U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE ON SAFETY

MONDAY, NOVEMBER 29, 2010

The Subcommittee convened via teleconference at 10:00 a.m., Lyn Redwood and Alison Tepper Singer, Co-Chairs, presiding.

PARTICIPANTS:

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)

SHARON LEWIS, Administration for Children and Families (ACF)

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

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

TABLE OF CONTENTS

PROCEEDINGS

(10:06 a.m.)

Dr. Daniels: Hello. This is Dr. Susan Daniels, Deputy Director of the Office of Autism Research Coordination at NIH and Executive Secretary of the brand new Subcommittee on Safety of the Interagency Autism Coordinating Committee.

I'd like to welcome all our remote listeners to this call, an opportunity to listen to the first meeting from the Subcommittee on Safety.

And this Subcommittee was formed, at the request of the full Committee, at the last full Committee meeting October 22nd. And the Subcommittee has six members, and I'd like to take roll call right now to see which members we have on the phone.

Our two Subcommittee Chairs are Lyn Redwood and Alison Tepper Singer.

And so I'll begin roll call.

Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Alison Singer?

Ms. Singer: Here.

Dr. Daniels: Coleen Boyle?

Dr. Boyle: I'm here. I'm here, can you hear me?

Dr. Daniels: Yes.

Dr. Boyle: Okay.

Dr. Daniels: That was Sharon? Sounded like Coleen. Sorry. So Coleen is here.

Is Sharon here? Not right now. Sharon said that she might be joining us for part of the call.

Ari Ne'eman is not going to be able to be with us today on this phone call, but is a member of the Subcommittee.

And Peter van Dyck. He will be joining us a little bit later as well.

So, currently we have three Subcommittee members on the phone call, which is a quorum, so we may begin our Subcommittee business.

Dr. van Dyck: I'm here.

Dr. Daniels: So we have four members on the call.

At this time I'd like to turn the call over to Lyn Redwood and Alison Singer as the Co-Chairs of the Subcommittee.

Ms. Redwood: Hi. This is Lyn Redwood.

Thanks so much for joining us today, and welcome to the people on the line with me to the call.

As Susan mentioned, at our last IACC meeting the full Committee decided unanimously to establish the Subcommittee on Safety. And this was after we heard a presentation from the National Autism Association regarding elopement and wandering in ASD and the urgent need for additional data and resources.

In 2007, the National Autism Association conducted a survey where 92 percent of parents reported that their children with ASD had wandered from the safe environment one or multiple times. And although there may be some bias in that the parents who reported that their children have wandered may have been more likely to respond to the survey, this issue is one that is paramount to our families and one that urgently needs to be addressed.

During the presentation and public comment, we heard multiple incidents where individuals with ASD, mainly who were children, were able to escape the watchful eye of their parents or caregivers and they put themselves in harm's way. These events often ended with tragic consequences, such as drowning, being struck by a motor vehicle or deaths secondary to prolonged exposure.

These cases were then compared to rescue logs that have been compiled by Project Lifesaver where individuals who participated in the program were readily located within minutes to hours after being reported lost.

NAA also reviewed other research that reported elevated death rates for individuals with ASD compared to the general population. Causes of death that were identified included seizures, suffocation, and drowning. Research from Denmark also found mortality risks for individuals with ASD to be twice that of the general population.

This situation that we currently encounter with ASD was compared to data regarding Alzheimer's. And according to the Alzheimer's Association, more than 60 percent of those with dementia will wander. If a person is not found within 24 hours, up to half of the individuals who wander will suffer serious injury or death.

Through the Department of Justice, Alzheimer's receives 5 million each year for first responder trainer and grants for tracking technology. In addition, wandering-related dementia carries a medical diagnostic code.

There is also an emergency broadcast alert system called the Silver Alert which was created for seniors. It's often referred to as the AMBER Alert for seniors. And the system is not able to be utilized for individuals with ASD because the Department of Justice, which established the criteria for these systems, says that they only apply to cases of abduction or Alzheimer's.

We currently have no formal estimates regarding wandering in ASD. There's no data available to show how many wander, how often they wander, where they wander, when they wander, or how many die each year and what factors are associated with the risk of death from wandering.

One of the options might be that CDC could add this as a reportable event and collect data, much as they do with suicide and homicide, and that's something we'll discuss later on in the call.

NAA also reported that parents are hesitant to call 911 should their child go missing for fear of arrest or being reported and the child being removed from the home due to the parents being perceived as being neglectful.

Parents also report a pressure to allow the child more independence, but then at the same time they face harsh judgment, should the child elope.

We also heard that families are living under a great deal of stress. Many are unable to leave home, and they suffer with low quality of life and they report very little support from physicians, relatives, neighbors, friends, schools or first responders in events of elopement or wandering.

The presentation included several recommendations for what we need in an effort to better address this issue for families and assure that individuals with ASD remain safe and protected from harm.

One of the needs is data collection. We need to identify:

How many individuals are at risk for wandering;

From what settings they wander;

What are the circumstances surrounding the wandering incident;

What promoted the incident;

And if these incidents are being reported to authorities.

Without such critical information, it's going to be very difficult for us to conduct a cost/benefit analysis in looking at using tracking systems versus what the current state, which is search efforts.

We also need awareness resources and policies. One suggestion was to create tool kits for parents to implement prevention strategies to disseminate information to caregivers through the American Academy of Pediatrics Autism Tool Kit, and through CDC's "Learn the Signs. Act Early."

We also need to create wandering awareness materials for school personnel, first responders and physicians and develop training programs for first responders on the specific challenges faced when searching for an individual with autism.

It's also going to be important to have some type of central source dedicated to focusing on autism related wandering issues that can serve both as a distribution center for information and also a registry for at-risk individuals that can provide quick access to information for first responders should there be an event of wandering.

