

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

WEDNESDAY, SEPTEMBER 7, 2011

The Committee convened via teleconference at 3:00 p.m., Thomas Insel, Chair, presiding.

PARTICIPANTS:

THOMAS INSEL, M.D., *Chair*, National Institute of Mental Health (NIMH)

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

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

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

JUDITH COOPER, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing James Battey, M.D., Ph.D.)

GERALD FISCHBACH, M.D., Simons Foundation

LEE GROSSMAN, Advance Enterprises, LLC

**NEAL R. GROSS**

COURT REPORTERS AND TRANSCRIBERS

1323 RHODE ISLAND AVE., N.W.

WASHINGTON, D.C. 20005-3701

(202) 234-4433

[www.nealrgross.com](http://www.nealrgross.com)

## PARTICIPANTS (continued):

ALICE KAU, Ph.D., *Eunice Kennedy Shriver*  
National Institute of Child Health and  
Human Development (NICHD) (representing  
Alan Guttmacher, M.D.)

LAURA KAVANAGH, M.P.P., Health Resources and  
Services Administration (HRSA)

WALTER KOROSHETZ, M.D., National Institute  
of Neurological Disorders and Stroke  
(NINDS)

CINDY LAWLER, Ph.D., National Institute of  
Environmental Health Sciences (NIEHS)  
(representing Linda Birnbaum, Ph.D.)

SHARON LEWIS, Administration for Children and  
Families (ACF)

CHRISTINE McKEE, J.D.

LYN REDWOOD, R.N., M.S.N., Coalition for  
SafeMinds

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

ALISON TEPPER SINGER, M.B.A., Autism Science  
Foundation (ASF)

LARRY WEXLER, Ed.D., U.S. Department of  
Education (representing Gail Houle,  
Ph.D.)

TABLE OF CONTENTS

Roll Call..... 4

Administrative Comments..... 6

Approval of July 19, 2011 Minutes..... 11

Discussion of Letter to Secretary..... 12

Vote on Submission of Letter  
to Secretary..... 45

Adjournment.....51

## PROCEEDINGS

3:02 p.m.

Dr. Insel: Yes, thank you. Good afternoon everybody and welcome to this conference call of the Interagency Autism Coordinating Committee.

We want to start off just by making sure we know who is on the call, so let's do a quick roll call.

Susan will take us through it. She will call out the names and if you can just say here.

Dr. Daniels: Okay. We have Tom Insel.

Dr. Insel: In the room, yes.

Dr. Daniels: Judith Cooper?

Dr. Cooper: Yes, on the phone.

Dr. Daniels: Linda Birnbaum?  
Cindy Lawler?

Dr. Lawler: I'm on the phone.

Dr. Daniels: Thank you. Ellen Blackwell? (Silence) Coleen Boyle?

Dr. Boyle: I'm here.

Dr. Daniels: Henry Claypool?

(Silence.) Geri Dawson won't be able to join us. Gerry Fischbach?

Dr. Fischbach: Here.

Dr. Daniels: Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Alice Kau?

Dr. Kau: On the phone.

Dr. Daniels: Larke Huang? She may be joining late. Yvette Janvier is not going to be able to join us. Laura Kavanagh?

Ms. Kavanagh: Here on the phone.

Dr. Daniels: Walter Koroshetz?

Dr. Koroshetz: Here in the room.

Dr. Daniels: Sharon Lewis?

Ms. Lewis: Here.

Dr. Daniels: Christine McKee?

Ms. McKee: Here.

Dr. Daniels: Ari Ne'eman is not going to be able to join us. Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Denise Resnik?

Ms. Resnik: Here.

Dr. Daniels: Stephen Shore.

(Silence.) May be joining us later. Alison Singer? (Silence.) Marjorie Solomon is not going to be able to join us.

And Larry Wexler?

Dr. Wexler: Here on the phone.

Dr. Daniels: Great.

Dr. Insel: Good. Well, we have a quorum and we will proceed.

Ms. Blackwell: Tom, this is Ellen Blackwell. I'm here as well.

Dr. Insel: Great, welcome Ellen.

Dr. Daniels: Thank you, Ellen.

Dr. Insel: I think all of you hopefully have received an agenda and minutes of previous meetings as well as the letter that is going to be discussed today.

Before we start, I wanted to do two administrative things. First, to welcome Laura Kavanagh who has been named as the representative from HRSA with Peter Van Dyck's retirement recently. So, Laura, welcome to the group.

