U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

JOINT MEETING OF THE SUBCOMMITTEE ON SAFETY AND THE SERVICES SUBCOMMITTEE

THURSDAY, MAY 19, 2011

The Subcommittees met in Salon F of the Grand Ballroom of the Bethesda North Marriott Hotel and Conference Center, 5701 Marinelli Road, Bethesda, Maryland, at 10:00 a.m. Sharon Lewis, Lyn Redwood and Alison Tepper Singer, Co-Chairs of the Subcommittee on Safety and Ellen Blackwell and Lee Grossman, Co-Chairs of the Services Subcommittee, presiding.

PARTICIPANTS:

SUSAN DANIELS, Ph.D., *Executive Secretary of the Subcommittee on Safety and the Services Subcommittee*, Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

SERVICES SUBCOMMITTEE MEMBERS

ELLEN BLACKWELL, M.S.W., *Co-Chair of the Services Subcommittee,* Centers for Medicare & Medicaid Services (CMS)

LEE GROSSMAN,* *Co-Chair of the Services Subcommittee*

PARTICIPANTS (continued):

ROSALY CORREA-de-ARAUJO, M.D., Ph.D.,
U.S. Department of Health & Human
Services (DHHS), Office on Disability
(representing Henry Claypool)

GAIL HOULE, Ph.D., U.S. Department of
Education (attended by phone)

LARKE HUANG, Ph.D., Substance Abuse and
Mental Health Services Administration
(SAMHSA)

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

CHRISTINE McKEE, J.D.

ARI NE'EMAN,* Autistic Self Advocacy Network
(ASAN)(attended by phone)

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

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

STEPHEN SHORE, Ed.D., Adelphi University and
Autism Spectrum Consulting

BONNIE STRICKLAND,* Ph.D., Health Resources
and Services Administration (HRSA)
(representing Peter van Dyck, M.D.,
M.P.H.)

PARTICIPANTS (continued):

SUBCOMMITTEE ON SAFETY MEMBERS

SHARON LEWIS,* *Co-Chair of the Subcommittee on Safety,* Administration for Children and Families (ACF)

LYN REDWOOD, R.N., M.S.N., *Co-Chair of the Subcommittee on Safety*, Coalition for SafeMinds

ALISON TEPPER SINGER, M.B.A., *Co-Chair of the Subcommittee on Safety,* Autism Science Foundation (ASF)(attended by phone)

LEE GROSSMAN*

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

ARI NE'EMAN,* Autistic Self Advocacy Network (ASAN)(attended by phone)

BONNIE STRICKLAND,* Ph.D., Health Resources and Services Administration (HRSA) (representing Peter van Dyck, M.D., M.P.H.)

OTHER IACC MEMBERS

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

*Member serves on both the Services Subcommittee and the Subcommittee on Safety

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PROCEEDINGS

10:03 a.m.

Dr. Daniels: So I'd like to welcome everyone to the Joint Meeting of the IACC Safety and Services Subcommittees. We'd like to welcome all of our IACC members, attendees who are here with us in the audience and our listeners on the phone and the webcast. Just a housekeeping note, for those who are listening in on the call and watching the webcast there's a 45-second delay in the sound and so you may want to listen to one or the other to make it easier for you.

I'd like to welcome you all for this meeting. We are going to be discussing the really important issue of seclusion and restraint. There are a lot of complexities to this issue, many different agencies involved at different levels and many concerns from the public and so we wanted to be able to delve into this topic at a level where the IACC members could really explore the issue in depth and so we have put together this program today. And I'd like to thank all of the IACC members who assisted with preparing this program. I'm going to start by doing a roll call for members of both subcommittees. Ellen Blackwell?

Ms. Blackwell: Here.

Dr. Daniels: Cathy Rice?

Dr. Rice: Here.

Dr. Daniels: Henry Claypool -- or Rosaly?

Dr. Correa-de-Araujo: Rosaly. Very different from Henry Claypool.