Federal funding is also needed for families who are unable to afford or gain access to home safety and security measures like tracking technology. And this is something that I had mentioned previously is available to the Alzheimer's community.

So, the specific recommendation to the IACC was to add a new objective to the

Strategic Plan that would focus on ensuring the safety of individuals with ASD. And also one that I added would be research into determining why individuals with ASD wander or elope. And also, the establishment of a Subcommittee to focus on safety issues, which is why we're all here today.

So that's sort of a brief overview of our last meeting when this Committee was established.

And one of the first items that we wanted to discuss today was a draft letter to the Secretary voicing these concerns. And Alison, I'll let you take it over from there.

Ms. Singer: Well, I just want to echo Lyn's sentiments and thank the National Autism Association, particularly Lori and Wendy, for their outstanding presentation. I also wanted to thank Sheila Medlam for the courage that it took to get up in front of the IACC and share her heartbreaking story. With all of us, I think, everyone was incredibly moved by her story and the stories of the other children. You know, for so long we would say that no one died from autism, people lived a long, full life. But that's not the case anymore. We are seeing more and more that children are dying from autism-related accidents.

So, again, my thanks to you, Sheila, Lori and Wendy. And I think all of us agree that this is an urgent matter and that we don't have a day to waste. Because every day that we are waiting, another child or many children's lives are put at risk. So we want to move quickly.

We have two drafts of letters in front of us. One came from NAA, and my thanks again to Lori and Wendy for getting that to the Committee. And then there's another letter that came from the OARC staff.

I think both of the letters are much more similar than they are different. They both have the same recommendations.

Really, the differences that I saw were that I think one of the drafts, I think, incorporates more of Sheila's personal story. And to the extent that Sheila feels comfortable sharing that story with a broader audience, I think that really helps to outline that this is a very personal issue and that real people are affected. So I found the addition of Sheila's story to really be strengthening to the letter.

So, I think we probably need to check with Sheila and make sure, if that hasn't been done yet, to make sure that she's comfortable with this information being included in the letter to the Secretary. But I would say that that absolutely strengthens it.

But again, I think the letters are more similar than different. They have the same recommendations to the Secretary.

I think one thing we need to talk about is, does everyone on the Committee agree that these are the recommendations we want to make? And then I think we talk about prioritizing the recommendations and making sure that what we're asking the Secretary to do is within the purview of HHS. I think there is some overlap between what she can do and what she needs to take over to DOJ. And I think we need to talk about what is the best way to make that happen.

Because the goal here is not to just, you know be another Committee that issues a white paper or a list of recommendations, or another plan. It's to actually get this done. So I think we have to talk about what is the most expedient way to get this done.

Ms. Redwood: I agree 100 percent, Alison. The letters are very similar. And I think it would be easy to somewhat combine the messages. It strengthens the letter to add the person's story, Sheila.

Dr. Boyle: So, Susan, when you

wrote this letter, did you talk to Sheila? Was she comfortable including this?

Dr. Daniels: This is Susan. We did not speak with Sheila. We just included it.

Ms. Singer: I mean, my guess is that given that she stood up in front of the IACC and shared her story that she would probably be okay. But I think we do need to just make sure she's okay with it.

Dr. Daniels: One thing I wanted to add for the public is that these materials are --

Ms. Singer: Hello? Hello?

Dr. Boyle: We're still here.

Ms. Singer: Hello.

Dr. Boyle: I believe we lost Susan.

Ms. Singer: Hello? I think I lost the call.

Dr. Boyle: No, no, you didn't lose it. Can you hear me? This is Coleen.

Ms. Singer: We hear you, yes.

Dr. Boyle: Yes. So I think we just lost Susan.

Dr. Daniels: I'm here.

Dr. Boyle: Are you? Okay.

Dr. van Dyck: This is Peter. Can you hear me now?

Dr. Boyle: Yes, we can.

Ms. Singer: Yes.

Dr. van Dyck: Okay. I've been on the call since the beginning.

Court Reporter: This is the transcriptionist. Dr. Daniels, I think you keep cutting out.

Dr. Boyle: You may be on a phone where when someone else speaks, maybe they cut you off.

Ms. Singer: All right. Well, does everyone have the letter in front of them that starts "Dear Madam Secretary," the one that on page 1 lists a sampling of fatal incidents in the past year?

Dr. Boyle: Yes. Now, who composed that, Alison?

Ms. Singer: That one was put together by Susan.

Dr. Boyle: Okay.

Ms. Singer: And I think it --

Dr. Boyle: Well, I haven't had a chance to look at that yet. I looked at the one that was originally drafted.

Ms. Singer: They're very similar. I mean, the recommendations are the same. There's one, two, three, four --

Ms. Redwood: The recommendations, I like the first page of the draft letter from OARC. But I think that the recommendations in the draft letter from NAA are a little bit more succinct. So maybe we could combine the two?

Ms. Singer: Well, let's go through them, I think, one-by-one. I think we need to agree on them and just go through each one.

Dr. Boyle: You mean in terms of the recommendations?

Ms. Singer: Yes.

Dr. Boyle: Okay. Go ahead.

Ms. Singer: All right. So the first one on Lori and Wendy's letter is: Establish a medical diagnostic code for at-risk individuals with ASD who are prone to wandering. And that is number two on the OARC letter.

Ms. Redwood: And one of the things I spent this morning trying to determine the process for establishing a medical diagnostic code. And it looks as though those are established with the AMA and also -- let me see, let me find my notes here.

