U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE ON SAFETY

WEDNESDAY, JANUARY 12, 2011

The Subcommittee convened via teleconference at 11:00 a.m., Sharon Lewis, Lyn Redwood, and Alison 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)

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

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

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

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PROCEEDINGS

11:02 a.m.

Dr. Daniels: Hello, this is Dr. Susan Daniels, Deputy Director of the Office of Autism Research Coordination at NIMH and I'd like to welcome you to this phone call of the Subcommittee on Safety of the Interagency Autism Coordinating Committee, the IACC. I'd like to start with a roll call to identify which members of the subcommittee are present. Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Alison Singer?

Ms. Singer: I'm here.

Dr. Daniels: Sharon Lewis?

Ms. Lewis: Here.

Dr. Daniels: Coleen Boyle?

Dr. Boyle: I'm here.

Dr. Daniels: Ari Ne'eman?

Mr. Ne'eman: Here.

Dr. Daniels: And I believe Gwen Adam on behalf of HRSA is going to be representing Peter van Dyck?

Dr. Adam: Yes, I'm here. Thank you.

Dr. Daniels: And Lee Grossman is not going to be able to attend today to my knowledge so I believe all of the subcommittee members except for Lee Grossman are here. For our agenda today we are going to be first briefly considering the minutes and then we will move on to the agenda items. And all of the materials are posted on the web for public listeners who may want to access those materials. So I would like to start by asking if there are any comments on the draft minutes that were circulated from the previous meeting of November 29?

Ms. Lewis: Susan, this is Sharon Lewis. I guess my only request - and I don't know what the appropriate way to reflect this in the minutes - is that because of technical difficulties, I - I mean, it indicates that I was present but because of the phone problems

I wasn't able to speak for the majority of the call.

Dr. Daniels: Okay.

Ms. Lewis: - able to comment. Is there a way to -

Dr. Daniels: Yes, we can insert a note into the minutes.

Ms. Lewis: I appreciate that. Sorry. Thank you.

Dr. Daniels: That's no problem. Okay, so we will do that. Are there any other comments on the minutes?

(No response.)

Dr. Daniels: Hearing none, are the minutes approved? If so, please say "aye."

(Chorus of ayes.)

Dr. Daniels: Any opposed?

(No response.)

Dr. Daniels: Okay, the minutes have passed. And at this time I would like to turn the call over to the three co-chairs, Sharon Lewis, Lyn Redwood and Alison Singer to lead us through the materials. And so starting with the draft letter to Secretary Sebelius.

Ms. Singer: Okay, this is Alison, I'll start. The three of us had a conference call earlier this week where we went through the draft of the letter. And prior to Sharon becoming a co-chair of the committee, Lyn and I had put the letter together. So at the meeting this week we went through Sharon's input. I want to thank Sharon for her detailed reading and all of the suggestions that she made, most of which we incorporated into the current draft that you see before you today. There are still a few issues that the three of us could not come to a resolution on that we wanted to bring to the full committee for its consideration, but maybe where we should start was I think you can all see the changes that Sharon suggested. If there are other committee members who wanted to comment on the changes in the letter that you see in front of you now versus the letter that you saw at our previous meeting maybe we should give all the other subcommittee members an opportunity to comment on those first.

(No response.)

Ms. Singer: Okay, hearing none we can move on.

Mr. Ne'eman: I was actually going to comment with regards to the discussion around - the recommendation around an alert system.

Ms. Singer: Okay, we're not really there yet. Let me say that the three issues that we had some disagreement on I think one we resolved. I'm not sure if Sharon had a chance to weigh in because she had to leave our call early and we came to sort of a resolution on one of the three issues after she left so we need to get Sharon's input there. But this is where - really around, one was how we expressed a sense of urgency that was really characteristic of the way the IACC acted subsequent to the presentation by the National Autism Association at our last meeting, and how we could reflect that sense of urgency and the unanimity of the IACC in creating the Safety Subcommittee to look at this issue, how we could reflect that in the letter to the Secretary, that was the first issue. The second issue that we wanted to bring to the full subcommittee had to do with the concept of creating the medical subclassification and the third issue had to do with the idea of the AMBER or Silver alert.

So I think what we - let's take the sense of urgency first. And after Sharon had to get off the phone there was a suggestion made by Susan that I think both Lyn and I liked which was, rather than just describe the sense of urgency, what she did was she added language that actually related the activities that took place at the IACC meeting. So if you look at Page 2, Paragraph 3 where previously the sentence said, "ASD-related wandering: immediate action needs to be taken to address the urgency of ASD-related wandering," there was some concern about that sentence. What was added here was to describe the sense of urgency that took place at the IACC meeting. And now it says, "At a meeting of the Interagency Autism Coordinating Committee on October 22, parents and advocates shared their experience and urgent concerns with members of the committee. The committee responded unanimously to form a Subcommittee on Safety and to take appropriate actions to address this issue." So that's a change since - do we want to - how do people feel about that change?

Dr. Boyle: This is Coleen. I think that - it reports what happened and I think that's a true - for me I'm comfortable with that.

Ms. Lewis: And Alison, this is Sharon and I know I had to jump off the other call and I appreciate your work and Lyn's work and Susan's work to come to this. I think this is a great approach because I think, again, just representing factually what has taken place makes more sense than expressing opinion.

Ms. Singer: Great. Okay. So is everyone comfortable with the content of the letter up until we get to the recommendations? So that would be through Paragraph 3 on Page 2. Does anyone have any other comments to make on that part of the letter, Page 1 and Page 2 through Paragraph 3?

Dr. Boyle: No, I'm fine with it.

Ms. Singer: Okay. So let's move on to Action Item No. 1 which has to do with the need to collect data. Some changes were made to that paragraph but I don't think any of the three of us had concerns about those changes, so are there any other subcommittee members who have issues with the way Action Item 1 is now presented?

Dr. Boyle: No, looks good.

