at the first meeting for our Subcommittee, where I said that CDC would take a look at whether or not this was a possibility of investigating whether or not a new code could be developed.

So, from our perspective, the subcommittee really sets the strategy, and agencies then look into whether or not they can implement that strategy.

We did move quickly, and the reason for that was that in starting to investigate this, we learned that there was a time window, the ICD-9 CM was really just entertaining changes up to, I guess this is the last revision that will go into effect before ICD-10 comes out, and that won't be until 2014.

So this was an opportunity, and

the proposals were actually due on January 7th, 2011, so just a couple of months ago. And I apologize for the background noise, I am in the airport. So hopefully everybody can hear me. Is that correct?

Ms. Redwood: Yes, we can hear.

Dr. Boyle: Okay, great. So I'll speak louder. So we, in developing the proposal, we were working with the National Center for Health Statistics Coordinating and Maintenance Committee. That's the group that oversees this process.

I had not been and my group had really not been through this process before, so they really guided us in terms of the development of the proposal.

And essentially, what this is is a code for wandering and diseases classified elsewhere.

And I do want to emphasize that we followed the regular process for the National Center for Health Statistics Coordinating and

Monitoring Committee schedule, so this wasn't an expedited review or a special review or anything like that. It was just part of their regular process.

And just to go through what that process was, just very, very quickly, the tentative agenda for which codes were going to be added was initially posted by NCHS on their website on February 8th. And at that time, the wandering code was included in the tentative list.

And there was call-in information included in that tentative list for their upcoming meeting. And then there was a Federal Register notice on February 16th. And again, the wandering topic was included within that Federal Register notice.

And then there was a meeting last week, I guess, on March 9th and 10th of the maintenance -- the Coordination and Maintenance Committee, and the documents for that were actually available ahead of time.

And according to NCHS, this was sort of one of their first meetings where they've done that, because they've gone green, and they've made everything available prior to the meeting.

So, again, in terms of full disclosure and letting people know what's going on, I think that that has happened. And what we are told is that the materials and a summary of the meeting will be posted within a week on the website for anyone who wants to review or wasn't able to listen in -- I guess they had about 250 lines, as well as people who were able to attend. And then there's also opportunity to comment.

The meeting discussion itself was much -- very technical, and sort of, where's the best place to put the code. And again, my understanding from talking to the woman who oversees this process is that the committee determines whether the code sort of fits within the classification concept, and

wandering, as you know, you alluded to that we discussed this back in September, or our first meeting, whenever that was, that wandering is a concept that's already included in ICD-9 specific to two conditions, Alzheimer's and vascular dementia, and that ICD-9 clearly classifies as diseases, disorders, and syndromes, as well as a wide variety of signs and symptoms, including behaviors and risk factors, so it's not just sort of medical conditions.

And to give an example, and this is an example that was given to us, is that there is a code for stereotypic movement disorder, body rocking and head-banging. So again, just trying to emphasize that not all the codes are medical.

And importantly, the proposed code would not be part of the diagnostic code used for autism or other developmental disabilities, but really could be used in conjunction with other diagnostic symptom or

procedure codes. So it's really kind of a stand-alone, secondary code in that way.

You know, the coordinating and maintenance committee has received comments, I understand, and we'll review all of those comments. And the committee does not consider, in making their decisions -- and again, I don't want to speak for the committee, but this is my understanding of it, it does not consider alternative uses for the code, because that's, you know, and I guess an example might be, you know, a billing-related issue, because that would sort of paralyze them from trying to determine every use for the code.

But they do consider if the information for the code will be something that would be available from a medical record, so I think that's a very important comment. And a couple of comments, I think the -- I don't think, I know the public comment period ends on April 1st, close of business, so if

there are issues that you also feel that need to be raised, this is the formal way to do that.

So just in summary, you know, I think we were responding to the need expressed from this subcommittee. We did move quickly based on the deadlines and the opportunities that we knew would not be available. And we followed the process, and the process is a very standardized process that -- and as those of you who did listen in and did see the agenda, wandering was one of, maybe, I don't know, 30 different proposals that were reviewed during that two-day committee meeting. So that's it.

Mr. Ne'eman: So, Coleen, this is Ari.

Dr. Boyle: Yes.

Mr. Ne'eman: Just a quick question here. So I know that the agenda with wandering on it has been available to the public since February, but the specific

details of the proposal, the information that we have had available to us as IACC members, and that you mentioned was made available to the public prior to the meeting, when was that made available to the public?

Dr. Boyle: The actual proposal itself, Ari?

Mr. Ne'eman: Yes.

Dr. Boyle: According to my notes, I think that was made available just prior to the meeting. So there was a Federal Register notice on 2/16 that wandering topic would be included.

There was a tentative agenda posted for the meeting, but the document with all the proposals, not just the wandering proposals, all three proposals, I think was available on the day of the meeting, electronically.

Mr. Ne'eman: Okay. So the fact that it was on the agenda is available beforehand, the details of what's on the

agenda is made available the day of?

Dr. Boyle: Right. And I think all the proposals were still being finalized, Ari.

Ms. Singer: Coleen, for members of the public who are listening in, can you share the URL where people who are interested in making a public comment can do so?

Dr. Boyle: I don't have it, but I know it's on the -- because I'm in the airport, but I know it's on the IACC website under non-IACC sponsored activities, right, Susan?

Dr. Daniels: Yes, it's on the left navigation of the IACC website. There's a tab for non-IACC meetings, and the ICD-9 meeting was listed there, and there were links to some of these materials that you all just mentioned.

And there is the email address for Donna Pickett, who is the person that is going to be receiving the public comments. And the

deadline is there, so I believe -- is it already in a past meeting -- oh, so it's already -- it's listed as a past meeting at the bottom of the page, so I think anyone in the public should be able to find that information. And if you have trouble, just email our office.

Ms. Redwood: Coleen, this is Lyn. I want to thank you and CDC for moving so quickly on helping to establish some type of code for wandering so we can collect necessary data, and try to determine the extent of this, and possibly even help parents whose children are wanderers to prevent the tragic consequences that can occur.

Does anybody else have any questions on item number two regarding the ICD-9 meeting and the proposal for wandering code?

If not, we'll move on to the IAN survey.

Alison, can you walk us through

what's transpired to date?

Ms. Singer: Yes, happy to. As we've been talking about, there is a true lack of data regarding the critical safety issue of wandering. So we've been moving forward quickly with the survey through IAN.