Currently there's the Ninth Edition of the International Classification of Disease, which are the ICD-9 codes. And those are actually developed by the World Health Organization. They're in the process of developing ICD-10 codes. But it looks as though there's a code in there already, 294.11, that is dementia that might possibly be able to be utilized without the necessity of establishing a new code. It actually states that you can have dementia in children, which I typically think of dementia as being a disease of the elderly and that it can occur with either a regression of skills or with a plateau and a lack of further development, which obviously fits the category of many of our children with ASD.

There's also a caveat to that code that has dementia NOS, not otherwise specified, with behavioral features. And when you look at behavioral features, one of those is wandering.

So, I'm wondering whether or not there might already be a code available that physicians could use. So I think we need to check into that. But I wouldn't delay sending out this letter to check into it.

Dr. Rice: Lyn, this is Cathy

Rice.

A quick question. So with the symptoms you mentioned, so wandering off is one of them, my concern would be does that really put the focus on dementia, and then the issue becomes proving that the child has dementia, which may divert from the actual purpose of saying this is a clear safety issue about the wandering off.

So, the code that's used for dementia with wandering off specifies the wandering off component, so I'm not sure if the solution you're proposing would really get to that safety issue or would it focus on the dementia?

Dr. Boyle: And also, Lyn, one last thing too, we are investigating with NCHS whether or not there is still opportunity to consider amendments to ICD-10. And this was the CM version, the clinical modification version of ICD.

Ms. Redwood: Yes.

Dr. Boyle: So we are looking into that and we'll try to get an answer to that soon for you, or for us.

Ms. Redwood: Well, that would be wonderful if you could --

Dr. Boyle: We are investigating that piece of it.

Ms. Redwood: We need to know, and you may already know this, if the 294.11 is the code that is currently being used in Alzheimer's to justify monitoring system?

Dr. Boyle: So, my understanding, and again, this is still preliminary, is the CM code is an F code, F02.81.

Ms. Redwood: Okay.

Dr. Boyle: And other diseases classified elsewhere with wandering off.

So, you know the dementia is the focus in nosology from my understanding. In nosology that would be the focus. So, I'm similar to Cathy, I'm a little concerned about the dementia piece of it.

Dr. van Dyck: This is Peter. I agree with both Cathy and Coleen. I think dementia implies something else completely, and I think it would be a problem with the coders.

Ms. Redwood: And as I said, I thought that too, Peter, until I was looking at the definition. And the reason I was checking into this is I was just concerned that since this is such an urgent issue and that it may take quite some time to be able to establish an ICD-9 or 10 code, that this might be something that could be used in the interim. So that's why I brought it forward.

Ms. Singer: What is the definition of dementia, and why would it not apply in this situation?

Ms. Redwood: Hold on. I actually printed it out, if I can find it. I've got several papers here.

Dr. Boyle: And also, Lyn, while you're looking that up, Cathy and Becky and I here are just chatting. Our understanding of the CM version is that's supposed to be sort of this living, breathing document. So, you know I hear you in terms of the urgency here.

Ms. Redwood: Yes.

Dr. Boyle: And, hopefully, we can have some guidance from NCHS. We just haven't been able to connect with them directly yet.

Ms. Redwood: So, Coleen, do you want to take on that piece?

Dr. Boyle: Yes, sure, that's what we were doing, things that we felt we had the expertise, then we'd be happy to help trying to guide a law.

Ms. Redwood: Right. Let's see if I can pull this up real quick.

Ms. Singer: All right. So --

Dr. Boyle: At this point we could provide what the options are.

Ms. Redwood: Alison, do you want to move on to the next one while I'm looking that up?

Ms. Singer: Yes. Before we leave this one, even though there's more information to be gleaned here, I still think we need to include it somewhere in the letter. That we need to either create a medical subclassification or utilize an existing subclassification to indicate that autism with wandering and/or dementia is a medical diagnosis. So, I don't want to just leave it on the table.

Ms. Redwood: Absolutely.

Dr. Boyle: Alison, we had rewritten that piece a little bit, so I'm going to send it after the Committee call for your reflection or consideration, and it actually includes the Alzheimer's and other dementia example, to be more specific here.

Ms. Singer: As we're moving to the next one, the next one on the list talks about creating a policy recommendation for an emergency broadcast system, which is sort of a combination, really, of the AMBER alert, which is the alert issued for minors who have been abducted, and the Silver Alert, which is the alert issued for senior citizens suffering from Parkinson's disease with dementia.

I think what we really are looking for here is a combination AMBER/Silver Alert in that our population has some symptoms of each of these, and that they are children but also developmentally disabled or suffering from dementia or dementia-like symptoms.

When I was looking into this and researching this it was very interesting to me that a lot of the opposition to the Silver Alert when those laws were being passed, had to do with the fact that these were adults and not children. And it was brought up during the debate on the Silver Alert about children with developmental disabilities. So, I don't think that population-wise there's going to be opposition to something like this. And, in fact, it was brought up as an example of something that needed to be included as the

Silver Alert was being debated.

And I also think that combining the AMBER Alert and the Silver Alert may negate the need to actually wait until we are able to classify the kids with dementia or dementia-related. But I think this is one that we can move on quickly because the AMBER Alert, all of the infrastructure is in place for the AMBER Alert and the Silver Alert. And I think this is one where I think the Secretary can intervene, can make recommendations regarding legislation. And I think this is one where I think we could get some really good quick traction. So to me, this is the number one priority.

Dr. van Dyck: So if we can specify --

Ms. Singer: Hello? Cutting out.

Dr. van Dyck: I wonder if we can specify what federal agency has the responsibility? Because my copy just says "federal guidelines recommend." Do we know which federal agency has responsibility?

Ms. Singer: It's the Department of Justice. The Department of Justice oversees both the AMBER and the Silver Alert.

Now the Silver Alert is not federal legislation right now, it's just several states. But there's pending federal legislation regarding the Silver Alert.