Ms. Kavanagh: Thank you very much.

Dr. Insel: And also we have Larry Wexler with us who is here representing the Department of Education. Larry, thanks so much for joining.

Dr. Wexler: Thank you for having me.

Dr. Insel: As we've done in the past meetings just take a moment to give you some overview issues.

In terms of where we're at with the IACC and its future. The Combating Autism Act, as you know, has been a topic for Congressional discussion. There was a markup this afternoon or I guess late this morning on the Senate side which means that there was a decision to go ahead and approve the reauthorization at a level of the committee, Health, Education, Labor, and Pensions Committee, HELP Committee for the Senate. That still will need to go to the floor. It may happen through unanimous consent. We

don't know at this point exactly when that will be or how it will proceed. But that's a very good sign.

We have not further information about what's happening on the House side so as far as we can tell, there's no set markup for the House but we're expecting to learn more about that in the next few days.

Let me ask if there are any questions about that?

And, Susan, do you want to mention something about some of the upcoming meetings?

Dr. Daniels: Yes, I wanted to just quickly make announcements about the next upcoming meeting. I know that you've received emails and we have posted information on our website about next week. September 15th, next week, the IACC Services Subcommittee will be hosting a workshop called Enhancing Support for People with Autism and Their Families, Community Integration and the Changing Delivery System. And there will be several topics that will be covered including self-



determination, safe and supportive environments for people with autism, criminal justice diversion, home and community-based services, American Disabilities Act and the Olmstead enforcement, managed care, services provision and rehab research and employment services. So, we hope that many members of the public and that the IACC members will also be able to join us. This will be taking place at the Bethesda Marriott - Pooks Hill in Bethesda, Maryland. And info is on our website and we'll be sending out an email about that.

We also have an upcoming workshop that is not a part of the IACC but it's being hosted by NIH in response to one of the objectives in the strategic plan. It's called Ethical, Legal and Social Implications of Autism Research and it will be held on September 26th, 2011, at the Bethesda Marriott North here in Bethesda, Maryland. And that will also be a one-day, all-day workshop and the public is welcome and IACC members are

invited. So, I wanted to make you aware of those items.

And I also just wanted to remind everyone that on today's call if we come to vote that only those who are present on the call will be able to vote, that we won't be able to take votes, you know, via email and the board after the call.

And one other announcement is please be expecting the Summary of Advances ballot so that IACC members can finalize some midterm summary of the nominations.

Participant: Can we ask you to speak up a little bit or move that microphone?

Dr. Daniels: Sure. I think I'm finished now but --

Participant: Okay. That's great, thank you.

Dr. Daniels: Thank you.

Participant: Much better.

Dr. Insel: All right. We're moving the microphone anyway. Is that better?

Participant: Much better.

Thanks, Tom.

Dr. Insel: Okay. Moving along here unless there are other questions about those overview items. I wanted to have you quickly take a look at the minutes from both the July 11th meeting and the July 19th meeting that were sent to you and let us know if you have any particular comments, revisions, edits, concerns. The 11th was the joint conference call on the Subcommittee on Safety and Services and the other was the full Interagency Autism Coordinating Committee Meeting.

Ms. Kavanagh: This is Laura Kavanagh. I had one minor correction to the July 19th minutes.

Peter Van Dyck is listed as attending and he was not present at that meeting.

Dr. Daniels: Okay. That will be noted.

Dr. Insel: Anything else?

With that revision can I ask for a

motion to approve the minutes?

Participant: So moved.

Dr. Insel: Okay. Let me ask if there's anyone opposed to approving the minutes? I'm going to assume that everybody else is in favor and we'll move along with the main item for today which is the discussion of the letter or potential letter to the Secretary with respect to seclusion and restraint.

And this has already, of course, been the topic of several other meetings. We decided at the July 19th meeting to revisit this with the Department of Education since there was quite a bit of activity there and there have been some changes made. I'm hoping you can see those in the versions that were sent to you that actually reflect both the discussion as input from the Department of Education.

We're getting some interesting sounds coming into this call. I hope you're able to hear us still.

All right. So, let's open this up and see whether there are concerns about any of the changes made or additional discussion about intent of the letter.

Ms. Resnik: This is Denise and I think the letter was excellent.

Dr. Fischbach: This is Gerry. I also think it was excellent, especially the ending of it which qualifies the use of restraints.