As you'll recall, this project is being jointly funded by the Autism Research Institute, the Autism Science Foundation, Autism Speaks, and the Global Autism Consortium, which includes the National Autism Association and SafeMinds.

And I think I speak for all of the funding partners when I again extend sincere thanks to Sheila Medlam and to everyone at the Mason Allen Medlam Foundation for everything that they have done to support this project as well.

So, as I said, this survey is being done through the IAN network. It's the Interactive Autism Network, which is a database with over 36,000 participants

registered.

It's the largest pool of autism data in the world. It's overseen by Dr. Paul Law and his very dedicated and committed team at the Kennedy Krieger Institute in Baltimore.

And the IAN database has been funded in the past by -- and in the present by Autism Speaks and the Simons Foundation.

So this will be the first study of wandering and elopement behavior, and the survey is designed to help researchers begin to answer important questions about wandering, such as, how often do individuals with autism attempt to elope, how often are these attempts successful, under what circumstances are they successful, which individuals are most at risk, is there a specific age at which individuals are at greater risk, how do efforts to prevent wandering affect caregivers and families, and what can be done to protect individuals with autism and support their families?

So, to really understand the issues of wandering, we need to be gathering information both from families of individuals who do wander and families who have individuals with autism who do not wander.

So, really, in order to determine who's at risk, we are going to be encouraging all families in the autism community to participate in the survey, whether or not their family members engage in wandering behaviors or not.

So the survey's going to be sent to a sample of IAN users, again, not just people whose family members are wandering, but a representative sample of the IAN database.

So where we currently stand on the survey is the survey design has been completed, the questions have been reviewed and revised by a panel of experts, and the project is currently in the final phase of IRB review at Kennedy Krieger.

We expect to launch the survey at

the end of this month, and we expect to have preliminary data available very quickly.

The IAN network is extremely robust and flexible, and we expect to be able to report data stratified by age, by location, by behavioral features of autism, by behavioral antecedents, and by a number of other variables.

So, as we've talked about in the previous topic, collecting data is always a critical step in solving any problem. So, on behalf of all of the funding partners, I want to just thank the entire autism community for coming together so quickly and so strongly to literally try to save our children's lives.

So the truly tragic stories of children with autism who die as a result of wandering, either by drowning, by car accidents, by exposure to the elements, continue to mount, so I want to thank everyone who has supported this important step towards protecting our children and saving our

children's lives.

Ms. Redwood: And Alison, I want to thank you personally for helping to move this forward so quickly, approaching the IAN network to conduct the survey, and orchestrating a lot of the details.

Dr. Boyle: Thanks.

Ms. Redwood: Does anybody have any questions about the survey?

(Pause.)

Hearing none, we'll move on to agenda item number four, which is an update on the HRSA survey from Dr. van Dyck and Coleen Boyle, Dr. Boyle.

Hello?

Dr. Daniels: I don't believe that Dr. van Dyck is on the phone. I don't know if Dr. Boyle might have some comments on this area.

Coleen, do you have anything to update us on, with regards to the HRSA survey?

Ms. Redwood: I know Coleen

mentioned that she was in the airport. I'm wondering whether or not she's already boarded her plane.

Dr. Daniels: Perhaps, so maybe we can come back to that at the end, and see if anyone's on who can update us on that.

Ms. Redwood: Would it be possible, Susan, to send Dr. van Dyck an email to see if he could join us, if maybe he's --

Dr. Daniels: Sure.

Ms. Redwood: That would be great, to update us on this item.

In the meantime, let's move on to item number five, seclusion and restraint.

Sharon Lewis, you were going to -- you asked that this item be added to the agenda?

Ms. Lewis: Yes, so, thank you. And really, I was hoping that we could start a conversation about how the subcommittee on safety might want to begin addressing this concern, as my understanding is that that one

was the primary reasons that the safety subcommittee was formulated.

And I know that we've had a lot of conversations about the wandering issue, and now that the letter has gone up to the secretary, I'm wondering if we want to begin some conversation around seclusion and restraint issues.

Really, the issues fall into a couple of discrete categories based on environment, in terms of the federal policy intersection. As many of the IACC members may know, the Children's Health Act of 2000 specifically addressed the issue of seclusion and restraint in community-based facilities, yet there have been no regulations that have been promulgated on this issue defining the extent of the entities that are covered under those provisions of the law. So that is one question that I think the IACC may want to discuss.

And then secondarily, as we all

know, there has been extensive press, as well as attention, legislation in the last Congress, I believe some of it will be reintroduced in this Congress by several members, related to seclusion and restraint in the schools.

And the Department of Education has collected -- has started data collection on this issue, and I'm wondering if this is a topic for which the Safety Subcommittee wants to engage further, potentially work with our partners on the services subcommittee, and move forward in terms of particular recommendations.

Ms. Redwood: Sharon, I know you're new to the committee, but do you have any idea what has transpired so far in the services subcommittee regarding seclusion and restraint?

I know it's been a topic that's been brought up before. What are their recommendations?

Ms. Lewis: Lee, could you answer that?

Mr. Grossman: Well, it's -- while there haven't been recommendations that have come out of the services subcommittee, it has been something that obviously we have discussed.

We were tracking and for the most part looking at the legislation that was introduced in the last Congress, because that was apparently the best attempt that we were going to have at getting stronger and better national efforts to respond to the seclusion and restraint at the school level. This is a big issue in terms of not only at the school level, but caregiver level, and elsewhere.

And Sharon, I was going to ask you the question of -- and because you're probably the most knowledgeable about this of anybody, is, are there recommendations that we can make out of the IACC that you think will be impactful on this, that go beyond what is

currently in the legislative effort? Do you have some specific thoughts on that?

Ms. Lewis: Well, I think within the purview of the IACC, one of the things that we might want to think about is requesting an update from SAMHSA and CMS on the Children's Health Act regulations and getting a status update on whether or not there is any -- there has been any activity to promulgate regulations related to the existing statute.

In terms of, you know, and then additionally, we may want to ask our Department of Education partners for an update on what they have learned. I know that their ability to regulate seclusion and restraint in the schools at this point is not within the bounds of their authority. That's why there was some interest in pursuing federal legislation.

That being said, I think that Secretary Duncan took a fairly strong stand in

directing states to look at this issue, collect data, and report back to the Department of Ed on their efforts to reduce seclusion and restraint in the schools.