And I found out that there is a person at the Department of Justice whose title is AMBER Alert Coordinator. And one thing I'm going to suggest is that maybe Lyn and I make an appointment to meet with this person at the Department of Justice and get his or her input regarding how we might be able to make this happen.

Ms. Redwood: I think that sounds great.

And also, you know, since it was Mason who brought this to our attention, I would like to suggest too if there would be any way possible to call it the Mason Alert, remembering this young man.

I just found the information on dementia. And what it says: "Dementia is uncommon in children and adolescents, but can occur as a result of a general medical condition." And they give an example of head injury, brain tumors, HIV infection, stroke. "Dementia in children may present as a deterioration in functioning, as in adults, or as a significant delay or deviation in normal development." And that was the definition that was utilized.

And again, I agree with everybody's concerns about using dementia, and I was just trying to find something that physicians might could use in the interim to help cover the costs for a parent to be able to purchase these monitoring systems for their children.

Dr. Boyle: And again, Lyn, I think -- and maybe as a second tier, let's try and see whether or not we can develop a code.

And I do think we need to have some clinical experts here in terms of guiding us on the development of the code, too.

Ms. Redwood: Right.

Ms. Singer: All right. So do we all agree, though, with the recommendation that appears in both of the letters that talks about developing an alert system similar to the AMBER Alert, similar to the Silver Alert, that would cover -- that would either expand the AMBER Alert to include children with developmental disability or would reduce the age of the Silver Alert to include children with dementia or dementia-related type illness?

Dr. Boyle: Yes.

Ms. Redwood: Yes.

Ms. Singer: Okay. All right. So we have the first two.

The third recommendation talks about creating policy recommendations for federal programs related to first responder training, tracking technology, access and oversight, and swimming lessons. And this one is also in the OARC letter listed as number five: "Develop training for first responders in specific challenges." And I think it's also -- yes, it's number four and number five.

Ms. Redwood: Yes, absolutely. I think it's important to also include in the letter that this is something that is already in place for individuals with Alzheimer's or dementia.

Dr. van Dyck: I think this is important, too. I just wondered about the inclusion of swimming lessons alongside responder tracking, tracking technology, access and oversight. It just seems like a different category of something, and I'm not sure anybody's going to -- a federal guideline is going to recommend, in a set of guidelines, swimming lessons.

So, I think it's important, but I wonder if it takes away from first responder training and tracking technology, access and oversight?

Ms. Singer: I think that's a good point. It's also, I don't think it's within the Secretary's purview.

Dr. Rice: This is Cathy.

Was there room for a recommendation that intervention and treatment plans consider safety for that individual on what types of things need to be taught or worked on for that individual? It may not be under the Secretary's purview, but that's one element we're kind of missing in terms of the increasing teaching to safety skills as a primary focus in intervention plans.

Ms. Singer: And prevention, and focus on prevention.

Dr. Rice: Right.

Ms. Singer: So maybe we create a section that talks about family training that includes the importance of swimming lessons, access to swimming lessons, supplemental funds for swimming lessons, but also includes other training. So, maybe as part of on the OARC letter there's information about increasing awareness by disseminating materials about ASD-related wandering. Maybe we can include the need for swimming lessons in the awareness materials.

Dr. van Dyck: That's a better place for it.

Dr. Boyle: You know, Alison, maybe that we want to be a little bit more broader about advocating for prevention measures. Could we develop a separate bullet geared towards that, and it's not just a communication.

Ms. Singer: That's a good idea, preventive measures including parent training. I don't know that many parents when their child is diagnosed with autism are even told about the issue of wandering.

Dr. Boyle: Yes.

Ms. Singer: I mean, I think you

don't realize it until your child does it for the first time.

Dr. Boyle: Right.

Ms. Singer: And, you know, your life is scared out of you. But it should be.

Dr. Rice: Yes. And along those lines -- this is Cathy again -- I mean, teaching the safety skills too, is prevention too. So like you said, when you get the diagnosis, how can we provide materials and information that say, well let's consider safety issues first. The child's not responding to their name, and those types of things that may be preventative measures as well.

Ms. Redwood: I also think it would be important to utilize the data collection process to be able to really drill down and identify what the respecters are. What are the events that lead to elopement and wandering? And then we can really develop materials that address specifically what we know about those occurrences, which we have very little information right now on except for just anecdotal reports from parents.

Dr. Boyle: Right. Definitely.

Ms. Redwood: But yes, Alison, I think we're all in agreement that we need to take out the swimming and put it into a separate category that addresses the broader issue of prevention.

Ms. Singer: Right. Okay. Now I'm just writing all this down so -- and we can rewrite it.

Okay. And then so we talked about data collection, which is the last item in the NAA letter, but there's one that we skipped, which is: "Establish formal safety information materials for caregivers, first responders." I think this sort of gets at the prevention issue. I think we can combine this and make this -- really label it: establish formal safety and preventative information materials for caregivers, first responders and physicians.

Ms. Redwood: And I also liked the idea of collaborating with the American Academy of Pediatrics on this and getting this into their tool kit.

Ms. Singer: So I think what we have to talk about is, yes, I agree that we should approach the AAP, but I don't know that that's something we want to include in -- is it something that we want to include in the letter to the Secretary? I think we need to make sure that the letter to the Secretary is full of things that she can actually act on.

Ms. Redwood: Right. I think we need to --

Ms. Singer: So she doesn't say, well, this is not within my purview, sorry, they're all great ideas but I can't help you. I would like to have a list of things that she can actually do.

Ms. Redwood: And I think we need a secondary list of action items, though, too to address the safety issues that are outside the purview of the Secretary.

Ms. Singer: Agreed. Agreed.