Ms. Singer: Okay. Let's move on to Action Item 2. As I mentioned this was one where there were some differences of opinion among the subcommittee chairs and this one has to do with creating a medical subclassification coding or general medical coding for ASD wandering and similar neurological disorders. Such a medical coding could be used to collect data on ASD-related wandering and could also help validate insurance coverage for tracking devices and related expenses to help families. So Sharon, do you want to talk about - do you want to maybe -

Ms. Lewis: Sure. So, a couple of things. I think that first and foremost, you know, CDC has made the decision to bring this before the committee that works on the ICD coding issues and it will be discussed at the beginning of March and will be - there will be opportunity for public comment and input on this particular issue. And I think that that is the appropriate forum for that conversation to take place, and just wonder if this is something that we need to suggest to the Secretary at all given the fact that CDC has already taken action on it. So that's my first comment.

And then secondly kind of contextually, as I did outreach with the University Center and others on kind of the state of play in this conversation I heard very mixed concerns from folks around - is this premature in terms of what would then be the recommended quote/unquote “treatment protocol” if someone was given a secondary diagnosis of wandering-related, you know, ASD-related wandering and what would the basis for that diagnosis be. And so again, as someone who is not a medical researcher and I depend upon the expertise out in the field I have questions about making this recommendation in this way and essentially endorsing a particular protocol, i.e., tracking devices as something that should be covered under, you know, a medical payment. So those were my two questions and concerns that I wanted to hear further discussion from the committee on.

Ms. Redwood: Hey Sharon, this is Lyn and I just wanted to respond to those first. At the actual meeting when the National Autism Association did their presentation there was discussion about the need for diagnostic code and at the time there weren't questions regarding that from the actual committee. So it is something that we did discuss. We feel as though it was necessary and I would like to bring it back to the committee. Also with regard to establishing a treatment protocol, that would be the responsibility of the actual treating clinician or physician who is evaluating that child. So they would be the ones to establish the protocol based on the utilization of that diagnostic code. And again, determining whether or not that code should be utilized -

let me finish. And determining whether or not that code would be utilized, that would be the professional judgment of the treating clinician. So I think that that's up to them whether or not they want to utilize that code and if they feel as though that particular individual is at risk for wandering and related injury.

Mr. Ne'eman: Lyn, this is Ari Ne'eman. I'd like to just comment with regards to particularly the first point. My recollection of that meeting was there was consensus to create a Safety Subcommittee to explore these issues. But I'm reasonably certain that the committee did not vote to endorse any particular recommendations at that time. Certainly and I was present, that was not my intent and I think that would probably be the impression of a number of other committee members.

With regards to this broader issue, I obviously share the sense of urgency that all the committee members have about this and all the subcommittee members have about this, but I share Sharon's concern and I have a few of my own. For one thing, I feel there is a real possibility that if we medicalize this phenomena we run the risk of (a) acting before we have the appropriate amount of research and evidence, but (b) potentially raising other safety issues both from a rights protection perspective and from restricting the opportunities that adults have to address safety concerns around caregiver abuse, for example, restraint and seclusion. I think the fact of the matter is that if we do see a medical subclassification code here, you know, put aside for a moment the fact that ethical concerns could also apply to children, but I think the reality is that if it's applied to a child, that subclassification, that diagnostic coding will stay in place as that child grows to adulthood. So if we define this solely from a medical perspective and as a medical issue rather than a service provision issue I think we run a very real risk that we're going to be interfering with the self-determination rights of a number of adults on the autism spectrum and also potentially opening up new safety concerns around caregiver abuse and restraint and seclusion which would certainly I think be an unintended consequence that nobody here would like to see.

Ms. Singer: But Ari, just because we make tracking devices available to families doesn't mean that we are requiring everyone with autism to use a tracking device.

Mr. Ne'eman: But the nature of -

Ms. Singer: It would be opt-in.

Ms. Redwood: And they're available now.

Mr. Ne'eman: - context.

Ms. Singer: Exactly. They're available right now. The issue is that they're not equally distributed. I mean, if you have money and can pay for it you can as a family get access to a tracking device.

Mr. Ne'eman: I think the equity argument makes a lot of sense if we're in agreement that this is the appropriate course of action, but you know, the nature of a context in which there is caregiver abuse most likely implies that there's going to be a very significant difference of opinion between the person being abused and the abuser as to where that person should go and what they should be allowed to do.

Ms. Redwood: Is there evidence for caregiver abuse with regard to the utilization of a tracking bracelet?

Mr. Ne'eman: There's evidence for caregiver abuse against individuals with developmental disabilities including on the autism spectrum.

Ms. Redwood: But this is a different issue though. Ari, I'm aware of that but I'm just having a difficult time understanding how a tracking device to locate an individual who has wandered and is at risk could lead to abuse and if there's any research to link those two together.

Mr. Ne'eman: Well -

Ms. Lewis: Go ahead Ari, and then I actually have something I'd like to add.

Mr. Ne'eman: I think it's fairly clear that if you have a situation in which an individual is being abused and is trying to escape an abusive setting, the problematic aspects of restricting that person's freedom of mobility are fairly self-evident, and I think there's a wealth of research literature documenting - as well as the kind of anecdotal news reports and other information that have gone into this discussion so far documenting the extent of the caregiver abuse issue as well as the restraint and seclusion issue.

Ms. Lewis: This is Sharon, and kind of going back to your question, Lyn, I guess the question that I have, and again, I don't pretend to be an expert in - of particular approaches here and what I'm hearing from the field is that we don't have enough information. I mean, do we know for example if we decide that establishment of a medical code and a clinician has to make those decisions about how to proceed given this particular diagnosis, does enough research and data in the field to support that decision exist? And that's my concern whether it's, you know, tracking devices or positive behavior court interventions, or if there are particular questions that need to be asked around antecedents and behavioral support and need. I, you know, when we sent out in the AUCD and AAIDD both looked at this stuff across the experts in the field it was very difficult to find science and evidence base around research that's been done in terms of how to advise these clinicians should they have this particular code.