And it might be of value to look at what's happening and get an update on these issues at another -- at a full IACC meeting, or within the subcommittees, and then from that, look at whether or not there are additional administrative activities that could take place.

Absent federal legislation, I believe that it will be very difficult for the Department of Education to do much beyond collect data and provide guidance.

Mr. Ne'eman: Sharon, this is Ari, and actually, maybe it would be better to direct this question to Ellen, but I also like your thoughts.

You know, thinking back, just within the constraints of HHS, because that's where we have the authority to make

recommendations directly to the Secretary, my understanding is that some degree of Medicaid funds do go to the schools for various types of medical services.

Is there any possibility that that could be used as a point of leverage, to some degree, to give CMS some authority to look at how this issue is playing out in the school system?

Ms. Lewis: I think it's difficult to use that hook for a variety of reasons, in part because I think that what the research has shown is the most successful attempts to manage seclusion and restraint in the schools is when it's done systemically.

And Medicaid billing by the schools is not done systemically. It's done on an individualized basis. And so I think that that would be a difficult implementation issue in terms of trying to use the Medicaid tie-in.

And I think a similar difficulty

exists in terms of the schools, specifically related to the Children's Health Act language of 2000, because that is tied in to entities that receive funds under the Public Health Service Act, which is not all schools.

Mr. Grossman: Sharon, this is Lee. I think there is a strong appreciation from those that are familiar with this topic of how rampant seclusion and restraint is going on.

The GAO study that came out that prompted Chairman Lewis in the legislation really --

Ms. Lewis: Chairman Miller?

Ms. Redwood: Yes, Chairman Miller, sorry. I elevated you there. Sorry.

And I just got off a plane myself. I was on a red-eye all night, so a little foggy here.

But the GAO report just showed how terrible a situation this is for seclusion and restraint throughout the nation. And so, at

least for me as an IACC member, I'm struggling to figure out how it is the best we can respond.

This is primarily an education issue, and Ari so well pointed out that our authority really is to the Secretary of HHS, who --

Mr. Ne'eman: We've made recommendations that are outside of HHS before. I, you know --

Ms. Lewis: So, you know, so I think -- and I think you guys are right. So I think that's why certainly, looking at the Children's Health Act and where we're going with that is one element that's directly within the purview, but then I also just wonder if utilizing the IACC to potentially gather some information and again, create recommendations perhaps related to guidance or other administrative activities that may be pursued to improve the situation, you know, absent legislation, I think that one of the

things that we noted anecdotally, and again, I want to stress that this is anecdotal and not a research-based observation, is that simply by virtue of the hearings, the debate about the legislation, the collection of data and the Department of Education's interest in this topic, we certainly heard from school districts and individual school buildings and states that were taking a look at this issue, utilizing the attention to generate awareness and consider opportunities to define policy consistent with best practices, and really, you know, move towards the culture change that I think is going to be necessary to really address this issue.

And I think it is across settings, as Lyn had noted, the New York Times article in this weekend about caregiver abuse, seclusion and restraint is a significant component of that. And, for example, Michael Carey, who is a parent who is quoted in the article, whose son died in a facility in New

York, his son was one of the GAO case studies in terms of individuals who were subjected to inappropriate restraint and seclusion.

He was in one facility in which he was inappropriately secluded, and in a second facility in which a staff person inappropriately restrained him in a vehicle, and that's how he was killed.

So I think that this is a critical issue across settings. And, you know, in terms of injuries and fatalities, it is, you know, it is an emergent -- and I don't even want to say emergent, an urgent issue that we need to begin to get our arms around, and better understand what is -- where there are opportunities to influence across federal agencies.

Ms. Redwood: Susan, this is Lyn. I have a question with regard to all the requirements of the IACC as a FACA committee. Are we allowed to establish a task force to address such critical issues?

Dr. Daniels: You are allowed to establish working groups. The full committee can establish a working group if they feel the need for a working group, and working groups can include people who are not a part of the committee.

But they are temporary. They are not standing groups that can stay forever. They can come in to do a task, and then they're done. But often, the full committee chooses to use a subcommittee.

What kind of thing did you have in mind?

Ms. Redwood: Well, I was thinking, just based on what Sharon had shared earlier, that one of the things we need to do is to get these reports back.

Sharon, you had suggested updates from the Department of Education. I would like to see a request go out for those to the IACC committee members that represent those agencies, and ask that it would be possible

for those reports to be ready by the next IACC meeting, and have this as an agenda item, and consider it at that time with the full committee, because it is such an urgent need to establish a task force with the goal of coming up with some type of white paper that would provide guidance for what the task force would see as being the most appropriate way to respond to this issue.

Dr. Daniels: Well, that's certainly something that the full IACC in April, if they decided they wanted to establish a working group to work on this, in terms of requesting data, we likely can do that.

I'll need to look into what the specifics are, and I can get back to you all after this meeting.

Mr. Grossman: Yes, Lyn, this is Lee. We at the Autism Society have put out quite a bit of information that could essentially be compiled to become a white

paper on this issue.

Jeff has done quite a bit -- Jeff Sell has done quite a bit of work on this, and we have data from many states. We know what states have training mandated in their state legislation.

Unfortunately, most of those states' programs aren't working well, because the rate of seclusion and restraint in the schools has not diminished in most of the states.

So that information is already there, and I think can be fairly easily compiled and put into a report.

Mr. Ne'eman: One thing that does occur to me is, it would seem to an increasing degree, Secretary Sebelius and also Secretary Duncan in the Department of Education are playing a vocal voice in some of the legislative policy debates that are going on.

So, I mean, I think even if one element of what we do with this is we

communicate very clearly, and I don't know if it's through a letter or some other means, to Secretary Sebelius that we would like her to be a very active voice in encouraging a comprehensive effort to stop restraint and seclusion to be included in the Elementary and Secondary Education Act by Congress, you know, I think that that could have some impact, if only to really send a message to advocates on the Hill that the IACC and as a result, to some degree, the autism community is really very strongly behind comprehensive legislative action on this matter.

Ms. Singer: This is Alison. I think one piece of data that would be very useful would be to have a one-page graphic that really outlined who has responsibility, who has authority. Because one thing we hear over and over when we talk about seclusion and restraint is, it's the executive branch, it requires an act of Congress.

So, I think often, we end these

discussions, and there's really no resolution on the action steps because there's confusion with regard to who has the power to pull the levers.