Dr. Boyle: But, Alison, I guess I would also say that we can -- you know our agencies, both Peter's and CDC, can work with the American Academy of Pediatrics. And that's how we do our business, really, in terms of thinking through how -- incorporated within their materials. So, I mean it's not necessarily outside their purview, it's just how it's worded.

Ms. Singer: Oh, I see. Okay.
So, we would recommend to the Secretary that CDC and that HRSA would --

Dr. Boyle: Encourage federal agencies to blah, blah, blah; something like that.

Ms. Singer: To work with the AMA and the AAP?

Dr. Boyle: Right.

Ms. Singer: And the AAFP?

Dr. Boyle: In developing appropriate or revising appropriate material. And that's kind of not family material, health care providers.

Ms. Singer: Okay. No, that's a great way to put it in there. I agree.

Ms. Lewis: Hi. This is Sharon Lewis.

I apologize. I've been on the call since 10:00 a.m., but they had difficulties with my line, and I'm now finally able to speak. Can you hear me now?

Ms. Redwood: Yes. Welcome.

Ms. Singer: So, Sharon, thanks for joining us. Did you want to comment on anything that you have heard but were unable to jump in and comment on?

Ms. Lewis: Yes. Let me -- and I apologize because I have an appointment at 11:00 a.m., so I'm only going to be able to be the call for another 20 minutes.

Dr. Daniels: I've been trying to

speak as well throughout the call and haven't been able to be heard.

Ms. Lewis: Okay. Just one quick -- I guess, and I'm glad to hear where we're going in the conversation right now. But my overall concern about all of this is in acknowledging and appreciating the importance and the concerns about elopement and wandering and how we might address this. I guess two things.

One is, I do think that the focus on family education and prevention and opportunities to address the issue from a prevention and behavioral perspective as opposed to medicalizing this and putting tracking devices out there immediately as an option, or as, you know, the best case scenario when we still have so little information is of concern to me, especially as it relates to -- you know, it's one thing when we're talking about kids, but as individuals get older, I have huge concerns about any type of approach that would conflict with an individual's self-determination and ability to have a level of independence. And I would caution us all as we move forward in this conversation to keep that in mind.

And I disagree that this is something that is easy to address in the same way that an AMBER Alert or a Silver Alert has been established. And there was substantial debate about this on the Hill when the discussion came up. And I don't know that this is an easy legislative opportunity.

So, I wanted to throw those two things in, kind of backpedaling against earlier conversations. And I apologize that I wasn't able to make those comments in a timely manner.

Ms. Singer: Well, what were the concerns that you heard on the Hill?

Ms. Lewis: Primarily that, you know, individuals with developmental disabilities, it is a different situation than dementia. You know, determining the gray areas around who this might be applicable to and, again, those concerns about self-determination and affecting the independence of individuals that we're working so hard to support to move towards independence was of grave concern.

Additionally, tying these two issues together in terms of developmental disabilities and aging populations was of concern to the disability community.

Ms. Redwood: Sharon, I guess I see this as being something that, it cannot be mandatory. And, you know, having a child that was on the spectrum who wandered is just a nightmare. And I guess I feel a little bit different in looking at this from a child who is not able to care for themselves. They have no idea something might be harmful and that we do need these kinds of mechanisms to protect them and to be able to locate them quickly when they do wander.

And it's just amazing how skillful they can be at getting out and getting away from parents and school officials.

I know my son was lost several times at school. And I see this as something that would be completely voluntary and only utilized if the parents and the physician felt that it was necessary to ensure the safety of the child.

Ms. Singer: This is Alison.

And I also think we're talking about different levels on the hierarchy of needs. I mean, when we talk the goal of self-determination it's hard to really think about a child achieving self-determination when they're still at the point where they're at risk of being hit by a car or drowning, or you know they don't respond to their name so they can't respond when a first responder is searching for them when they're lost.

So, you know, to me it's sort of, we're at the very basic level of needs here and the issue of self-determination comes into the picture down the road.

Ms. Lewis: Well, and I guess I would -- also as a parent whose child has escaped from school, so I get it. I understand, and I understand the terror in that. I just caution us, again, as we do this and we think about this to think about, how do we ensure that some of these safety and protection issues then do not impede the need to ensure that we're teaching kids and moving kids toward self-determination. And that these are -- I hear that it's optional. I think that we need to continue the pursuit of self-determination at a very early age and I would hate to see tracking devices become something that, frankly, makes it easier for the adults to keep track of children in a way that then does not foster that growth towards independence, you know.

You know, I'm not saying that the two can't co-exist. I'm saying that I think it's something that needs to be considered as we move forward on this. Because I think the difficulty will become when these young people are turning 17, 18 and what opportunities will they have to have a voice in what happens next?

Ms. Singer: Well, one of the issues that came up again and again when I was looking at the transcripts on the Silver Alert legislation is people kept saying, you know, these are adults, these are not children. And there was clearly a differentiation between a child and an adult. So maybe if we talk about specifically children or adults for whom their parents are the legal guardians because of the level of their cognitive and intellectual disability and limit it to children, would that address your concern?

Ms. Lewis: It begins to address it, yes. You know, and again I think it's also as we draft this letter to the Secretary and as we look at this policy issue I think that focusing on what we know in terms of the research base out of -- regarding family support, family education training, positive behavior supports and other ways to address this that are less invasive, need to be critical components of what we're talking about here. As it was acknowledged at the beginning of the call, one of the deficits that we're operating against is the lack of data and a lack of solid information. And absent that, I think that we also need to turn to what we do have and what we do know as it relates to family support writ large. And I would encourage us to think about that.

Ms. Singer: Okay. So I think we can make sure that we're clear throughout this letter that we are focused on children who are under the guardianship of parents. So, I guess that's children up to -- is it 18 or 21?