Dr. Insel: Sharon or Larry? Comments about this? I know both of you have been -- Sharon, in particular, have been very involved in this process. And we've been particularly mindful that the Department of Education has a number of things going on in this sphere so we wanted to make sure that there was coordination between HHS and Education.

Dr. Wexler: This is Larry. We are coordinating with HHS but when it comes time to vote, I have a statement to actually read relative to the letter.

Dr. Insel: Sharon. Anything to add? We can't hear you if you're speaking. Maybe on mute or -- wonder if we've lost you.

Let me raise one issue then towards the very end of the letter that I'd like some help with, which is concern about the members of the IACC who are employees of HHS and what they can and cannot say with respect to legislation. So, I'd like to recommend a very small change in the wording to reflect that the last section under the bold print that says "Reduce or eliminate the use of seclusion and restraint in school" says "Given the current lack of Federal authority to regulate these interventions in education settings, legislation is urgently needed to ensure the safety of all students and staff."

Fair enough.

It goes from there to say that "Members of the IACC support Federal legislation" which is where I have a little bit of concern. I'm wondering how the group would feel about simply striking that part of

the sentence to say "Proposed Federal legislation would require states to establish minimum standards" and to go on from there. We've already made the point that we think it's important to regulate these interventions without having to then suggest that the members of the IACC are supporting any specific legislation.

Dr. Fischbach: Will you repeat that first part again?

Dr. Insel: Yes. I said the only changes in the second sentence it would say "Proposed Federal legislation would require states..." It would take out that. So, "Proposed Federal legislation would require states to establish minimum standards for schools" and the rest of it remains the same.

Participant: I see.

Dr. Insel: So, that refers to what is happening without having to say specifically that members of the Executive Branch are lobbying for a particular piece of legislation.

Ms. Redwood: Tom, this is Lyn and this came up during one of the meetings we had, the joint session between the Safety Subcommittee and the Services Subcommittee. And it was my understanding that the way that it was worded would be allowable. Susan, could you shed some light on that?

Dr. Daniels: My understanding is that it would be allowable. However, I think that there are Federal representatives on the Committee that still feel uncomfortable with it. So, I think that's the issue that Dr. Insel is bringing up. I think it is allowable the way it is, but you know, we may want to consider -- I think it would make it easier for people to support it.

Ms. Redwood: Would it be possible to separate out the public members from the Federal members and say --

Dr. Insel: Let's talk about that but I'm not sure that serves the needs of the Committee. But I'm comfortable with that as well if you think that -- I actually got to



this solution as a way of avoiding having to say, non-Federal members or something like that.

Ms. Redwood: The reason I think that's so important, Tom, because when you boil down the entire day where we heard all these presentations, the take home message was that we did need Federal legislation. So, I would hate to sort of lose that portion of the letter.

Dr. Insel: Well, I wasn't saying to strike that. We would keep that in. All I'm saying is that you would take out the piece that says "Members of the IACC support" since that's actually already stated in the previous sentence.

Ms. Lewis: Hi, Tom. This is Sharon Lewis. I'm so sorry I'm on a cell and my phone dropped there for a few minutes.

Dr. Insel: Good. Welcome back.

Ms. Lewis: Thanks.

Dr. Insel: So, we were hoping to get your input on the other changes which I

know you've been involved with. But right now we're talking about this piece at the very end of the letter.

Dr. Koroshetz: I don't think it changes the substance of the letter to just say, the proposed Federal legislation would require states to establish as opposed -- the meaning is the same if you take out that part about the IACC supporting Federal legislation which is a problem for Federal employees if you're on official duty.

Dr. Insel: And if you were to say non-Federal members then it implies that the Federal members might not support it. I don't know. It's just a way of trying to simplify this to get to the same end point.

Mr. Grossman: Yes, this is Lee. In the wording that you're proposing, Tom, certainly if we have to take that out for the Federal employees to be comfortable with it, then we need to do that.

It does for me, at least, change the wording from an action statement to just a

statement of fact. And I'm wondering if there is some how we could put it in there to suggest that there is support form the community for Federal legislation.

I think if we try to put the wording in there that the public members support this, that that does kind of show that it is -- it could be interpreted that there's a break between the Federal members and the public members. And also, I think that would delay the process because we're going to have to go back and talk to those public members who aren't on the call today and ask them if they agree to that wording.

Dr. Insel: Lee, I hear your concern about losing the kind of action language.

The previous sentence does say legislation is urgently needed.