Ms. Lewis: And can I jump in here for a second? I think that you're right, and I think that you could actually pull most of that out of the GAO report. And in terms of a better understanding, there is not going to be a single lever. I mean, I think that's part of the issue here is that -- that's why I started my comments with acknowledging that there are discrete issues related to particular approaches within different settings.

And what the bounds of current federal law provide the authority for, for example, when we're talking about entities like the -- entities primarily discussed in the New York Times article that are primarily receiving Medicaid funds, there are very strong regulations in Medicaid policy around

the utilization of seclusion and restraint and what's allowable.

The place where there is very little federal regulation is around the schools and around these community-based settings under the Children's Health Act that may fall into kind of a gray area in terms of receipt of federal funds.

So I agree that -- I mean, we can look at trying to clarify that in a simple way, but it is not -- I guess, part of my point being is that it is not going to be simple, because there are different regulations depending on the setting and the particular federal funds that are coming into that setting.

Ms. Singer: I totally agree with what you're saying, but I think what we're experiencing is as a result of that, we tend to have this conversation over and over, and it doesn't move from the point of all of us agreeing that action needs to be taken to the

point where we are taking action. So maybe one next step is to choose one lever from among the many, and go after that forcefully, and try to achieve change through that single lever, and then move on to the next. Or maybe work on two.

But I think we've really been stymied by this notion that there are so many groups involved and agencies involved, and so many issues to tackle.

My recommendation would be that we should try to identify the one or two areas where we can affect real change, where we would, as a subcommittee, have impact, and target that one, acknowledging that it won't solve the whole problem, but at least it's a foot in the door.

Ms. Lewis: I agree. And I think from my perspective, the probably -- the two places to potentially start that conversation given the jurisdiction of -- well, jurisdiction isn't the right word, but given

the purview of the IACC is looking at the Children's Health Act of 2000 and the regulations necessary to implement that statute as it is an existing statute and it is HHS, and then, secondly, whether or not there is an opportunity to consider additional guidance on an administrative level to the school systems, you know, in partnership with the Department of Education.

Ms. Singer: Now, what would your recommendations be for first steps for each of those two things? Not to put you on the spot or anything, Sharon.

Ms. Lewis: No, that's fine. So I think, you know, I think one thing, I mean, certainly for the -- you know, given that we don't have representation from the Department of Education in this subcommittee, I think that before we can -- you know, before we make recommendations about what they should be doing, we need to better understand what they're doing.

So I think a first step from -- in terms of addressing the schools issue is getting an update from the Department of Education to the IACC about their activities to address seclusion and restraint in the schools, their data collection activities, and, you know, frankly getting a sense of whether there's an opportunity to work collaboratively on guidance.

Ms. Singer: So, Susan, can we on the subcommittee make that request of the Department of Education representatives to the IACC, that she make that report at the April 11th meeting?

Dr. Daniels: Right now, I don't know that we have enough time on that agenda, but what I would suggest is that perhaps you call another subcommittee meeting and invite these people here. So invite SAMHSA, Department of Education, and HRSA to come and give you a report at a subcommittee meeting, and we can organize a subcommittee meeting as

soon as we're done with this one, if you can choose a date.

Mr. Grossman: Might we add CMS to that list? It would seem that they have some relevance here as well.

Ms. Redwood: Susan, is the agenda already completely full then for our meeting in April?

Ms. Singer: But what is more important? I mean, what's on the agenda?

Dr. Daniels: Well, we have invited a number of people from HHS and from the Administration to join us, so we have a number of activities around HHS Autism Awareness month. However, those --

Ms. Singer: Well, that's good because then they can hear this.

Dr. Daniels: Right, it's just that we've -- we currently are ending at 5:00 unless we extend it. Or some of these planned items might not come to pass, and then we might have more time on the schedule.

So, but I would suggest that you would perhaps want to just do this in subcommittee first, and do some data gathering, and then present it to the full IACC.

Ms. Lewis: I think that perhaps Susan is right. I mean, I think that, you know, again, getting our arms around what it is we'd like to bring back to the full IACC, in terms of being able to speak explicitly about the status of both the Children's Health Act and the Department of Ed activity, and then, as Lee has so graciously offered, any additional outside data that may be available, compile that at the sub-committee level, invite in our partner agencies to help us understand that landscape, and then go back to the full IACC with a recommendation in terms of, you know, task force or additional action.

Mr. Ne'eman: So, I agree. This is Ari. I agree that we may get more done on this if we address it as a subcommittee first.

But I don't want to detract from the urgency of this matter, you know, given the overwhelming evidence, research, and information that we have that it is a really pressing problem.

Is there any way that we can schedule a subcommittee meeting before the next IACC meeting? That way we can get this updated and really begin to discuss the possible policy solutions and policy recommendations even well before, you know, the next IACC meeting occurs.

I know we're under some restrictions because of when we put things in the Federal Register.

Dr. Daniels: Yes, you have a 30-day window, and it's already passed. The next IACC meeting is on April 11th, so we're clearly not within the 30-day window to make this announcement publicly about a meeting, so it would have to be after the full IACC in

April.

Ms. Redwood: Susan, could you send us the agenda for the next IACC meeting, the draft agenda?

Ms. Singer: Maybe we can eliminate the round robin at this meeting, and use some of that time for the Department of Education?

Dr. Daniels: There isn't a round robin planned right now, but we're working on that agenda, and we'll share it with you as soon as it's more solidified.

Ms. Singer: But I think the fact that HHS representatives are coming to this meeting makes it a perfect opportunity to have someone from the Department of Education.

I would also say, another potential avenue would be to invite the Carey family to participate in public comment, and describe their experience through the public comment vehicle, if we can't get the Department of Education on the agenda.

Mr. Ne'eman: I think that's a great idea.

Ms. Redwood: Yes, and also, one of the things about the task force that would be nice is that we could include stakeholders like the Carey family, the advocacy organizations like ASA, Autism Speaks, the National Autism Association, to participate, as well as representatives from federal agencies, so we could really get our arms around this issue and try to move forward as quickly as possible with the development of a white paper that could then be shared extensively.

So, I'm wanting to see if we could possibly go ahead and sort of come to some decision on this. Would it be possible to go ahead and approach the two recommendations that Sharon had?

First would be to look at the Children's Health Act of 2000 and the regulation, and to see what the status is with

regard to how they are implementing the statute now, who would be the best person to ask for that information?