Ms. Singer: Okay, so what if we try to come to some sort of resolution. What if, you know, to address, Sharon, the point you're making about not enough data yet and I think using some of the techniques that we've used in the past to try to get to some compromise here by focusing on facts-based, what has actually happened. What if we amend this paragraph so that instead of "create a medical subclassification" we put in "investigate" which would speak to the need to create data, investigate a medical subclassification and then describe what the CDC has already done in terms of already submitting its suggestion for medical coding, since that has in fact taken place.

Mr. Ne'eman: I think that -

Ms. Lewis: I was going to say I think that my concern about that, and Coleen knows this, is that then as a member - as a Federal representative of the IACC I'm being asked to endorse the CDC's actions and I don't know that that's a position that our office is going to take. And that's why I'm saying that

I don't know that this is - for us to ask Federal representatives to weigh in given that there's going to be a public comment process and opportunity.

Ms. Singer: Well, we don't have to say we support the CDC, we can just say "investigate development of a medical subclassification coding or general medical coding for ASD-wandering and similar neurological disorders" which speaks to the need to collect data. Then we can just describe "The CDC has already submitted." We don't have to say "We support this." We can just say "The CDC has already submitted ICD data for a change to add this coding."

Mr. Ne'eman: I think there's an imputation of support there and I think the other concern that I have here with regards to that is we haven't explored any of the other possible options and responses to this problem. To some degree I think it's premature for us to go forward with a recommendation around the medical subclassification coding whatever we may think of it if we haven't even explored positive behavioral supports options, if we haven't heard from experts around how various residential service provision settings address this issue. I mean, there's been very little investigation on the part of the Services Subcommittee so far around the range of options here.

Ms. Redwood: Alison, I appreciate your desire to create some compromise and I think what you offered is appropriate, but I'm a little concerned in that this does get to the clinical treatment of a child with autism which is a little bit different than support and services. And I would like to recommend taking this back to the full committee, saying that you know this is what we're proposing although it was not a unanimous decision by the committee. Because there are several members who are on the full committee who are actual clinicians, and I think it's important that we get feedback from the people who are providing clinical care to children and adults with ASD because to my knowledge I'm the only one that actually has a clinical background in terms of a medical background in treating children with ASD. I don't know if anybody else on the phone from HRSA or Coleen, if that's your background as well, but I think if we're talking about what could be considered a medical device then we should take that back to the full committee with regard to how this should be structured at the next meeting.

Ms. Singer: I would support that. This is Alison.

Dr. Boyle: And this is Coleen. I guess it would be helpful for me with these two paragraphs because in some way it's the second paragraph there really just talking about two very different issues. One is the attempt to get better information about what is happening and trying to characterize the problem, and the second piece is talking particularly about, you know, reimbursement issues for services. Tracking devices are just one service that families could perhaps be reimbursed for. There are a lot of other issues that I think we've talked about and even tried to add to the research plan, and the letter at least to some of it in the paragraphs that follows I kind of feel like we might need to do a little bit more tweaking of both of these paragraphs. And I kind of see the one about data to maybe be a little bit more explicit, you know, because we have added questions to one of the surveys that HRSA and NIH are funding, but there are a lot of other opportunities to add questions about safety as well as the specific aspects of wandering to that. I would really like to I guess encourage the Secretary and the sort of power she has over the various agencies to consider adding additional questions so that we get richer data so we can actually be able to address some of these. I'm not trying to derail it, but I guess the need of a medical subclassification code is just one attempt to get better information, but it's also an attempt to get reimbursement issues. So I'm wondering if we can have one paragraph focusing on the data issue and maybe one paragraph or issue focusing on if we can perhaps help families now with this issue.

Mr. Ne'eman: I wonder if we should seek the advice of the Services Subcommittee with regards to this. Lyn, I know you've commented on this in primarily a medical context, but it would seem to me that this could just as easily be looked at in a services and supports context, and part of the research question or part of the review of the research that we need to undertake to determine, you know, what our appropriate course of action is is to determine whether or not this is most appropriately defined as more of a services issue or more of a medical treatment issue. So you know, just to weigh in on the point you raised earlier, Lyn, I'd like to see if we can't, in addition to going to back to the full committee, let the Services Subcommittee know that we'll be having this discussion and ask them to weigh in with their opinions with regards to this recommendation.

Ms. Redwood: Well Ari, people who are on the Services Subcommittee will be at the full committee meeting which is less than a week away now so I think we can solicit their input at that time. And this committee was created separately from the Services Subcommittee to deal just with safety issues so I think it does lie within our jurisdiction to address this. Now, if the Safety Subcommittee wants to look at services in terms of what they might be able to research or promote to prevent wandering behaviors I think that's fine, but I sort of see this as a separate issue from the Services Subcommittee.

Mr. Ne'eman: I suppose my concern with regards to that is I don't think we're prepared either as a subcommittee and certainly not as an IACC to state conclusively that this is an issue that should fall within the context of medical treatment as opposed to service provision. As a result, until we are prepared to state that I think it's appropriate for us to ensure that the Services Subcommittee is fully informed and has the same opportunity as the Safety Subcommittee to comment on these issues as a subcommittee in advance of the IACC.

Dr. Adam: This is Gwendolyn from over at HRSA and I'm wondering if there's a way to kind of have a middle step in this which would be that we would look at creating the medical subclassification coding which would generate the need for a documented plan for safety which would include potentially obviously parental or other guardian input, you know, perhaps other systems input as well so it would look at the medical if there were mental health providers in there or other service practitioners in there, that getting the code instead of - one treatment that has not been - the tracking devices, that we don't have the research to support necessarily as the best mode of action, that instead the code would generate the need for a very detailed plan which could be customized and could include a tracking device in certain individual situations. It would potentially generate - these plans could potentially generate the ability to look at what are the processes we're using and if there are poor outcomes what are the kind of plans that are linked to poor outcomes or better outcomes as well.