Ms. Blackwell: This is Ellen, Tom. What if we just change the wording in the second sentence and say that "members of the IACC support proposals that would..." I

know, but --

Dr. Koroshetz: That's weaker than what Tom proposed. You want to have the word "Federal legislation."

Ms. Blackwell: Okay.

Dr. Insel: And we start off by the subheading here is "Reduce or Eliminate the Use of Seclusion and Restraint in Schools." That seems like a pretty strong statement.

Ms. Lewis: This is Sharon and as someone who has participated in the conversations both at the Subcommittee level and with several of the Federal members who had concerns about supporting legislation, I think that, Tom, what you proposed is pretty reasonable and actually frankly sets a good precedent with us in terms of navigating this issue because it's not, you know -- if the IACC is not subhead, I'm sure this is not the first time that this circumstance is going to arise.

Ms. Redwood: Tom, this is Lyn.

If that's what it takes for the Federal members to feel comfortable then I support it.

I just wanted to make sure that the Federal members knew that this was the strong sentiment coming out of the committee meetings that we had.

Dr. Insel: All right. We're sensitive to that. It's just constraints that we operate under as well.

I think while it is allowable, this is the kind of thing that -- it's in the gray zone. You know, I'm not sure that almost in any other situation we would find ourselves signing on to language like this. It's just a very different kind of role for us. And all of us are wearing multiple hats here.

Ms. Singer: Hi, this is Alison.  
Can you guys hear me now?

Dr. Insel: We can.

Ms. Singer: Yay. Okay. I've been on and I've heard you but no one has --

Dr. Insel: Well, okay.

Ms. Singer: -- been able to hear

me.

Dr. Insel: I think we had you in the original roster but welcome.

So, I'd like to also just invite other general comments about the letter and whether there's anything else that people see a need to change at this point before this goes forward for a vote.

Dr. Boyle: This is Coleen. I guess I'd like to hear that the written statement from the Department of Education prior to the vote.

Dr. Insel: Larry, is that something you can share?

Dr. Wexler: Well, the statement is for the vote but we intend to abstain with an explanation.

Dr. Lawler: Can we hear the explanation now?

Dr. Wexler: Well, I think I'd wait for the vote. I've been advised by my general counsel that that would be the approach that they're most comfortable with.

And I don't mean to be difficult. Those who know me, well, maybe you wouldn't believe that. But that really is not my --

Dr. Boyle: Well, Larry, this is Coleen again so last time when this letter came to the committee I think the reason it didn't come to vote is that we wanted to make sure that there was a conversation between HHS and the Department of Education. And I guess I'm feeling the need to get a better sense of what that conversation was and what the issues were.

Dr. Wexler: I think that it would be fair to say that the issue has already been articulated by you all in terms of the position of Federal departments in terms of advocating any support of legislation that is before or will come before Congress without it going through the administration.

Dr. Boyle: But hasn't that now been eliminated? Hasn't that language been stricken so that it doesn't read as if the Federal members are supporting legislation?

Dr. Wexler: I think it's as someone said a gray area and I would defer to the statement that I would read.

Dr. Insel: Larry, can we get some clarification about one of the things that's been added here is a sentence that says, "The Department's Office for Civil Rights initiated significant restraint and seclusion data collection requirements in 2009-2010 for public schools through their annual Civil Rights Data Collection survey. The first report date is expected to be available later this year."

Since that's a new piece of this can you verify that that's the case that --

Dr. Wexler: That's accurate. We worked with them on that. They're expecting to publish those data in the fall. I can't say exactly when in the fall. I will say and one of my responsibilities is all of the data in special education is that the -- our experience is that the first round of a Federal data collection, the validity of the



data is usually fairly weak. But you have to start somewhere.

Dr. Boyle: But what are the data that are being collected through that survey and are they again focused on death and serious injury or are the data more broad and consistent with other data that's being collected by other groups?

Dr. Wexler: Well, I don't know what's being --

Ms. Lewis: Larry, I can help out a little bit here. This is Sharon.

Actually, Alison, the data that the Department of Ed are collecting through this survey tool will be some of the best data once it gets going. As Larry has indicated, you know, it takes a couple of years especially on some of these broader data collections before you have consistency and validity in the data. But what the data is asking the districts to report are individual incidents of both seclusion and restraint with definitions that were published in the Federal

Register that are fairly consistent, I think, with the positions that the IACC has been interested in and actually getting well beyond the death and serious injury data that was referenced in the conversations when we had the services meeting.