Ms. Lewis: I would probably start with Larke Huang. And I'm happy to touch base with her and see where they are, if any place, on those regulations.

Ms. Redwood: That would be great. And then you were also suggesting the Department of Education to see what their activities have been to date to address the issue in the school system, and if there's any opportunity to work with the Department of Education on this?

Ms. Lewis: Yes, so I think since Gail Houle has been representing the Department of Education, I think we'd start with her. Certainly Alexa Posny, the Assistant Secretary has been well-versed in the dialogue and debate on this issue, and I don't know what they will have to add at this point.

Ms. Redwood: So, Sharon, do you want to touch base with them off-line and gather information in writing, or by conversations and then decide whether you want to invite them to -- at a meeting?

Ms. Lewis: So, what I, you know, I guess I'm just wondering about sequencing here. If what we'd like to do is get an update from them at the next safety subcommittee meeting, it sounds like that's going to be mid-to-late April at best, given our 30 day Federal Register requirement.

And frankly, I think that it's only fair to give them that amount of time to gather the information and be able to provide us comprehensive response to these questions.

So I would suggest that, yes, what we do is we invite both -- we invite SAMHSA, CMS, I think -- I don't know if HRSA has a role or not.

I think it's been primarily CMS and SAMHSA looking at the seclusion and

restraint issue, but we can -- Larke will know -- and the Department of Education, to provide that information to the safety subcommittee.

And I understand that it's frustrating that we have this missed opportunity in terms of the April IACC meeting. Perhaps what we can do is update the full committee on this conversation and suggest the need for -- that we may be looking at a task force or other activities depending on what we hear back from the federal partners in late April.

But I don't see -- it seems to me that trying to push this into the April 11th agenda when we're not certain what the landscape even looks like currently is not going to be productive.

Ms. Redwood: Well, Sharon, why don't you reach out to them and then see just at the outside chance that maybe they already have a report compiled, or that there would be some information that we could share with the

committee.

And Susan, we will have an opportunity for subcommittee updates at the April meeting?

Dr. Daniels: Yes, you will have a subcommittee update for the safety subcommittee, and there will be a services subcommittee update. The planning subcommittee hasn't met recently, so they don't have an update.

Ms. Lewis: And can I just circle back? Lee, in terms of, you know the services subcommittee, did you guys have anything more concrete, or do our have any suggestions on how we might best coordinate on this, and does it make sense?

And I don't know if I'm breaking all kinds of boundaries here. Susan, jump in and tell me if I am.

But does it make sense to consider, you know, a joint services and safety subcommittee meeting in which we ask

these federal partners to present the information?

Dr. Daniels: We can do that. We can -- we've had joint subcommittee meetings before. It practically becomes the full committee at that point, but we have had those meetings before.

And if we have a date set before April 11th during your update, you can let this whole committee know that you're going to be having this session of the safety and perhaps services subcommittee to talk about this issue, and just let them know, so that way they can put it on their calendars, too. Of course any IACC member or any member of the public is welcome to listen to these.

Dr. Daniels: Lee, what do you think about that as the other services chair?

Mr. Grossman: This is Lee. And this -- there's so much information out there on positive behavioral support and how to handle a situation where restraint may be

involved that can come through the services subcommittee, because these best practices are out there.

I guess one of the things that I think is important is the discussion that we've been having here relates only to the school-aged persons, and these issues extend into the adult sector.

And I think it's important for us to look at what is happening in several workshops, and segregated environments and institutions, et cetera, as important as issue here as what we're dealing with with school-aged children.

The aspect of injury and incarceration and in many, many cases death, as the result of seclusion and restraint are rampant and well-documented, and probably not documented well enough in the adult sector.

So I think that anything that we are doing on the school-age level, we also need to look at it as a life-span problem.

Ms. Lewis: I would agree. I think the question is kind of back to the question that came up earlier in terms of coming up with a manageable scope as a starting point, and it just -- it is, I present this as a question.

Do we want to take a holistic perspective in looking at this across all settings? Because I agree, Lee, there is substantial evidence that we have not managed in particular the issues of seclusion and restraint in, you know, in all kinds of both residential and educational and medical settings, did -- when you had Ms. Huckshorn present at the services day-long meeting, did she have any update on national data?

Mr. Grossman: She, from what I remember, she had data from the program that she was running. I'm not -- I can't recall if there was much on a national level that she was presenting.

Mr. Ne'eman: Sharon? This is

Ari. I'm just curious. I know ADD funds some of the best data collection system.

Do the National Core Indicators Project -- does the National Core Indicators Project or the UCEDD network have any useful data for us on this?

Ms. Lewis: I don't know whether NCI includes seclusion and restraint data. I'd have to look. And there is no systemic seclusion and restraint data collection that I'm aware of that our university network is currently collecting.

I think one of the things to note about many of our data projects is that they are somewhat dependent upon the data collection that exists within the systems, and then what the projects often do is take that information and aggregate it and dis-aggregate it and analyze that information, and what we know about seclusion and restraint is that we do have a data collection problem.

Ms. Singer: But that data

collection problem is not going to go away. And what we do have in terms of seclusion and restraint is plenty of white papers already gathered, as we pointed out, plenty of groups that have already presented on and spoken about this problem. And it's just so frustrating to me to continue to listen to this conversation over and over and to realize that we are missing out on an opportunity when we have HHS officials coming to the April IACC meeting to still be talking about a joint subcommittee meeting.

What is the downside to presenting this at the April subcommittee meeting? To me, it can only move things forward.

Dr. Daniels: Alison, this is Susan. I would just mention that previously, when the subcommittee tried to bring issues forward that they hadn't fully, thoroughly discussed, it was not as successful in full committee.

Ms. Singer: How much more can we

discuss it?

Dr. Daniels: This is your first discussion on this topic that you've ever had. It's only been half an hour.

Ms. Singer: Okay. But so this group has not discussed -- but it's been discussed in the services, there were panels at the services symposium, other groups have discussed it, members of the committee have discussed it in their own organizations and in other symposiums.

I don't think the committee disagrees on the presence of the issue or the seriousness of the issue or the fact that, you know, every minute that we're sitting here talking about the procedures here that people's lives are at risk.

It just seems irresponsible to me to continue to talk about procedure this way when we have this opportunity in April to actually affect real change.