Ms. Lewis: Well, it's 18 unless parents pursue --

Ms. Singer: Okay. Or those for

whom their parents are appointed as legal guardian. I think we can make sure that that's clear.

Okay. So have we talked about each of the recommendations that were in both drafts of the letters? I think we've gotten to all of them.

Did anyone have any other recommendations to be added, or did anyone feel that some of the ones that we've talked about don't belong in here?

Ms. Redwood: Alison, one that we missed was data collection through the CDC. And I wonder if, Coleen, if you could speak to that issue and what might be available?

Dr. Boyle: You're talking about the recommended data collections for CDC. We added the CDER and we added the Health Resources and Services Administration in our redraft here which we haven't shared with everybody. Because HRSA does have two very powerful surveys; one on children with special health care needs and one on children in general that captures children with autism and other developmental disabilities.

So, within the context of CDC's work, we have the National Health Interview Survey which captures the fairly small sample of children with autism on a yearly basis but cumulatively that information can be helpful in terms of looking at trends.

We've talked with NCHS about one issue so far, and that was they are adding questions to a specific study, which is a follow-up study of one of the surveys, the National Survey of Children with Special Health Care Needs, and they're adding two questions that will actually go in the field in 2011. And, Cathy, do you remember what those two questions were specifically?

Dr. Rice: It's frequency questions about how often has this been a concern in terms of wandering and --

Dr. Boyle: I don't remember the

second question.

Dr. Rice: Yes, and then the second is a follow-up from that about the level of concern that was raised from that.

So, I can get the specific questions and share them with the Committee.

Dr. Boyle: Yes. And we can work with Sheila and Laura in terms of developing those questions so they have input to those.

But anyway, Peter, I don't know if you want to speak to your two surveys, and I will follow up with the National Health Interview Survey to see what the opportunities are for additional questions.

I'll get you the actual numbers of children with autism that are identified there. And I want to say it's something like 70 kids, something like that a year, so very small numbers there. But Peter's survey are much richer in that regard.

So, Peter?

Dr. van Dyck: Well, our two

surveys do sample on a population base the number of children with autism. But in the past we haven't asked any questions about wandering per se, because we weren't aware it was such an issue until just lately.

We are currently developing the final question set for the survey that's going in the field in 2011. And I'll review just what questions are in there.

Dr. Boyle: And, Peter, we do have a series of questions that we worked with Michael -- not Michael, Stephen Blumberg in developing. So, we'd be happy to share those with you.

Dr. van Dyck: That would be good, Coleen.

Ms. Singer: Is there any plan to publish in the near term in the *MMWR* on this issue?

Dr. Boyle: Well, we'd have to have something to actually publish.

Ms. Singer: Well, I mean --

Dr. Boyle: Other things we were thinking of, Alison, was actually doing some type of multiple cause of death analysis. So we're looking at any -- and we've done this on other, on disabilities, on children with special health care needs. So looking at essentially the mortality experience of children with autism and what are the other associated causes of death, so what are the injury-associated causes versus other types of causes? So that sort of gives you a better sense of how children with autism might compare to children with other types of chronic health conditions.

Ms. Singer: Right. Unfortunately, I think that's the data we need.

Ms. Redwood: Is there any way to make a report of these in terms of the deaths, the same way you do suicide and how people collect -- track other data with reportable diseases?

Dr. Boyle: I missed the first

part of what you said, Lyn. I'm sorry.

Ms. Redwood: I'm just wondering if there's a way to actually make it mandatory that physicians or medical examiners report when a child with autism dies?

Dr. Boyle: As a condition that's reported on the death certificate?

Ms. Redwood: Right, or that they report it to some type of national registry, the same way you collect data on homicide and suicide.

Dr. Boyle: Yes. The way they collect information on suicide and homicide is really from death certificate information.

Ms. Redwood: Well, is there a way, would it actually say on the death certificate that the child had autism as well? Is there a way to collect that data?

Dr. Boyle: Yes. So if it's something that was related somehow to the cause of death and the examiner was aware of that, it would be included as a condition listed, sort of in the causal chain when they'd fill out the death certificate. If it's incidental, probably not.

Dr. Rice: This is Cathy.

Just to add, that's one of the -- Coleen had mentioned us looking at the mortality data where we would be able to cross the death certificate information with the kids that we've identified with autism for our prevalence studies. So that's fortunately not many children when you're looking at the sample that we have, but it will be some to be able to look at, for those children, what was the cause of death. So, we'll have some information on that.

Ms. Singer: And when will you have that?

Dr. Rice: We're in the midst of obtaining the death certificate information. I'll check with the person that --

Ms. Singer: And where are you going to report those data?

Dr. Rice: We hadn't decided on reporting. Certainly a publication of sorts. We could consider MMWR or a journal. We hadn't gotten that far yet because that analysis hasn't been done yet.

Ms. Redwood: Cathy, any idea when it will be done?

Dr. Rice: That's what I'm not sure about how long it will take to get all of the death certificate information and matching it. I'm not doing that directly, but I'll ask the person that is and we'll find out.

Ms. Redwood: It would be great to know too how difficult it is to go back in and data-mine death certificate information.

Dr. Rice: Yes.

Ms. Redwood: And if a lot of it now is electronic, that means it might be easier to access.

Dr. Rice: Yes.

Ms. Singer: Another possibility would be to use the Interactive Autism

Network, which I don't know -- Lyn, what was the “n” on the NAA survey? How many families did you include?

Ms. Redwood: You know, this was taken from the presentation that Lori and Wendy did. And I don't -- let me see if I can call up the actual PDF, but I did not see an n. I'm sure they sent it out to their listserv.

Ms. Singer: Because one thing we could do is to try to increase the n is try to get a survey through the Interactive Autism Network, which has about 13,000 families registered now.