The biggest downside to the OCR tool is that it only goes to districts of a certain size and I don't know if you know that off the top of your head, Larry. I can't remember what it is. But, you know, it doesn't get the small, rural districts. It's, I think, in districts of -- I forget. I want to say 3,000 kids or more. But it is part of a broader Civil Rights Data Collection tool that is well established. It also will distinguish and provide demographic breakdowns in terms of the students affected as it relates to whether or not they're students with disabilities under IDEA or under Section 504 of the Rehabilitation Act, as well as I believe age and ethnicity data, as well. So, I think in terms of longer term and kids

specifically and education data this will be a great data set that will be very informative.

Dr. Wexler: And I would add to that and Sharon is completely correct. I would add to it that if you just Google a Civil Rights Data Collection, this is an OMB-cleared collection. So, the forms, the definitions, and the data points -- all the data points are online. It's public information. So, I encourage you to go to it because as Sharon says it's really going to provide some great information and typically these new collections are tweaked over a period of time as there's always unintended consequences in a new data collection.

Dr. Insel: Can I ask you about this. This is Tom. I'm new to this area and I'm just wondering in terms of the letter, on the one hand we're just getting into the data collection but on the other hand we're asking to promulgate regulations. Is that the right order of things? Or would it make sense to promulgate the regulations after you have the

data in hand?

Ms. Lewis: I think that the request for the regulations are primarily focused out of HHS-related statutes and where there has been data collection in terms of deaths and injuries and that the data collection that Larry and I are referring to is specific to the education area and the overall umbrella and others on the subcommittees, Ellen or Alison, please jump in if you have a different understanding of this. But I think that one of the primary concerns of the members as they worked through this letter were both where were there opportunities within existing statutes or regulations to move forward on ensuring that there are regulations in these areas. And on the Health and Human Services side, you know, there are statutory requirements and final rules have just not been promulgated. Whereas, on the education side, there is this need for legislation in order for there to be an authority.

Secondarily, I think that the committee was very interested or the subcommittee members were very interested in where are their opportunities for collaboration, coordination, and consistency across settings? Because as the GAO and several researchers have acknowledged, the current regulatory framework and approaches are very, very different for individuals with autism or other disabilities depending upon the setting and who is providing the funding.

Dr. Insel: That's helpful, Sharon, but even on the HHS side, I understand that there's been an interim final rule in place for a long time.

Is there some reason why that was never finalized? Was there an absence of some information or something about this problem that led this to be hung up at the interim stage?

Ms. Lewis: I don't know the reasons why it's been hung up at the interim stage nor the reasons that the non-medical

community-based facilities rule has not been promulgated.

Dr. Insel: Okay.

Ms. Blackwell: Tom, this is Ellen. I mean, I don't know quite how to answer your question either but it may have been an artifact of the people who were in charge at the time. It certain doesn't mean that it can't be addressed.

Dr. Insel: And, finally, you know, for those of us who aren't in this area, maybe you can help us on one other issue and that is using Larry's phrase, What are the unintended consequences that we should worry about with this? What are the things that whenever you have additional regulations or when you're creating reporting requirements that aren't there, are there things that we should be thinking about that could actually end up working against the ultimate goal? Is there something we can try to protect against in doing this?

Ms. Lewis: This is Sharon. In

terms of the data collection I'm not sure of any unintended consequences and I guess I would see that the Department tweaks to things as they collect the data and learn more, maybe more related to "Did we get the definitions right? Are we on track in terms of the trade-offs related to burden and the information that we're collecting?" and things like that that I don't know on a technical basis that there is any way to protect for those things other than going forward and, you know, obviously on that data collection there was a public notice and comment period to try to manage those expectations to the greatest degree possible.

And I would say the same thing on the regulations. I mean, I think that there are plenty of opportunities for the various stakeholders to weigh in if the Department were to move forward on promulgating regulations under the statute that Congress has implemented to address these concerns.

Dr. Insel: Well, I guess if I

could interrupt. I was just thinking, you know, part of our task here is to advise the Secretary.

Ms. Lewis: Right.

Dr. Insel: And that's what this letter is all about. So, if there is anything that we know about that we want her to be mindful of with any of these suggestions. For instance, you know, if there's a concern that increasing reporting requirements might make this more expensive or might drive people out of the field or might -- and this is just, you know, a fantasy. But there are institutions that say, you know, this is just too much of a hassle with a kid who has had a lot of head-banging episodes, we're not going to take him into our facility because we don't want to deal with the reporting that would be required.