Dr. Daniels: But are you ready to

make a recommendation already? Have you -- do you feel like --

Ms. Singer: Not to make a recommendation but to hear, as Sharon suggested, a report from the Department of Education official about what she's identified as item two, providing administrative guidance to schools, and for that to be given in the presence of HHS officials, so that we then skip that step.

I mean, sure, she can present that at a subcommittee meeting, but that subcommittee meeting won't involve HHS officials, so it won't be as potent.

Why would we miss this opportunity in April is my question to the group. Not to make a recommendation, but to gather information in front of a larger group and in front of HHS officials from the Department of Education. What is the downside to that?

Ms. Lewis: I think -- I can tell you as a federal official, if we want to get

the best information from the Department of Education in terms of a comprehensive understanding of what they have been able to do administratively in -- you know, since this issue really came to light in the last -- really, it's been in the last two years where there has been a very focused effort on behalf of Congress and the Administration in terms of understanding the data collection, I think if we want to get a truly informed and comprehensive update, I do not believe that there is any report as you were wondering if there's something that they could -- that exists that they could report on.

I believe that we will be asking them to be pulling information together for this meeting, and if -- I think some of it is really getting a sense from them on when they may be able to do that, given the constraints of the federal agencies in collecting such information, and then putting it together and getting through clearance processes and making

it publicly available, and whether this is an adequate amount of time, and whether there's enough time on the agenda.

I would like to see a more substantive conversation and not a five to ten minute update, which, what I'm hearing from Susan, giving the Autism Awareness activities and the various competing factors on the April agenda, I'd like to make sure that we're doing this in a thoughtful way where we have enough time for a robust conversation on the issue.

Ms. Redwood: What if we, at the April meeting, during our report from the subcommittee, at least make the request at that time to establish a working group, acknowledging the fact that we need to bring together expertise that's outside the IACC to really address this issue comprehensively, and at least get permission at that time to establish this task force or working group, and then have a working group meeting -- or establish a task force, bring them together,

and have an official report and possibly an hour on the agenda at our next meeting, which, Susan, is that in June?

Dr. Daniels: July. July 19th, I believe.

Ms. Redwood: In July, and then at that time, we would have the report from the Department of Education and HRSA and hopefully much more information and possibly even compiling a guidance document.

Would that -- I think that might help to address the sense of urgency that we all feel with this.

Does that sound like a viable alternative to at least get the conversation rolling in a more substantive manner than waiting for more reports and more research?

Ms. Singer: I think that's a good compromise.

Dr. Daniels: I think that that's fine. I think, you know, I think that that's a more focused activity that I think is going

to be ultimately more beneficial in moving the conversation forward with the level of urgency that I think we all feel about this issue.

And I think what will be critical is making sure that we have adequate capacity and knowledge on any such task force to put together that kind of work.

I mean, building a white paper in a two-month period is going to, you know, take a substantial amount of time and energy, so I just want to point that out.

Ms. Lewis: Could we have email discussions, Susan, between now and the April meeting, as to what the ideal composition of this task force would be, so we could actually have some recommendations at the April meeting to put forth to the full committee with regard to the composition of the task force?

Dr. Daniels: You definitely can make suggestions to the full committee at the April meeting, and so if you've discussed it ahead of time via email and have ideas of

people that you think would be useful on a working group, you can propose it.

I would recommend that you go ahead and set a date for another subcommittee meeting or a joint subcommittee meeting or whatever you want to have that be as soon as possible so that we can have it in April, because of the 30-day window.

And if you have other data gathering you want to do, you want to have certain speakers come in, that meeting can be as long as you would like it to be, if you want it to be a half a day, a full day, you know, you would have that as a way to bring together people that you would like to have provide you with information for you to formulate any recommendations or whatever.

Ms. Lewis: Well, and I -- I just wonder, given that, does it make sense to use that as the opportunity to really determine whether, you know, I mean, I hate to kind of feel like we're going in a circle here, but to

determine whether or not a task force is necessary, or if there was a, you know, substantive three-hour conversation or meeting, even, whether it's in person or via a conference call, specifically focused on seclusion and restraint with the right people in the room, whether out of that we could gather enough information to bring back to the full IACC and really fulfill our primary purpose, which is, again, to inform and advise in terms of bringing some of these issues to light.

Mr. Ne'eman: I guess one concern I would raise here is, you know, there are the steps that we can take that provide the appearance of action, and there are the steps that we can take that provide action.

Ms. Singer: Exactly.

Mr. Ne'eman: And in some ways, I worry that if we once again delegate responsibility for discussing of this even further, you know, create a new body, a task

force or what have you, which I'm not necessarily averse to, but I'm somewhat cautious with regards to, that's going to be more procedural discussions, and more time spent not discussing specific policy recommendations that could actually make an impact here.

So, one thing I would hope that we could take out of this meeting is a commitment to hold the call either -- or just have a safety subcommittee specifically focused on restraint and seclusion, to discuss nothing else but the policy measures we can take on restraint and seclusion, so that we can not just call attention to this as a problem -- I think every single member of the IACC agrees this is a problem, in some instances, maybe the only thing every single member of the IACC agrees on -- but so that we can actually have some ideas about what we're going to do about it.

Ms. Singer: But I think we have

that expertise on this subcommittee. So why could we not, as part of the subcommittee's report at the April 11th meeting, have some policy recommendations from the members of this subcommittee to address the two items that Sharon has identified as our first initial steps, acknowledging to Lee's point that there are many, many other issues, but that these are the two that we're going to start with, and include specific policy recommendations that we might then turn into some sort of letter or further policy action?

Ms. Lewis: I guess, number one, I don't know that we have enough time in the 15 minutes that we have left on this call with additional items still left in the agenda to get to a place where we are going to have recommendations that can come out of this subcommittee for the full IACC. And so I'm sorry, I know the process pieces feel difficult, and I share your frustration. I feel that frustration every day. It's the

reality of the constraints of operating as a FACA committee and the rules that we have to follow. So I don't --

Ms. Singer: But let's at least try. I mean, we have so many white papers already, all of which make recommendations.

And if we continue this work by email, maybe we would have recommendations that we would all agree on that could be submitted as part of the subcommittee's report. Maybe we wouldn't, but maybe we would.

Ms. Lewis: And that's fine, I think -- I mean, I also, though, think it's really, critically important, and Lee, please weigh in here, that we do this in conjunction with the services subcommittee, given that frankly, they've had much more extensive and substantive conversations about seclusion and restraint than we have within the safety subcommittee.