Ms. Redwood: Right. That would be another great way to do it. And it might also decrease the bias if we could get everyone to respond, or at least a percentage, enough to decrease bias.

Ms. Singer: All right. So let's put that on the list of other things we need to do. But certainly, if we could get data that were published in the MMWR, that would be -- I mean, that's the data that the Secretary is going to respond to. So that's what we need.

Dr. Boyle: All right. Well, we could try to at least outline the feasible projects that might help provide some better information here. So, I think that's an important next step for us.

Ms. Singer: I also think if we could get some wording on an objective for the Strategic Plan that specifically relates to how we would do this, and we could include it in Chapter 7 or we could recommend to the Subcommittee on Planning that we include it in Chapter 7 of the Strategic Plan. I think that might help as well in increasing the speed.

Dr. Boyle: Okay.

Ms. Singer: Do you agree, Lyn, that we should put something like that right in the Plan?

Ms. Redwood: Yes, absolutely.

Ms. Singer: Or that we should recommend to the Committee that it be considered for the Plan?

Ms. Redwood: Well, since we're both on the Committee --

Ms. Singer: Exactly.

Ms. Redwood: -- that we add it to the Plan, I think we could easily recommend that. And actually, I think there were two of them. One would be under the infrastructure. And then also another research need to try to determine what causes these episodes of wandering and if it's related to any specific medical conditions or any type of specific brain pathology; I think it would be important to try to dig a little bit deeper in.

Ms. Singer: I agree.

So, Cathy, do you think you could draft those objectives and we could take them to the other Subcommittee?

Dr. Rice: Sure.

Ms. Singer: Which is meeting on

Friday?

Dr. Rice: Sure.

Dr. Boyle: I'm not clear what they are and since I'm in charge of Chapter 7 on my other duties here --

Ms. Singer: Well, I think as Lyn said, one is a short term objective to just crack this data. To cross-match, as Cathy was saying, the death certificate data with the prevalence data.

And then the long term objective that Lyn was describing was to try to understand the underlying cause behind wandering.

Dr. Boyle: All right. What about the prevention?

Ms. Singer: And prevention.

Dr. Boyle: Do you want to think a little --

Ms. Singer: That might go in Chapter 2, or Chapter 4, or Chapter 7. We'd have to find the right place for it.

Dr. Boyle: Three objectives, essentially?

Ms. Redwood: I think four with treatment. Also, I don't know what does the future hold --

Ms. Singer: Well, underlying cause, though, might be Chapter 2 -- anyway, we don't have to haggle about this now.

Dr. Boyle: Well, we can definitely take this, the one on data and something on prevention. And maybe, Lyn, you can draft the one on the causes issue.

Ms. Redwood: Right. Sure.

Dr. Boyle: Okay?

Ms. Redwood: And, Susan, you'll be circulating after the call sort of a summary with action items for the Committee members?

Dr. Daniels: Yes. Can you hear me?

Ms. Redwood: Yes.

Dr. Daniels: Yes. So I will be submitting something to you so that you can see what the action items are following the call. And if you have language that you want to work on before December 3rd, I'd recommend going ahead and doing that quickly because we do have our meeting coming up.

And I'd just like to make one reminder regarding FACA. We can only have one representative per agency on the call. So, it's fine if you've decided, Dr. Rice, to join as a guest consultant to consult on some things. But Coleen Boyle is the official representative on this call for the CDC.

Ms. Singer: Okay. Are you, Susan, are you going to take some of the conversation that happened on this call and use it to do another draft of the letter, or should Lyn and I do that? How should we handle that?

Dr. Daniels: How would you like to do that?

Ms. Singer: I'm happy to do it with Lyn if Lyn's up to it. Is that okay with you?

Ms. Redwood: Yes, no, that's fine. All right. I think it'll be easy to include these in the letter and have something that we circulate to the Committee one more time for review and then submit for our full Committee meeting. When is that? December 14th, I think.

Dr. Daniels: Yes. December 14th. And if anyone is sending additional language for the Strategic Plan, if you could please copy the Subcommittee members as well as Della Hann and myself on any emails for FACA, that would be helpful. Thank you.

Ms. Singer: And what's the procedure? Does the Subcommittee actually have to vote on moving the final draft to the Full Committee, so do we have to leave a certain amount of time in the work plan for that?

Dr. Daniels: I don't believe that you need to necessarily vote. If you can come up with a plan today for what you want, go ahead and make your changes. Then the two Chairs can bring that to the full Committee, and then it will be voted on at that time.

Ms. Singer: Great.

Dr. Boyle: And I have to actually run soon. Since Cathy can't be my delegate here, so I don't know if we're concluding --

Dr. Daniels: Yes, she can replace you if you're going off the call. But she and you cannot be on the call at the same time both representing CDC; that's my point. But if you're leaving, she can replace you.

Dr. Boyle: Okay. Wonderful.

Ms. Redwood: Were there any other comments on the draft letter, or suggestions or comments from the earlier discussion?

Ms. Singer: Okay. So let's talk about the action item list.

So, Lyn and I are going to work on redrafting the letter, tightening it up and adding the comments that we heard from the call today.

I will go ahead and contact the Interactive Autism Network and see what's involved in doing a bigger survey.

And then, Lyn, did you want to follow up on the ICD codes?

Ms. Redwood: Right. And I'll work again with Coleen on that to see. They were offering to be sort of the point, important person on that initiative.

Ms. Singer: Okay. And then Coleen or Cathy, one or both of you are going to submit the new objectives to the Strategic Plan Committee for its consideration at this Friday's meeting.

Dr. Rice: Yes.

Ms. Singer: Okay. Have I missed anything?

Ms. Redwood: And I'll draft one regarding research into mechanisms.

Ms. Singer: Have I forgotten any action items that we've discussed?