If there's anything like that that those of you who do this kind of work know about from previous experience, we should help the Secretary to weigh all those issues so



that she can take this advice in the most comprehensive way possible. You know, I don't want us to shortchange her if we're giving her information or making suggestions, I think we need to be as clear and honest and comprehensive about it as possible.

Dr. Wexler: Tom, this is Larry again. Again, I will echo what Sharon said and I was mainly referring to the data collection. I mean, what tends to happen when I say "unintended consequences," well, what tends to happen is elements that are crystal clear to us in our office, when it gets sent to the, you know, 15,000 school districts in the country, there are things that we just didn't anticipate in terms of how people would interpret those elements. And that's really the tweaking we're talking about.

You can assume that there will always be concern about data burden on states and school districts and every other entity in the country but that's -- there's always a concern about that and that's why OMB is very

careful and takes very seriously what we're asking to collect.

I mean, that being said, if there's a legitimate purpose for the collection, there really is rarely a major problem.

Ms. Singer: Well, this is Alison and to Tom's point of unintended consequences I'm going to speak as a mother of a child with behavioral problems who has been to IEP (Individualized Education Program) meetings and I have been told that one of the reasons that the districts ask for restraint and seclusion provisions to be included in the IEP is because they want to be able to protect the staff. And that in the absence of those, they fear that they will lose staff or that staff could be injured. I don't agree with that but that is something I've heard that since Tom brought up the question of what are we not talking about, I just want to put that out there.

Ms. Lewis: Well, I think that

that's right, Alison. And I think that's certainly one of the things that we've seen anecdotally in terms of the various concerns of different communities is when staff -- whether or not it's in the IEP, when you have staff that are not trained, they are more likely to be injured if they choose to use seclusion and restraint. If there are not policies and procedures in place, both students and staff are at greater risk of injury and I think that that's probably part of the reason that, for example, you know, Secretary Duncan did articulate the nine principles that he did in the letter in support of there needing to be additional Federal legislation on these issues.

I think in terms of other unintended consequences --

Ms. Singer: But here the unintended consequence is that a child could be kept out of a school or out of a class --

Ms. Lewis: Right.

Ms. Singer: -- if parents aren't

willing to accept a restraint and seclusion line in the IEP. And that is absolutely an unintended consequence.

Ms. Lewis: And that again remains to be seen in terms of the Department not having the authority without Federal legislation to protect students from those unintended consequences. But right now, that's already happening. I mean, whether or not we advise the Secretary and there's more regulations, right now you have -- it has been widely reported on an anecdotal basis that families have been pressured into consenting to seclusion and restraint in order to retain a placement in a particular school. Families have consented to seclusion and restraint in order to keep their kids in school period. And I think that are no, you know, from a Federal perspective at this particular juncture, there are no protections either for these kids or the schools in this area of Federal policy in education.

I know that having spoken

repeatedly to Assistant Secretary Posny and as she reported and mentioned in the services day when we discussion seclusion and restraint that the Department of Ed is working on a principles document SAMHSA and now Ed has provided our input and that document is in the process of being developed and hopefully will provide some additional guidance to schools out of the Department of Education.

Unfortunately, again, absent legislation, the Department of Education does not have any authority to manage those unintended consequences one way or the other.

So, to your point, Tom, in terms of, you know, things that we need to advise the Secretary on, I mean, I think that certainly the members of the Subcommittee have looked at the interests of people with autism and their family members and that the letter is reflective of that perspective. I don't know that there are substantive concerns related to cost that any of us would anticipate in these recommendations.

I didn't hear, is anybody from SAMHSA on the call? I think that they would be, you know, in the best position in terms of identifying any other potential unintended consequences but they were in support of these recommendations in the letter.

Dr. Insel: I'm sorry the last thing you said, Sharon, is they were or they were not?

Ms. Lewis: They were.

Dr. Insel: They were in support.

Ms. Lewis: Yes.

Dr. Insel: Are there any other comments about the letter or other issues people want to bring up?

Dr. Koroshetz: This is Walter. You just mentioned that the Department of Education is working on a guidance?

Ms. Lewis: Yes.

Dr. Koroshetz: That's not in the letter anywhere. Should that be in the letter?

Ms. Lewis: I don't -- Larry, my

understanding and tell me if you have a different understanding, Larry, is that the Department of Education didn't have anything to comment on at this point on that guidance.

Dr. Wexler: That's correct.

Ms. Lewis: So, that was suggested and I think we were not able to get that in.