Mr. Ne'eman: So the one concern I would raise there is I don't know that we should be prepared to endorse this diagnostic code because that is a statement that regardless of the appropriate treatment protocol, that this is in fact a medical phenomena. And it sounds from Sharon's outreach to the UCEDD system that the research community may not be ready to conclude that as of yet.

Ms. Redwood: I think that there are several people on the call, I know myself and I would assume Alison are prepared to include this the way it was written along with the description, Alison, that you provided where we're describing what CDC has done. And I'm just concerned that we've been going over this for quite some time and we've not been able to reach consensus with regards to the best way to go and that we should take this back to the full committee to discuss. I mean, that would be my recommendation.

Ms. Singer: I agree with that and I think to your point, Ari, about the members of the Services Subcommittee, they are all members of the full committee and will all have an opportunity at the full committee to comment. And in addition, members of the IACC who are neither members of the Safety Subcommittee nor of the Service Subcommittee will also at that time have an opportunity to share their opinion. So I am in favor of taking this to the full committee.

Ms. Lewis: Can I ask - I agree that we need to take this back to the full committee and I guess what I would observe is that we do best at the full committee when we are looking at concrete options for folks to consider. And maybe what makes sense is for this particular issue to have two distinct drafts because I think - I appreciate what Coleen was saying around making the distinction between the data collection aspect of this and the need for better understanding in terms of the implications related to treatment or behavior support, and I would propose that what I hear you saying, Alison and Lyn, is you know you really want to keep this thing tied together and in terms of using the ICD-9, the ICD code both for data collection and then to be able to refer to treatment protocol. I hear Ari's discomfort in both parts of that, but I think that we can maybe dissect this a little bit further and potentially have an option of a paragraph that, you know, is essentially as you guys had proposed it, Lyn and Alison, versus a different draft that perhaps, Ari, if you wanted to take that up or Coleen. I'm happy to help but again, I don't feel like I have the expertise here to propose a different way to structure this conversation and bring those two drafts before the full committee.

Mr. Ne'eman: I think it would be - I think it would be appropriate to have you be one of the lead people with regards to the alternate drafts just because you're a subcommittee chair and you know we're not. So I think if we're going to reflect division within the subcommittee and it sounds like we're not prepared to make concrete recommendations, that we need to present both options which, you know, I certainly agree with you with regards to that, Sharon, it may make sense for us to have the respective subcommittee chairs present the various perspectives if we've got some of them on each side.

Ms. Redwood: Alison and I can work on alternative drafts to what is there now that we can present, and then Ari, if you and Sharon want to work on something or other members of the committee and we'll put both of those forth to the full committee.

Dr. Daniels: This is Susan. I want to remind you that the next IACC meeting is on Tuesday, the day after a Federal holiday, so we only have two working days in which to get anything done before the committee meeting, and we need to be able to distribute all materials to the committee. So, that would -

Ms. Singer: That was my next

question was your friendly reminder, Susan, so if we were to have drafts that need to be distributed in committee when would that have to be done?

Dr. Daniels: It would have to be done by tomorrow.

Ms. Singer: Okay.

Dr. Daniels: So it's one paragraph so it's not like writing a -

Ms. Singer: Yes, I think we can do it.

Dr. Daniels: - item. So if you could have something to me by noon tomorrow for both drafts then we could incorporate those.

Ms. Singer: Okay. Just, you know, Coleen, what would be helpful for us, can you send us just two sentences on what the CDC submitted so we can incorporate that? Hello? Coleen?

Ms. Redwood: Wonder if we lost her?

Ms. Singer: Okay, well I have that longer email so I'll dig it up. Okay. So moving on to the next issue over which there was still some disagreement among the committee chairs was the third action item which for those of you who don't have the materials in front of you says "Explore and research the potential need for and utility of an alert system similar to the AMBER alert or Silver alert, but tailored to the specific needs and characteristics of people with autism who wander to help families and communities rapidly locate children with autism who have wandered." So I guess to reflect the conversation, Sharon, do you want to go first?

Ms. Lewis: Sure. I mean, again, I want to be clear, I think where we've ended up I'm fine with consideration of this item, you know. The initial paragraph as presented to us didn't accurately reflect the status of AMBER alert system in terms of what the

Federal role is in that and that was my major concern, was that we did not have accuracy in the paragraph both in terms of the Federal resources that are utilized and how they're utilized, and making sure that we're clear that in the conversation all we can recommend is really exploration because in order to do what was originally proposed which was to expand the AMBER alert system specifically to address the needs of individuals with ASD and other developmental disabilities when they are missing or not - or have fled or otherwise they're lost then it would take a statutory change. And so there was extensive conversation back and forth about what do we know about the AMBER alert system and the reality of it is that the Department of Justice is very constrained by the statute in terms of what the AMBER alert system is and can be used for and we did not want to get into a situation in which we were making legislative recommendations. So that's the context of the changes to the AMBER alert language.

Ms. Redwood: So Sharon, are you saying you're in favor of what's currently in the draft?

Ms. Lewis: I'm fine with where we've ended up, yes, in terms of the changes. I mean, I think it now - let me just read through it again. Yes.

Ms. Singer: Yes. We took out the reference to DOJ, Sharon, that you had concerns about and we added the words "explore and research."

Ms. Lewis: Right

Ms. Singer: We added the word "potential."

Ms. Lewis: Right, and so I think it's fine.

Mr. Ne'eman: So the only thing I would add with regards to that is I think we should include something in here to make clear that we're talking about this as a system as I understand that we are, and correct me if I'm wrong, but we're talking about this as a system for children rather than for adults.

Ms. Singer: I think we tried to make that clear. Sharon brought that point up and we specifically put in the word "locate children with autism." We put in the word "child" in the second sentence and in the third sentence "children." So the word "children" or "child" appears in every sentence in this paragraph.