Ms. Redwood: Meeting with someone over in the Department of Justice.

Ms. Singer: Right. Right. I'll try to see if I can set that up.

Ms. Redwood: If it would be possible to set that up either prior to our meeting on the 14th or some time when we're already in D.C., or I don't know, if we could even meet by conference call. But either the 13th or after the 15th would be great.

Ms. Singer: Okay. No, I agree. I also have to travel for these meetings. So I like to get as much done when I'm there as I can. Okay.

Ms. Redwood: Susan, were there any other action items that you had?

Dr. Daniels: I believe you got them all.

Ms. Singer: Susan, do we have to take a federal representative of the IACC with us if we meet with DOJ, or can Lyn and I just go?

Dr. Daniels: I think you can go and then just report back.

Ms. Singer: Okay. Great. Yay.

Ms. Redwood: Susan, what's the deadline that you would need the letter to be approved by the 14th to be included in the packet?

Dr. Daniels: What would be -- what my view is, is if before your meeting with the DOJ, I wonder if you could get Della or me on the phone for that, that might be helpful. Actually, a federal official probably should be involved because it is official Committee business that you're discussing, correct?

Ms. Redwood: Right.

Dr. Daniels: So one of us on the phone, that would be helpful.

Sorry. What was your question, Lyn?

Ms. Redwood: Oh, a deadline for when we would need to get the final copy of the letter to be voted on at the full

Committee meeting on the 14th for you to include in the packet?

Dr. Daniels: I'll send it out in my email when I send it out. I don't have my calendar in front of me right now, but it will be within a few days.

Ms. Redwood: The other thing, Alison, we had talked about would be sort of next step with regards to the Committee. I know our first action item was getting the letter out. But I also thought it might be important moving forward if we could possibly solicit a request for information from the autism community to find out what are the key issues that they worry about the most in terms of safety of their children. We might be able to get a lot of good information that way, too, along with specific questions with the IAN Network.

Ms. Singer: That makes sense.

Ms. Redwood: And that's not something that we discussed on the call today, but I think it would be something great to go out with, maybe the first of the year. Do the other Committee members have comments on that, suggestions?

Ms. Singer: This is Alison.

I agree that that's a fine thing to do, and some issues may come up that we haven't thought of. But I also think that we need to continue to move forward on this issue and also on seclusion and restraint, which we know have been identified as key issues.

Ms. Redwood: Right.

Ms. Singer: And not wait for the RFI responses before we move on those.

Ms. Redwood: Oh, yes, absolutely not. But that would just be a way to make sure that we are acknowledging --

(Simultaneous speakers.)

Ms. Singer: To broaden, yes.

Ms. Redwood: -- the safety issues that are out there.

Ms. Singer: Yes. You know, I

think we're talking about the same thing. We want to do these things in parallel. We want to make sure that aren't other safety issues we need to consider, but we also want to move on the ones that we've already identified.

Dr. Daniels: Lyn, for the request for information, what type of request for information, what types of questions do you want to ask?

Ms. Redwood: Can we draft those, and Alison and I can do it via email?

Dr. Daniels: And then it needs to be discussed in a public meeting. So then we maybe could discuss it at the next meeting. Unless you -- you still have 45 minutes if you want to discuss it now.

Ms. Redwood: I think the questions could be somewhat broad in terms of allowing enough space for people to write in what their concerns are and to possibly rank them in terms of, whether or not it's elopement, whether or not even safety within the house, if it's first responder training.

One of the things we didn't touch on is also educational programs for teachers and paraprofessionals. Because a lot of these cases of wandering and elopement do occur in the school system. So, I think that that's also a need we need to discuss with the Department of Education folks. Just try to get a better idea of what the concerns are that families have.

Does anyone else on the call have specific questions they would like to see asked in an RFI?

Dr. Daniels: So, Lyn, this is Susan.

So are you saying, perhaps, it would be a question like what concerns do you have regarding safety for people with autism, something along those lines, just an open-ended, broad question?

Ms. Redwood: Right. With a little bit more detail than that. I would have to really sort of sit and think it out to figure out the best way to word the question to get the information that we really want and need.

Dr. Daniels: Actually, you have two ways that you could do it. You could come up with something and bring it to the full Committee. However, then the Subcommittee wouldn't really get a chance to deliberate it --

Ms. Singer: Hello? Hello?

Ms. Redwood: This is --

Dr. van Dyck: The Subcommittee could do it by email. Lyn could draft the questions. It's easier to respond to something, and we could respond back on the email.

Dr. Daniels: -- a question before December 14th, and then bring it to the full Committee to ask them. Because you will need their --

Ms. Redwood: Okay. Add that to

my to-do list, and I'll draft up some questions and then circulate it to the full Subcommittee for input. And then we can bring those forward at the meeting on the 14th too. Because I know that process takes some time to set up.

Is there anything else, Alison?

Ms. Singer: No, not right now.

Ms. Redwood: Well, I think we have our work cut out for us, at least for the next two weeks.

Dr. Daniels: Well, thank you all very much. It sounds like you've accomplished what you wanted to on this call.

I will send out an email following up for getting information ready for the full Committee meeting on December 14th --

Ms. Singer: Hello?

Dr. Daniels: Yes. Did anyone just hear me, or do I --

Dr. van Dyck: You're cutting out a little bit, Susan.

Dr. Daniels: Sorry. So, this is Susan. I wanted to let you know that I will send you all an email outlining the action items from today's call as well as deadlines for getting any information to us prior to the next Planning Subcommittee and full Committee meetings.

And just wanted to thank you all for participating in the call and for all your work on this Subcommittee.

And with that, if no one else has any other items? All right. Well, thank you, everyone.

(Whereupon, at 11:14 a.m., the meeting was adjourned.)