Mr. Grossman: As much as I'd like

to move this conversation forward, because of the urgency of it, we have April coming up just a few weeks away. And services subcommittee is having their meeting on March 29th.

And there are some urgent matters that I know that I'm going to be asking the subcommittee to consider that we'll discuss during our services subcommittee report in April, at the April meeting as well.

As much as it is an urgent matter on this, I'm just not sure how we're going to be able to put together thoughtful recommendations in the short amount of time that we have.

We can attempt to do it, but it's my understanding that this committee, the safety subcommittee, would have to meet again to agree on what recommendations are going to put forth to the IACC. That's my understanding.

Ms. Redwood: Guys, I hate to

interrupt, but we have approximately 10 minutes left. We still have two items on the agenda, and we need to set a date for our next meeting.

So just to make sure that that happens within the next 10 minutes, could we possibly go to our calendars now and set a date for our next meeting?

And then I would like to move back to the proposal of making the recommendation and present it as a motion to establish a task force to work on this at the next meeting, and see if that carries.

But let's go to our calendars real quick and look at dates for our next call.

Susan, what would be the earliest we could have it? If it takes a month, how many -- what is your process for getting this advertised in the Federal Register, and what would be the earliest date available?

Dr. van Dyck: And Lyn, this is Peter. I've been on the call and I haven't

been able to talk, but I'm now on the right --

Ms. Redwood: Ah, okay, because we were looking for an update, Peter, on the HRSA survey as well.

Dr. van Dyck: Right. When you're ready.

Dr. Daniels: So this is Susan. In terms of the calendar, it would probably be better to do this by email rather than use up precious time on the phone.

I will mention, I believe Passover is in April, and so we usually don't hold meetings during religious holidays to try to accommodate people.

And so I remember that we originally had scheduled our IACC meeting for April 19th and had to move it because of Passover, and so there may be some dates in there that are unavailable.

Ms. Redwood: Well, let's do this by email.

Ms. Lewis: Hi, this is Sharon.

I'm sorry to interrupt Lyn, but can I request that we back up for a second? And would it be of value, and Lee, I'm going to put you on the spot a little bit as the services co-chair, and I know that you may need to go back to your committee to answer this question, but would it make sense to schedule the next safety subcommittee as a joint meeting with the services subcommittee, make it a little bit longer meeting, and explicitly agree to focus completely on seclusion and restraint and the development of recommendations and information that we feel would be most valuable for the full committee to consider in terms of informing them on this issue, whether that means a task force or some other proposal?

To me, that seems like it -- you know, given the level of interest across two subcommittees, the complexity of the issue, the time constraints that we're dealing with, I would like to put forward a proposal that,

in figuring out this scheduling, that what we shoot for is a joint meeting with the services subcommittee, focused on seclusion and restraint.

Perhaps it's a longer meeting, a three-hour meeting, maybe even trying to get some of us in the same room.

Ms. Redwood: Susan, can we do that at this late date?

Dr. Daniels: Yes. It would be after April 11th.

Ms. Redwood: After April 11th.

Dr. Daniels: You can have a --

Ms. Lewis: I thought it was March 29th was the next services --

Ms. Redwood: No, not that we would tag on to the existing services subcommittee, that we would schedule a separate meeting in late April to do this.

Dr. Daniels: Right, and you can have it -- if you wanted to make it an all-day meeting, you could make it an all-day meeting.

We don't have a limitation on the number of hours. Normally subcommittees meet a maximum of like three hours, but if you have enough agenda items to cover an entire day, you could do that and invite all the different people in.

I would just mention in follow-up to the discussion of forming a working group, there are a lot of procedural issues with that. And so, if your interest is getting it done quickly, you might consider just inviting in the members of the public that you feel would be able to contribute to your discussion, just listening to what they have to say, and then having members of the committee do all the writing and so forth to keep it simple and fast, because whenever you start forming a working group with outside folks, there are more procedures involved, and it just takes longer.

Ms. Redwood: Okay, I was under the impression that we could not do that, that

we could not invite people outside of the public to our subcommittee meetings. I know we had tried to do that previously on this committee and were told --

Dr. Daniels: Oh, no, as long as it's an in-person meeting. Right now, you have members of the public listening in by phone. We just don't have members of the public talking on the phone. But if we have an in-person meeting --

Ms. Redwood: I understand.

Dr. Daniels: -- you can have members of the public there. And if you would like to invite some of them to speak to you about certain issues, if you have members of advocacy organizations that you want to hear testimony from, you can invite them to give testimony. But we need to do that in an in-person meeting.

Mr. Ne'eman: So I think that would be considerably more productive than the creation of a task force, just because of the

procedural issues associated with a task force.

The request I would make is if we can put the issue of chemical restraints on that agenda as well, just because I think it's very much related, it's critical, and we weren't able to get to it in time for today's meeting.

Ms. Redwood: Absolutely. Okay, so --

Mr. Grossman: And speaking to the -- I'll put on my services subcommittee hat here. I see no objection to that. And I would support it.

The one caveat is is that that's going to have to be a decision by the committee, and we're going to meet on the 29th.

I would say, let's go ahead and try to schedule it, and I would think that the committee on the 29th would approve that.

With that said, as I mentioned

before, the Autism Society has done extensive work on this as we've worked on the legislation quite a bit, and we -- at such a meeting, we already have recommendations developed that we can come forward with.

Ms. Redwood: Alison, are you okay with that proposal?

Is Alison still on the line?

Ms. Singer: Hello?

Ms. Redwood: Hey, Alison, I was just wanting to touch base with you regarding the proposal that's on the table currently to have a joint meeting, scheduled as soon as possible in April, an in-person meeting, and invite people in for discussion.

Ms. Singer: Yes. No, I heard, I was just on mute. I think that's a good compromise.

Ms. Redwood: Okay. All right. Then let's move forward with that.

And also, Dr. van Dyck, since we now have five minutes left, could you give us

an update on the HRSA survey?

Dr. van Dyck: Sure, I can be quick. Sorry, I've been on the call, but when I went to talk, no one could hear me, so I dialed again.

I think this means the National Survey of Children's Health. It was done two other times, and in the last survey, we came out with the article which was in the annual report of the IACC about the prevalence of autism and other demographic issues.

The National Survey of Children's Health, the new one, has been in the field for a couple of weeks. It takes a year or a little more to do the whole survey. It samples about 100,000 families in the United States and it produces valid state as well as national data.