Mr. Ne'eman: I noticed we have in the second line, we refer to "people with autism wander." Maybe we can change the language there too, and I wonder if we might consider just to very clearly communicate the intent as I know in a lot of other instances things that have begun for children such as the registries have expanded for adults, that the intent of this is for specifically children on the autism spectrum and with other developmental disabilities, and not for adults. If we can state that explicitly I think that would be very valuable.

Ms. Singer: I mean, in this first sentence we use the word "people" because otherwise we would be using the word "children" twice but I am perfectly comfortable changing, using the word "children" twice in that sentence if that makes you more comfortable, Ari.

Mr. Ne'eman: Or we could use "minors" or "children or minors." And if we can include a sentence stating that this is not intended to apply to adults with or without developmental disabilities I think that would be very positive.

Ms. Lewis: The only question I have about that is that the fact is there are what I would refer to as adult children with autism who wander and elope from the safety of their families. And I'm just trying to see where they would fit into this. It's a big safety concern.

Ms. Singer: I was under the impression that if we - the way the wording was that it would include adults who were under legal guardianship. And Sharon actually pointed out that that's not the case so I think to Lyn's point we do have to make sure we make an effort to include those individuals as well.

Mr. Ne'eman: Well, I think that's a discussion we should have.

Ms. Lewis: I was going to say, then I'd have some discomfort with where we're going with it. Because -

Ms. Singer: Okay, so then why don't we just leave it where we are since we agreed on this, not - not try to add things that we don't agree on, but just move forward with what we do agree on.

Mr. Ne'eman: I mean I - from my perspective, for me to agree to this recommendation I think we need to make very clear that we are not intending this to apply to adults. Because if we are then I think there are serious concerns with the whole enterprise, and there's obviously a much broader discussion that should be had as to what is and what is not the most appropriate responses for adults under guardianship. But that's a discussion we need to have before we make a recommendation.

Ms. Redwood: Okay. Let's do this. Let's keep it with children because that's what we've agreed to now, but in future deliberations of this committee I do see that as an urgent need as well, and I think it's something that we need to bring up after this letter has been sent and also look at what can we do to help those individuals as well and their families, keep them safe.

Mr. Ne'eman: Well, by all means we should incorporate safety issues and give consideration as to the most appropriate responses for adults under guardianship. But you know, once again, what I'm trying to communicate here is before I'm comfortable with voting for this recommendation to move forward I would like to see a sentence clarifying that this is not intended to apply to adults, and then we can have a broader conversation later as to what we do intend to apply for adults.

Dr. Boyle: Ari, this is Coleen. So in the first sentence can't we just - I apologize, I lost connection so I am back. But couldn't we just change "people with autism who wander" to "children with autism who wander?"

Mr. Ne'eman: So we had discussed that.

Dr. Boyle: Okay.

Mr. Ne'eman: My concern here is that, you know, I think that's open to interpretation. I mean, people are still you know the children of their parents even after they have reached legal age of majority or so certain people would interpret. And I think it's important for us to be - to have a great deal of clarity, both because people can misinterpret our words and also because people could use this to endorse policy recommendations that go further than what the committee intends, to just be very explicit that this is intended to apply to children under the age of majority, not to adults.

Dr. Daniels: Ari, this is Susan. Would it help to have after "children" a parenthetical that says "minors?" Would that provide enough definition that it's talking about people that are under that age of majority?

Mr. Ne'eman: I mean I think that would be positive. I would suggest in addition to that placing at the end of this paragraph a sentence stating "This proposed system is intended to apply for minor children, not for adults."

Ms. Singer: But we haven't actually agreed to that because of the point that Lyn raised which is that there might be some adults for whom it would apply. So I think putting that in would also not reflect the feelings of the broader committee. I mean, I think the word "minor" actually moves it closer to what you're saying, Ari. I like Susan's suggestion.

Mr. Ne'eman: Well, it does, and I definitely approve of the use of the word "minor." I guess my concern here is I think we need a broader conversation about what the most appropriate response for adults are and until then I don't want us to be recommending anything that could be interpreted as applying to adults even incorrectly. So I'm comfortable with us saying here something to the effect of "The committee intends to look at adult safety issues later" or "makes no recommendation on the appropriate measures with regards to adults" but I think we need to be very explicit that this proposed system is only intended for the context of minor children.

Ms. Singer: Ari, I think if we changed "people" to "children" and we've used the word "children" or "child" in every single sentence in this paragraph. I think, you know, it doesn't apply to -

Dr. Boyle: I would agree, Ari. I would just put "children" and then Susan's suggestion on the parentheticals "minor" there. I think that really makes it very clear.

Mr. Ne'eman: In the interest of compromise let me suggest how about we go forward with Susan's suggestion around "minor children" for each of the areas where we mention children and then we just include a sentence indicating the intent of the committee to explore the appropriate responses for adults at a future time. And that way we don't comment at all as to what the most appropriate responses for adults are, but we also make clear that this recommendation, so far the committee is only prepared to go so far as to speak about minor children.

Ms. Singer: I'm curious to know if there are other members of the committee other than Ari who feel that as written the paragraph is not clear whether it refers only to children.

Ms. Lewis: I think that the concern - this is Sharon - I think that the concern actually, Lyn and Alison, you know we kind of experienced it ourselves in our own conversation because I think what I heard you guys say is the assumption that when we say "children" we include in that adults who are subject to guardianship. So I have been quiet through this conversation but I understand Ari's concerns and frankly it's a civil rights concern that I don't know that we want to get derailed in this conversation by, and it might be beneficial to add the clarity. And when I'm looking at the notes from the last conversation it does look like, you know, we were very clear that we were talking about children under the age of 18 in terms of our intent around the word "children" so I don't understand what the discomfort in being explicit about that is.

Ms. Singer: So that's fine, why don't we say "children under the age of 18?"