Dr. Insel: So, it says that the HHS effort should be coordinated with. It doesn't talk about the guidance.

Ms. Lewis: Correct.

Dr. Koroshetz: And then I guess the other point I was making and I wanted to bring up in terms of the business about the regulations. My sense, because I brought this question up during the discussion at the time, was that these regulations, if you look at the CMS requirements on their interim final rule, they include programs, educational programs, you know, reviewing situations, debriefing situations that the point there being that this leads to less of a use of restraint and seclusion. Actually, probably -- is more

beneficial than the use of restraint and seclusion toward the overall goal of managing behavior for the student or education for the student.

So, the issue is, I guess, Tom, the point of the regulation just wasn't, you know, you can't use them. It was, you know, you use them only in a certain context which is, you know, very goal-oriented toward your main goal. And does that not come through in the letter, I guess is the question. We do talk about things that, you know, they should be limited to the situation with the imminent danger of injury. We do talk about the fact that there are alternative methods. But does it read too regulatory and less kind of goal directed?

Dr. Insel: Well, no, I think it's okay in that respect. It says, recent research indicates that contrary to what was previously thought about these practices, there is very little evidence to indicate that seclusion and restraint practices hold



therapeutic value. And it talks elsewhere about the importance of PBIS.

There is this interesting sentence and it's probably important to keep it in, but it does raise a question about the Cochrane report which says that actually there's no evidence about either effectiveness, benefit, or harmfulness of seclusion or restraint. That just goes back to the need for more data. But I do think it's important to cite that in a letter like this so that in the spirit of being a full disclosure, the Secretary knows what it is that the subcommittee felt was important.

Are there any other issues?

Ms. Singer: This is Alison. The one issue that I had was in the paragraph about data collection across settings. When we originally wrote that, the idea behind it was that not that we needed more data but that we needed consistency of data and better coordination of data collection so that there could be comparables.

I don't know if people agree, but I think that the addition of the Department of Education line right smack in the middle of the paragraph sort of says, "but this problem is now solved." So, it sort of negates the need for the paragraph at all, particularly if real data are expected later this year if that is the case. So, I don't know if we can move that to the end of the paragraph and say, you know, "in addition to this the other agencies need to continue to coordinate" but it sort of -- I read this now as this is now done, we need not concern ourselves because data will be available this year.

Does anyone else have that feeling or am I alone on that?

Ms. Blackwell: No, this is Ellen.

And I think your suggestion to move it to the end or somehow qualify it is appropriate.

Dr. Wexler: Yes, this is Larry and again I'm not going to take a position on this, but you know, the Civil Rights Data Collection is one thing but you also talk

about including the evaluation of such data regarding outcomes and the impact and use of these interventions. That would not be addressed in the Civil Rights Data Collection.

Also, Civil Rights Data Collection will only be from schools. It will not be from residential treatment centers, community mental health centers, any, you know, hospitals or anything other than schools.

Ms. Singer: So maybe we could say that this data set is a great step forward with that coordination and consistency of data collection across agencies is still a needed goal.

Dr. Insel: Alison, would you be satisfied with just putting in a clause after the new language? So, before the sentence that says "current data in many other settings" you could say something like "while the Civil Rights Data Collection survey will be helpful, there's still a need for additional data in many other settings --

Ms. Singer: Yes.

Dr. Insel: -- beyond just death or serious injury?" Okay.

Ms. Singer: Yes, it read a little "mission accomplished" to me, but that's good.

Dr. Insel: Yes, and you know there are a couple of places both earlier on where it now says "coordinate efforts" and further in this paragraph where it says consistent incident data collected. I think the letter hits this issue about needing to coordinate and to standardize the collection. So, I don't see that as a remaining problem.

Ms. Singer: I'm good with that change.

Dr. Insel: Okay. Is there anything else?

Ms. McKee: This is Christine. Before a vote, I just want to try to channel Lyn Redwood's type of passion for a moment. And just say I think this letter is immensely important. As someone who walks the halls of schools on a fairly regular basis, I think the incidence data is going to be surprisingly

high and I think that the message from this committee to this letter is extremely important.

Dr. Insel: Good, helpful.

Ms. Blackwell: And this is Ellen.

I just have one more thing to add that the meeting that really the genesis of the letter is a great repository of information on seclusion and restraint and I would urge everyone who is listening to look at our website, to look at the presentations. It's such a really nice repository of information on this very important topic.