And one of the findings in the last survey was that about 40 percent of the young children who were ever diagnosed with autism according to the survey lost that

diagnosis over the next several years. And this survey's adding questions to find out a little more about that.

So we ask, age at first diagnosis, or are asking now, age at first diagnosis for autism and autism spectrum disorders, as well as for another group of behavioral and conduct problems and cerebral palsy and intellectual disability and behavioral -- cerebral palsy and Tourette's syndrome, just for comparisons of prevalence and for comparisons across various diagnoses.

And then there will be additional follow-up questions for children who have ever been diagnosed with autism. So we ask questions like the type of doctor who first told you your child had autism, to the best of your knowledge as a parent, did your child ever have autism, what might be reasons he no longer has autism, the treatment helped the condition go away, or it went away on its own, or symptoms changed, or a doctor changed the

diagnosis, but we'll also accept verbatim questions.

And can you help us, as a parent, give us reasons why the doctor or health care professional may have told you that your child had a condition and then told you that he doesn't have it now?

Was there more information? Was the diagnosis changed? Was the diagnosis given to you so your child could receive needed services?

Mr. Ne'eman: Peter, are there any questions, or would it be possible to add questions in terms of whether or not those children or adults, as they become adults, are still utilizing either special education or any other service provision or accommodations of any type?

Because I think one of the things that's come up in our experience is sometimes, people who are un-diagnosed are then, later in life, re-diagnosed when it's recognized that

what's actually happened is that their traits have changed with age.

Dr. van Dyck: To finish, yes, I'm about ready to say that.

Mr. Ne'eman: Sorry, I thought you were done.

Dr. van Dyck: Then to get with therapy services -- and I'm trying to be quick here and skipping over some things, did the child ever receive therapy services for autism? How old when the services began, currently receiving therapy services for autism?

So that gives you a quick idea of some additional questions we're asking, trying to get a little more information surrounding the initial diagnosis, time of initial diagnosis, reasons for losing the diagnosis if the child lost the diagnosis, whether you agreed or not as a parent, whether the service was just added for whether you were getting services or not, trying to get some more

information around that.

So that's what I'd like to report.

Ms. Redwood: Were there any questions -- my understanding, Peter, is that there were additional questions regarding wandering that were also added to the survey?

Dr. van Dyck: I don't believe so.

Ms. Redwood: Okay. I wish Coleen were still on the phone, because I was thinking that Coleen had said that she had worked with somebody on the survey, and that there had been questions surrounding the topic of wandering added. So maybe that wasn't the case.

Dr. Daniels: I think, Lyn, that the questions were added to the Special Health Care Needs Children's Survey.

Ms. Redwood: Okay.

Dr. Daniels: I think that's what you may be referring to, that Coleen had presented the recommendations on those questions in terms of the Maternal and Child

Health Board Survey that incorporated additional questions on wandering there.

Ms. Redwood: Okay. I don't know why we thought it was part of this survey. I apologize.

Ms. Singer: I thought it was part of the --

Dr. Daniels: There are so many surveys going on, sometimes it's hard to keep track of them all.

Ms. Singer: I thought it was part of this survey as well, so I am also confused by this. I thought Coleen had indicated that these data would be collected as part of the HRSA survey.

Dr. van Dyck: Well, we have two surveys, one for children's health, and one for children with special health care needs. The one that's going in the field now is for children's health.

Ms. Singer: And when will the one for children with special health care needs go

in the field?

Dr. van Dyck: Health care needs goes into the field in two-year intervals.

Ms. Lewis: And I believe that those questions were incorporated into the current cycle.

Ms. Singer: So when -- where are we in the cycle? When will it go into the field again?

Dr. van Dyck: It goes into the field again in two years.

Now, I'm -- there was talk about adding some questions. I'll have to double-check to see whether some were added in the current survey.

Ms. Singer: But I thought that Coleen had indicated that questions were added in the current survey, which is maybe what led both Lyn and I to believe that it was the broader children's health survey, and not waiting two years for the special health survey.

Dr. van Dyck: I'll have to check that.

Ms. Lewis: I would double-check it, but my recollection from the conversations with Coleen in December was that -- I mean, and that was part of the reason that there was such a short period of time to comment on those questions, was that they were trying to incorporate it into the current cycle.

It is my understanding, and I could be incorrect in this, that that has happened, and that the questions are currently being asked as part of the special health care needs survey.

Dr. Daniels: Sharon, that's my understanding, too. This is Susan, so maybe we should follow up with Coleen via email and just clarify that for the subcommittee, and then the next time the subcommittee meets, be able to share that with the public as well.

Ms. Lewis: And then that would mean, to your question, I think, Alison, you

were asking, then that means that that data -- and correct me if I'm wrong, Peter -- would then be available through this data collection in about 18 months.

Dr. van Dyck: We do the surveys, and I'll double-check that and report back by email to the committee.

I wasn't sure, just seeing the agenda this morning, exactly what was wanted.

Ms. Redwood: Right. Okay. Well, we are approximately, by my computer, three minutes over. So I know that there are strict rules regarding the length of the meeting.

Is there, since we do have chemical restraint and also caregiver abuse and those do somewhat fall together, let's add those onto the agenda for our next meeting.

And Ari, I heard what you were saying about the chemical restraint going into the joint meeting, and I think caregiver abuse could as well with the services subcommittee.

I know we also didn't get an

opportunity to discuss how to best interact with the services subcommittee.

I think that was something, Sharon, that you had asked on the agenda, that can also fall over, I think, to the next call.

So if there's -- is there any further questions of the committee?

Dr. Daniels: And so, this is Susan, I'll just add that I will follow up with you all by email.

I'll be emailing the services subcommittee as well to get a date on the calendar for April as soon as possible to have this joint meeting.

And you all can be thinking about what types of presentations you want at that meeting, who you want to have speak to you to give you information that you need on seclusion and restraint, and actually these other issues as well, chemical restraint, caregiver abuse.

And we'll try to organize that

meeting quickly so that you will have something to share with the full committee on April 11th about the plans for that meeting.

Ms. Redwood: Great. Thank you, Susan.

Ms. Lewis: Thank you.

Ms. Redwood: Okay. Thank you so much, everyone. We'll call the meeting to a close.

(Whereupon, at 10:35 a.m., the Subcommitttee Adjourned.)