Dr. Daniels: Yes, sorry. You're the -- standing in for Henry. Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Gail Houle?

Dr. Houle: Here.

Dr. Daniels: Larke Huang?

Dr. Huang: Here.

Dr. Daniels: Sharon Lewis is on her way. Christine McKee?

Ms. McKee: Here.

Dr. Daniels: Ari Ne'eman?

Mr. Ne'eman: Here.

Dr. Daniels: Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Denise Resnik?

Ms. Resnik: Here.

Dr. Daniels: Stephen Shore?

Dr. Shore: Here.

Dr. Daniels: Alison Singer?

Ms. Singer: Here.

Dr. Daniels: Bonnie Strickland? And I believe Bonnie may be joining us a little bit later. So most of our members have arrived and so I'd like to go through the minutes for each subcommittee. If you look in your packets, you have copies of the minutes from the Safety Subcommittee and the Services Subcommittee, so I'd like to do the Safety Subcommittee first and you only need to provide comment or votes for the subcommittees on which you sit. And so for the Safety

Subcommittee, are there any comments for the minutes, any changes that you see that need to be made?

Ms. Redwood: No, I don't see any, Susan. I think they look great. I'll make a motion to approve and call for further comment.

Ms. Singer: I second the motion.

Dr. Daniels: Okay. All in favor?

(Chorus of ayes)

Dr. Daniels: Any opposed?

(No response)

Dr. Daniels: Any abstaining?

(No response)

Dr. Daniels: The motion carries and we've accepted the Safety conference call minutes from March 16th. Then we're going to be looking at the minutes of the March 29th meeting of the Services Subcommittee. Are there any comments on these minutes, any corrections that need to be made?

Ms. Blackwell: Susan, I had sent

some corrections yesterday I just wanted to --

Dr. Daniels: Yes.

Ms. Blackwell: They're technical corrections, so.

Dr. Daniels: And those have been noted, thank you. Any others?

Mr. Ne'eman: Susan?

Dr. Daniels: Yes.

Mr. Ne'eman: This is Ari. You asked as to whether or not I was referring to the HHS Office on Civil Rights or a different office on civil rights.

Dr. Daniels: Yes.

Mr. Ne'eman: I was referring to the HHS Office on Civil Rights.

Dr. Daniels: Okay.

Mr. Ne'eman: Although I believe that Jeff was referring to the Civil Rights Division inside the Department of Justice.

Dr. Daniels: Okay, thank you. We will duly note that and make sure that that's carried through in the minutes. Any other comments? Okay. Is there someone who'd like to make a motion to accept the minutes?

Ms. Blackwell: So moved.

Dr. Daniels: Second?

Dr. Shore: Second it.

Dr. Daniels: All in favor?

(Chorus of ayes)

Dr. Daniels: Any opposed?

(No response)

Dr. Daniels: Any abstaining?

(No response)

Dr. Daniels: The motion carries and the minutes from March 29th have been accepted. And these will be posted on the IACC website very soon. So with that I'd like to turn the meeting over to our co-chairs of each of the subcommittees, Lee Grossman, Ellen Blackwell, Lyn Redwood, Alison Singer and Sharon Lewis, who will be joining us shortly. Thank you.

Mr. Grossman: This is Lee Grossman. I am the co-chair of the Services

Subcommittee for the Interagency Autism Coordinating Committee. I want to thank the committee members for being here, the people in the audience and those viewing through the videoconferencing or on the conference call. Thank you for being here for this very, very important day of presentations that we're having on seclusion and restraint. And people have asked, why do a workshop on seclusion and restraint? Well, we found that this is something that is a pressing issue here in the United States and something that the Interagency Autism Coordinating Committee should begin to address. Not only that, we're not really sure exactly the percentage of people with autism spectrum disorders that are -- have been subjected to seclusion and restraint but we do note the reports by professionals, family members and individuals with ASD that seclusion and restraint does occur and it does occur at an alarming rate. This issue continues to go on unabated and it needs action to address it and that is one of the purposes of the workshop today.