Dr. Insel: Very good. Susan, let's go ahead and I guess we'll have to do this vote by roll call.

Dr. Daniels: Yes, I'll have to take sort of a roll call. I think it might be most efficient to go through and ask who is opposed, who is in favor and who is abstaining and then get all of this down to make sure it's accurate. Because otherwise on the phone if people just say they're in favor all at

once, we won't be able to tell how many votes we have. So, this will have to be the way we have to do it.

So, I'll start off by asking every person when I call for the type of vote, please say your name and I'll verify that I've heard you.

So, we'll start with those who are opposed?

Do I have any votes that are opposed to this letter with the changes as described? This would include the change that Dr. Insel mentioned at the end, changing those key words. "Members of the IACC support Federal legislation to require..." and adding the clause that we just mentioned that would say that while the Department of Education's Civil Rights Data Collection survey will be helpful but additional data collection and coordination are needed. And then that's the end to that paragraph.

I believe those are the two changes that have been suggested. Is that

correct?

Dr. Insel: Correct.

Dr. Daniels: So, two changes.

So, is there anyone opposed?

I'm not hearing any opposed so  
let's go to in favor.

Judith Cooper?

Dr. Cooper: Yes, in favor.

Dr. Daniels: Cindy Lawler?

Dr. Lawler: In favor.

Dr. Daniels: Ellen Blackwell?

Ms. Blackwell: In favor.

Dr. Daniels: Coleen Boyle?

Dr. Boyle: Yes, in favor.

Dr. Daniels: I don't believe  
Henry Claypool is on the phone.

Gerry Fischbach?

Dr. Fischbach: In favor.

Dr. Daniels: Lee Grossman?

Mr. Grossman: In favor.

Dr. Daniels: Alice Kau?

Dr. Kau: In favor.

Dr. Daniels: I don't think Larke

Huang is on the phone.

Laura Kavanagh?

Ms. Kavanagh: In favor.

Dr. Daniels: Walter Koroshetz?

Dr. Koroshetz: In favor.

Dr. Daniels: Sharon Lewis?

Ms. Lewis: In favor.

Dr. Daniels: Christine McKee?

Ms. McKee: In favor.

Dr. Daniels: I don't believe Ari

Ne'eman is on the phone.

Lyn Redwood?

Ms. Redwood: In favor.

Dr. Daniels: Denise Resnik?

Ms. Resnik: In favor.

Dr. Daniels: I don't believe

Stephen Shore is on the phone.

Alison Singer?

Ms. Singer: In favor.

Dr. Daniels: Marjorie Solomon is  
not with us. And Tom Insel?

Dr. Insel: In favor.

Dr. Daniels: And then Larry



Wexler?

Dr. Wexler: Because the U.S. Department of Education is working collaboratively with the Department of Health and Human Services on matters related to the subject of this letter, the Education representative abstains from participating in the recommendations contained in this letter.

One collaborative effort is a resource document that is being developed jointly by Education and SAMHSA that describes principles to help ensure all schools and learning environments are safe for all children and adults.

Education will also work with SAMHSA and other entities to bring people and resources together to further explore what additional assistance and support can be developed.

Thanks.

Dr. Insel: Larry, can you send that to us and we can convey that as well?

Dr. Wexler: My understanding was

that it was being recorded and that you all would just pick it up off the recording.

Dr. Daniels: It will be a part of the transcript and we can insert the whole thing in the minutes if it's not too long.

Dr. Wexler: If you could. I'm sort of sitting in South Carolina at the beach right now. So, it's a little difficult for me to be sending things. So, if you could just pull it off of the recording, that would really be great.

Dr. Insel: Done.

Dr. Daniels: Okay. So, what I have is 15 votes in favor and one abstention. And so with that vote, the motion carries. There's a majority vote from the IACC to move forward with this letter so what the OARC will do is consult with the Subcommittee chairs to make the last couple of changes and then we will proceed with sending this to the Secretary.

Dr. Insel: Thanks very much everybody.

Any other business that anybody wants to raise in the time that we have left?

And Susan mentioned there are two upcoming meetings for the IACC. You have those that were sent to you earlier. We will keep you posted about what happens with the reauthorization. Certainly this will have to happen if it's going to happen in the next 25 days or 24 days, something like that. So, stay tuned and we'll make sure that you hear when we hear.

Thanks everybody for joining us from remote places and hope the rest of your week goes well.

(Whereupon, at 3:56 p.m., the Committee adjourned)