Ms. Lewis: Does that do it, Ari?

Mr. Ne'eman: It's better. I still would, you know, be curious as to folks - whether or not folks would be comfortable stating explicitly that the committee intends to address adult issues at a later time. But I think "children under the age of 18" goes far enough for me if the committee isn't comfortable taking the step of putting in the additional sentence. Folks?

Ms. Redwood: I think that works.

Ms. Singer: I think that's fine. I think, Sharon, that's a good suggestion. We can include "children under the age of 18."

Dr. Boyle: I agree.

Ms. Singer: Okay, so is there any other discussion about this action item before we move on to Action Item No. 4? Okay. The committee chairs had - were all - all three of us were comfortable with Action Items 4 and 5 so I want to give the broader committee an opportunity to weigh in on these as well. Action Item 4 is develop and test programs to prevent wandering incidents and Action Item No. 5 is work with the Department of Education to develop model policies related to parental notification of wandering or fleeing incidents in schools.

Dr. Boyle: I'm fine with these. My only issue would be - this is Coleen - would be perhaps sharing them with the member from the Department of Education prior to Tuesday's meeting so we can get their comments and thoughts and incorporate them.

Ms. Singer: That's a good idea. Are we able to send them to Gail, even though she's not a member of the subcommittee, ahead of time?

Dr. Daniels: I would recommend just doing it at the committee meeting given the time constraint and that we need to have the materials out by Friday morning. We need to get them to our contractor to be able to get them prepared for the meeting, so.

Ms. Singer: Maybe we can just give her a heads up that we're going to be coming to her for her opinion as the representative of the DoE?

Dr. Daniels: Sure. I can send her a note and let her know that this issue has come up, but I don't recommend that we wait for a response. We don't know if she's on travel or what, and we don't want this to get held up.

Ms. Singer: Right.

Dr. Daniels: But I'll be happy to send her a note after this meeting.

Mr. Ne'eman: And my only comment with regards to this is I just would like us to add training for individuals with the - on the list of possible preventative programs.

Ms. Singer: I'm fine with that.

Ms. Lewis: I think that's a great idea, Ari.

Ms. Singer: Yes, I agree.

Dr. Daniels: And where would that be added?

Mr. Ne'eman: It could include training for individuals with disabilities, comma, parent training.

Ms. Singer: Yes, where it says "parent training, teacher training" the list of preventative programs.

Dr. Daniels: Okay.

Ms. Singer: I think it could go right in there as another opportunity. It's a good one. I think we actually talked about that at one point. It was a while ago.

Okay, so we're now through the letter. The only issue that we need to bring for broader discussion to the full committee is Action Item No. 2, the investigation of medical subclassification. So I don't know what the procedure is. Susan, do we need to vote to bring the letter forward with the recommendation that the full committee consider Action Item 2?

Dr. Daniels: Alison, I have one question regarding the development test program to prevent wandering incidents.

Ms. Singer: Sorry.

Dr. Daniels: In that last sentence it says "The Department of Justice contributes over $1 million annually" and that was based on some information Sharon got. Are we comfortable with - I don't know, Sharon, how thorough you felt your research was on that topic.

Ms. Lewis: Yes, I pulled it down out of the appropriations language and I think that that's where the disconnect was. I think that what NAA was using was the authorization.

Dr. Daniels: They had the

authorization, but you feel that this is an accurate reflection of the spending?

Ms. Lewis: Yes. They spent $1.2 million last year.

Dr. Daniels: Okay, great. Thanks. Sorry. So go ahead, Alison.

Ms. Singer: I'm just - I'm asking a procedural question, if procedurally we now as the subcommittee need to take a vote on whether to move this item out of subcommittee and bring it to the full committee?

Dr. Daniels: Yes, you do need to do that.

Ms. Singer: Okay, so -

Dr. Daniels: - approved the rest of the language.

Ms. Singer: All right. So I'm making a motion that we bring forward the letter as amended per the discussion we just had, understanding that Action Item 2 needs to be discussed and potentially voted on by the full committee.

Mr. Ne'eman: Point of order. I just want to get clarity. When we discuss Action Item 2 I take it either Sharon or myself as appropriate will have the opportunity to present alternate language at the same time as the paragraph - as the Action Item 2 that you and Lyn will be presenting?

Ms. Singer: Yes.

Mr. Ne'eman: Okay, great.

Ms. Singer: I think, you know, we can talk about at that time the different opportunities for the type of language to include.

Dr. Daniels: For you all, if you give me the language, the two different alternates by noon tomorrow, I can incorporate those both into the letter so that the full committee will be able to see the two options.

Ms. Singer: And Coleen, while you were off the phone I was asking if you could just send us one or two sentences about what the CDC submitted for ICD-9.

Dr. Boyle: Sure, I'd be happy to do that.

Ms. Singer: Thank you. Okay, so is there a second to the motion?

Ms. Redwood: Second. Call the question?

(Chorus of ayes.)

Ms. Singer: All opposed?

(No response.)

Ms. Singer: Okay.

Mr. Ne'eman: Count me as an aye. Sorry about that.

Ms. Singer: Okay. I believe it is now unanimous. Okay, thanks to everyone who participated in developing that draft. I think it - I'm looking forward to moving it to the committee and getting their input as well. So we're now on to the next item on the agenda which is discussion of the RFI. I think, Lyn, you put together some of the RFI questions. Do you want to present those?

Ms. Redwood: Right. Let me just

open up the document. The other thing as I was looking over the comments that Coleen sent as well to the committee regarding wandering and there's also an initiative that's moving forward to collect data utilizing the IAN network that was discussed at the last meeting. And I guess before we move forward with this I'm wondering whether or not - what each one of your opinions would be in terms of trying to ask very similar questions so we're able to get broader representation from the autism community and then that way we can compare results, or would the committee feel as though it would be better to ask separate questions? And have the committee members had an opportunity to look over those documents?