We also know from the Government Accountability Office's report that hundreds of allegations are filed that children have been abused, and in some cases died, as a misuse of seclusion and restraint. And also, as was presented at Chairman Miller, who is the chair of the Committee on Education and the Workplace in the House of Representatives, at his hearings, that unlike hospitals and other facilities that receive Federal funding there are no Federal laws that address how and when seclusion and restraint can be used in schools. Currently only 23 states have meaningful seclusion and restraint laws or regulations, only 13 states ban restraint that impedes breathing and only 10 states ban mechanical restraints and 10 states ban chemical restraints. So this is an issue that we feel certainly needs to be addressed, because there is a disproportional number of people with disabilities and with autism that are now affected by these lack of legislations and regulations and the misuse of seclusion and restraint.

The true purpose of today's workshop is to hear updates on the activities from our Federal agencies and to take their comments and to make recommendations to the full Interagency Autism Coordinating Committee. And from there hopefully the full IACC will act upon the recommendations and forward them on to the Secretary of HHS, Secretary Sebelius. We want to hear from our presenters on what their recommendations should be to the IACC and we also want to know since the IACC can only make recommendations to the Secretary of HHS, what their recommendations would be to engage other Federal agencies such as the Department of Education and the Department of Justice in these recommendations. And with that I'm going to thank all of you for being here and then turn the mic over to Alison Singer.

Ms. Singer: Thanks, Lee. This is Alison Singer and I am the co-chair of the Safety Subcommittee. I want to add my thanks to Susan Daniels and the team at OARC and everyone who's participated in putting together today's conference. I also want to thank the co-chairs of the Services Subcommittee and all the members of both committees.

As Lee pointed out, issues of restraint and seclusion are of grave concern to the entire autism community and I think Lee just did a very nice job outlining the gravity of the situation. One of our goals at the Safety Subcommittee is to look at safety issues and not just talk about the problems and how to solve them, but to break down the issues into manageable, actionable steps and then begin to actually take those steps. We are doing that with the wandering issue and we also need to do that with restraint and seclusion. In the past, I think, the tendency of the autism community has been to look at these issues and discuss them, but then become stymied and overwhelmed by the magnitude of the problem which resulted in having these conferences and white papers being written and long lists being drawn up, but no action being taken. It's very hard, it's almost impossible to prioritize issues of safety, because they all deal with life and death. But we have to make hard choices here and we have to agree that to take some action step is better than to talk about taking more steps, and that the decision to take steps on some issues does not in any way mean that the issues that we are not addressing right away are not equally as critical. But we cannot do nothing simply because we cannot do everything.

So the Safety Committee -- and I'm only speaking now for the Safety Subcommittee, not the Services Subcommittee -- but the Safety Subcommittee, after discussing restraint and seclusion, has decided to focus in on two issues where we think we can take action and really effect meaningful change. And again, we chose these two issues because we think these are the areas where we can effect change, not because these two issues answer the whole problem or because we think that the other issues aren't important or because we think that these are the only two things that need doing, but because these are two areas where we think we can have immediate impact and improve people's lives. And we realize there's more to do than this, but we also recognize that we need to start acting.

So specifically, at our previous subcommittee meeting, Sharon identified and the subcommittee agreed that we wanted to focus in on the Children's Health Act of 2000, which specifically addressed issues of restraint and seclusion in community-based settings, but yet no regulations have been put forth based on this law. And so we feel that there's an opportunity here to submit specific recommendations with regard to the Children's Health Act of 2000. And secondly, we discussed the need to gather data from the Department of Education to determine areas where we could partner with DOE to address safety issues in school settings, again with the goal of submitting recommendations that could become part of a directive by DOE to schools. And we are urging that these two issues really be the focus of today's talk.