Ms. Singer: Of the IAN questions?

Ms. Redwood: Well, we - okay, I'm sorry, I wasn't clear on that. The IAN questions have not been developed yet. There's going to be a meeting actually during lunch at the upcoming IACC meeting and then there's another meeting scheduled - I think, Alison, is it the 25th of January?

Ms. Singer: The 25th.

Ms. Redwood: To develop a questionnaire that would be used in the IAN database. So I guess what I'm wondering is whether or not we would want to sort of postpone this RFI to coincide with the other two questionnaires, the IAN questionnaire and then also some of the items that are going to be addressed in the questionnaire that Coleen sent over. So is it premature to be developing this RFI until we're aware of what the other questions are, or do people feel strongly about moving forward with this RFI in advance of the other two surveys, and if so, what additional data would we want to add to what we have drafted so far?

Ms. Lewis: This is Sharon and I mean, my recollection was - and Susan, maybe you can help out here - was from Tom that if we were going to do this we needed - there was urgency related to procedural and structural issues that my fuzzy memory is recalling, and if that's not the case I think from a sheer policy perspective it makes sense to have consistency in the questions to the degree possible.

Mr. Ne'eman: I believe the only caveats I would add is I think we do need to, you know, ensure there's - hopefully the IAN folks will be willing to have some back and forth with regards to this because I know with the current draft I have a few areas of concern with the questions drafted at the end, you know, whether or not they're going to be relevant and applicable for all of the stakeholders we want to be reaching out to. So I think we do want consistency and let's take the time to get consistency, but let's also ensure that if there are issues of relevancy that we err on the side of accuracy and our own principles if those issues come up vis-a-vis whatever IAN puts together.

Dr. Daniels: Now, we won't really have an opportunity to critique what IAN is doing because that is a privately funded initiative, but I think there would be opportunity to review that and to use the questionnaire that's being developed by that committee to help inform us with regards to the question that we might want to ask as well.

Ms. Singer: I think that makes sense because the timeline for development of the IAN questionnaire is in the next two weeks, so we're not postponing by very much the development of this RFI, and I think it does make sense to wait for that data and see if there are areas where we do want to overlap, or areas where for the purposes of this RFI we want to ask different questions, complementary questions.

Dr. Daniels: And there are more stakeholder involvement in that with regard to parents who actually have children who wander and so I think getting that input would be helpful too in formulating our RFI.

Dr. Boyle: This is Coleen. I mean, it would be wonderful, Lyn, if we could actually include some of the questions that were developed. And I know the autism association did have input into the questions so it would be lovely to have some of the questions that were the same both on the national survey that's in the field now and the IAN questions. As far as the RFI, your questions are much more general about safety concerns which I thought were, you know, very, very appropriate. I'd have to think about how we'd actually be able to tailor some of these questions for the RFI. I think it would take a little bit of thought.

Ms. Singer: The survey questions are being used as input into the IAN questions.

Dr. Boyle: Right, but it would be nice to have just a few that we ask the same way even if you obviously ask many different kinds of - or go into much more depth about these issues, just so we can compare. I think that would just be really - a real advantage to get a better sense of sort of the representativeness of IAN versus the national survey.

Ms. Singer: Do you want to send us some of the questions that you suggest we duplicate?

Dr. Boyle: Sure.

Ms. Singer: That would be really helpful.

Dr. Boyle: I did send it originally, but I'll send it again to everyone.

Ms. Redwood: And I do have that in front of me and I think some of these are excellent, Coleen. Some of the questions are "From what setting has your child with autism wandered" and that's if they do in fact, you know, acknowledge that their child has wandered, and that's a lot of the - the type of data that we really need which will help us to focus our initiatives on those areas that are most common for wandering, whether it's at school or home, or if it's in public places. How were they able to wander? Was it through a door, a window, was it locked or unlocked? Those types of questions to be able to identify what are the areas of risk and what kind of steps could be made to prevent the wandering based on how the child was able to escape. So, and I do believe that some of the members that worked with this, Coleen, also are going to be on the committee that's working on the IAN wandering, and I know there's also a parent on that committee too that has an adult who also has wandering behavior, so I think it would be important to get that input too. So I guess what I'd like to do is defer this for now and that we on the phone today set a time for our next Safety Subcommittee meeting, and then I'll bring back a full report based on the development of the IAN questionnaire and correlate that with the questions we have now and what Coleen has provided.

Dr. Boyle: I think that's a great idea, and I would maybe then wait on the RFI as well.

Ms. Singer: Yes.

Dr. Boyle: Okay.

Dr. Daniels: So then this is then for - what I'm hearing, you'd like to continue refining this RFI based on some of the other surveys that are going to be going out, and you could continue working on that over the next couple of months, and then you would hopefully be bringing a final version of the RFI to the full committee on April 11?

Ms. Singer: Probably because we have the national survey questions and we'll have the IAN questions in two weeks, and so the committee can decide whether there are questions on either of those surveys that we want to include in the RFI. But we're not talking about months, we're talking about weeks.

Ms. Redwood: So could we also - one of the things that we've not really talked about with regard to the Safety Subcommittee is how often we would like to meet, and then moving forward with next steps. This is something that - Susan, how often does the Services Subcommittee meet?

Dr. Daniels: Subcommittees are permitted to meet as frequently as they wish to. Most of the other subcommittees determine each time when they need their next meeting and they don't plan in advance for the entire year how many meetings they're going to have. So it sounds - you would like to have at least one meeting - the April meeting if not more.

Ms. Redwood: I would like to propose another meeting within a month, or one month from now. Alison and Sharon, are you supportive of that?

Ms. Singer: Yes, I think that makes sense. I think we'll have much more data for the RFI in two weeks so it makes sense to meet in a month after we have time. We'll distribute that information and then we can have a conversation about the RFI at that time.