And again I want to thank Susan and the rest of the event organizers for including these topics on the agenda. And I would challenge all of today's speakers to please speak to these important points so that at the end of the day we can really meet our goal of developing specific recommendations on these issues and distribute them, as Lee said, in accordance with our charge to advise Secretary Sebelius. So again, thank you to everyone who's participating today and I'm really looking forward to a very productive day.

Ms. Blackwell: Okay, Alison, this is Ellen. Thank you so much, and Lee as well for your introduction. And with that I think we have come to the time to have our first speaker, Sharon Lewis, who, most everyone in the room already knows, is the commissioner of the Administration on Developmental Disabilities, a part of HHS's Administration on Children and Families. And Sharon also has the incredible distinction of being one of the country's leading experts on this topic, so it's wonderful that she can be here today to sort of lay the groundwork for our discussion. So with that, Sharon, I'm going to turn it over to you and say thank you so much for coming.

Ms. Lewis: Thank you. Thank you, Ellen, and thank you, Alison, for your introductory comments as well. I was asked to lay down some of the background related to seclusion and restraint and kind of frame the conversation. So I wanted to actually start with a little bit of history.

Managing difficult behaviors is absolutely not a new problem and this debate around utilization of techniques such as restraint and seclusion has raged for a very long time. Back in 1839, John Connolly was appointed the superintendent of the Middlesex County Asylum at Hanwell in England, and with political support -- and that's important -- of the magistrates who oversaw the institution, he worked to eliminate the high rate of mechanical restraint being used among the 800 residents. And in three months he was able to do so, in 1839 -- and we're still having this conversation. His comment was, quote, "In a properly constructed building with adequate attendants, restraint is never necessary, justifiable, and is always injurious." Dr. Connolly was one of many leaders of the non-restraint policy within the moral treatment movement influenced by Quakers and post-French Revolution reformers in France. Yet here we are, in 2011, still having the conversation.

In the United States, psychiatric hospital superintendents in the mid to late 1800s were divided on the use of restraint but generally opposed the non-restraint perspective of the British systems. Physical restraint became something that was viewed as a form of therapeutic treatment and became an accepted practice for dealing with patients with challenging behaviors. Some American psychiatrists have emphasized the value of restraint in managing behavior, while others have acknowledged the harm and even death for some individuals. Understanding this history and this "treatment protocol" -- and I say that in quotes -- and the related political and policy background is important, because in order to address the issues of restraint and seclusion across all settings, we must change the fundamental understanding and expectation that to use such powerful physical techniques against vulnerable individuals is not effective, and a focus on prevention of the behaviors and evidence-based alternatives is our ethical responsibility.

There is a basic cultural and attitudinal shift that must occur that is deeply rooted in the lack of respect for and lack of understanding of self-determination and the needs of individuals with disabilities that manifest in part in challenging behaviors.

Hearing the personal stories is also incredibly important as we think about our work today. In my former role with the U.S. House of Representatives Committee on Education and Labor, and in my current role within HHS, I have heard from hundreds, literally hundreds, of families with appalling stories of untrained staff utilizing dangerous restraint techniques against children and adults with intellectual and developmental disabilities. I'd like to share one story with you today as we set the stage for this important discussion.

A family of a young girl with autism described their experience as follows, and I quote. "Paige was then very small, barely 40 pounds. Within a week at her new school she came home bruised and told me, 'Mommy, my teacher hurt me and I couldn't breathe.' Concerned about this occurrence, my husband" -- this is from the perspective of the mom -- "went in the next day to speak to the teacher. The teacher stated that she could not have caused the bruise but did inform him that she had restrained Paige for refusing to stop wiggling a loose tooth in timeout by holding her. An aide later reported that the teacher had not just held Paige, but had forced her face-down on the floor and sat on her. For wiggling a loose tooth." In a subsequent event in the same family, when the daughter would not comply with her teacher's request -- and again, this is a 7-year-old -- "as the situation began to escalate, Paige was becoming increasingly agitated. Her teacher took her into an empty classroom, grabbed Paige's wrists in her left hand and forced them up between Paige's shoulder blades. The teacher then grabbed Paige's left ankle in her right hand, lifted her off the ground and drove her head first into the ground at a slight angle to the vertical, causing her to land on the upper right side of her body so she struck her head and shoulder on the ground."