Ms. Lewis: I think that makes sense and I would also suggest that as I understand it that, you know, wandering was but one issue that we were asked to address within that committee and that we begin a dialogue regarding seclusion and restraint, and whether or not we have any interest and recommendations to the Secretary on that particular front.

Mr. Ne'eman: I would add that I think it would be appropriate for us to incorporate those other issues like seclusion, restraint, caregiver abuse, drowning and other considerations into the RFI as well if we're taking the broader approach of Safety Subcommittee as opposed to wandering committee.

Ms. Redwood: Ari, are you also on the Services Subcommittee?

Mr. Ne'eman: I am.

Ms. Redwood: And I'm just curious what the Services Subcommittee has been working on with regard to seclusion and restraint.

Mr. Ne'eman: So the Services Subcommittee has been exploring some of the issues utilizing some of the expertise coming out of the mental health world, I think particularly trauma-informed care, and the topic was addressed in the workshop. We're currently in the midst of putting together recommendations to the Secretary on the topic, but I think we may want to explore it in both contexts particularly because the work of the Services Subcommittee has primarily been focused with regards to seclusion and restraint in the adult context. So I think we also need to explore it from the context of the K-12 education system.

Ms. Redwood: Right. How do other members of the committee feel?

Ms. Lewis: I think we just need to make sure we're coordinating our efforts so that we're consistent. I think let's move back to the, you know, the bigger conversation that Alan raised at the last IACC about the kind of odd crossover the very existence of this subcommittee creates because I think that safety issues are something that should be on the agenda of both the Services Subcommittee and as we talk about planning and research, that committee as well. And so it's just - I think it begs that broader question which I believe was tabled for the next IACC meeting.

Dr. Daniels: So - this is Susan - for the next Safety Subcommittee meeting - will work with you all to try to come up with a date. However, please understand that it takes us 30 days to get a notice into the Federal Register so we wouldn't be able to have a meeting 30 days from now unless we already have the date right now. So likely we will be working with you next week to identify a date so it will be more like five or six weeks depending on how quickly we can get agreement on a date.

Ms. Redwood: Okay. Susan, if we could work on something the end of next week. I'm traveling extensively for the next two weeks and I would hate to miss emails, so if it would be something we could maybe even, you know, look at on Thursday, Friday or Monday or Tuesday of next week that would be great. To come up with a day.

Dr. Daniels: Our staff is going to be quite busy getting ready for the 18th meeting and so I don't think we're going to be able to start working on it until the day after that meeting. So we will certainly turn our attention to that as soon as the 18th is over.

Ms. Redwood: Okay.

Dr. Daniels: If some of you have free dates that you know about already on your calendars feel free to just send those to us, but in terms of us reaching out to you to get information it won't probably be happening until after the full committee meeting on the 18th.

Ms. Redwood: So, based on the fact that it takes a month to get it out, you won't be able to work on it so it would have to be after February 20th sometime?

Dr. Daniels: I believe that's right. I don't have a calendar in front of me.

Ms. Redwood: Okay.

Dr. Daniels: Right, so it looks like we would be able to at the soonest have a meeting the week of the 20th.

Ms. Singer: That's the school break week which was very challenging for some of us.

Dr. Daniels: Then that would be the first week of March then.

Ms. Redwood: I'm open the first week of March. I'm wondering if we could come up with something on the call even today and then circulate it around to the people who - I guess the only person who's missing is Lee. Is that right?

Mr. Ne'eman: I'll be out of the country on the first week of March.

Ms. Singer: The first week of March?

Mr. Ne'eman: Yes.

Ms. Singer: The whole week? Okay. So second week of March?

Mr. Ne'eman: NCB meeting. Maybe it's better for us to do this via email.

Ms. Singer: Okay.

Dr. Adam: Yes, I don't have access to Dr. van Dyck's schedule at this point and so I couldn't commit for him to a date at this point. But I can make sure that his assistant responds very rapidly to the email today even.

Dr. Daniels: We will - will begin working with you on a date as soon as we can and try to find a date. You all have very busy schedules and it is often difficult to find a date that's going to work for the majority of the committee, but we will I'm sure be able to schedule something as soon as we possibly can get it on the calendar.

In the meantime you may be wanting to think about other issues that you would like to include in the RFI while also keeping in mind that you don't want an RFI with 50 questions because that would be difficult for the public to answer. So possibly if you're going to be covering multiple issues maybe only having a few questions per issue.

Dr. Boyle: This is Coleen. I'd be happy to work with whoever on, you know, thinking prior to our call about questions and the IAN questions and thinking about the RFI so we're well prepared in advance of the phone call.

Dr. Daniels: Absolutely. You're welcome to work via email, just please keep me copied on any emails that are regarding committee business.

Ms. Redwood: And Coleen, yes, we can work together on that.

Dr. Boyle: Great.

Ms. Redwood: And then also, if any other committee members have suggested questions, if they could refer those to us, gosh, at least a week before our next meeting by phone once that's established.

Ms. Singer: Okay, great. So does anyone have any other business to bring before the committee?

Dr. Daniels: This is Susan. I have one issue with the RFI. I just wanted to respond to Sharon's question about what demographic information we could collect, and to let you know that I'm looking into - some of these questions would be a little bit different from what we've done before, especially in terms of asking for information about somebody who's not the respondent to the RFI. I'm not sure if we would be able to do that. But we will find out the information and have it ready for the next phone call or meeting.

Ms. Redwood: Great, thanks Susan.

Dr. Boyle: Thank you.

Dr. Daniels: By the way, would you like to do the next meeting as an in-person meeting or a phone call?

Ms. Singer: I'm good with the phone call.

Dr. Boyle: Phone call.

Ms. Singer: I think we all travel enough.

Dr. Daniels: Thanks, and if you change your mind between now and then when we get it planned just let us know.

Ms. Redwood: Okay.

Ms. Singer: Okay, so I think we're adjourned. Thank you everyone.

(Whereupon, the conference call of the Safety Subcommittee was adjourned at 12:14 p.m.)