These stories are all too common. In circumstances when staffing is inadequate, staff do not have training and understanding of positive behavior management supports and strategies, policies and procedures are unclear, and a general culture of maintaining order and discipline pervades over and above an understanding of what constitutes abuse.

You are going to hear from several experts today who will speak to the specific legal and regulatory authorities available to address restraint and seclusion across many settings. In particular, restraint and seclusion in educational settings has garnered significant public attention in the past few years as a largely unmonitored and unregulated practice in many jurisdictions. Absent Federal legislation, families are faced with an uneven patchwork of local and state laws and regulations allowing restraint and seclusion in all kinds of school circumstances, ranging from non-compliance and disruption to property damage, to a prescribed approach in a behavioral plan, and, of course, to perhaps the only justifiable circumstance, a situation involving imminent danger of serious bodily injury to an individual or others.

Under the DD Act, Congress finds, and I quote, "The Federal government and the states both have an obligation to ensure that public funds are provided only to institutional programs, residential programs and other community programs, including educational programs in which individuals with developmental disabilities participate that meet the minimum standards relating to the prohibition of the use of physical restraint and seclusion for such an individual unless absolutely necessary to ensure the immediate physical safety of the individuals or others, and prohibition of the use of such restraint and seclusion as a punishment or a substitute for a habilitation program."

Unfortunately, the DD Act does not provide for enforcement of these findings in a manner that addresses Federally-funded programs and services. That being said, the fundamental perspective that Congress found, that restraint and seclusion is not an appropriate treatment nor punishment nor substitute for supportive habilitation is critically important.

As my colleagues from CMS and SAMHSA will discuss, the Children's Health Act of 2000 did establish the rights and requirements related to seclusion and restraint for hospitals, nursing facilities, ICFs, and other health care facilities, as well as non-medical community-based facilities for children and youth. This law is pretty straightforward, essentially stating that restraint or seclusion should only be imposed in emergency circumstances and only to ensure immediate physical safety. Staff should be trained and certified, and that in medical settings a physician's order is required.

Understanding the distinctions between various components of restraint and seclusion is also critically important. Restraint is really defined as any physical method of restricting an individual's freedom of movement, physical activity, or normal access to his or her body. Mechanical restraint involves the use of an object or device such as harnesses, flexible handcuffs, or duct tape in some situations to limit an individual's movement. Chemical restraint uses medication to control behaviors or restrict an individual's freedom of movement. And the topic that has been most discussed and debated is the issue of physical restraint involving one or more staff members using their bodies to restrict an individual's body movement as a means for reestablishing behavioral control and to establish and maintain safety for the individual or for others. The Children's Health Act, as it applies to non-medical community-based facilities, prohibits mechanical and chemical restraints and limits physical restraint to emergency circumstances and requires continuous face-to-face monitoring of children and youth in seclusion. It cannot be isolated.

As the research and evidence base has developed, it's clear that, in this day and age, each incident involving the use of restraint and seclusion is a failure of the system to appropriately address the behavioral support needs of the individual, as well as a failure to ensure that staff have training in and understanding of evidence-based alternatives. There is virtually no evidence to support the effectiveness of restraint or seclusion to change behavior, and we do need to distinguish a few points between the approaches. Seclusion is different from timeout. Timeout does have evidence of potential value in changing behavior, but does not need to entail seclusion. Research has also shown that when seclusion is utilized, physical restraint becomes more commonplace as a method to force an individual into seclusion. The practices often go hand in hand. Regarding seclusion in particular, there is absolutely no evidence base whatsoever for the effectiveness of seclusion. It is not effective as an emergency intervention, it has not been shown to positively affect behavioral change and it has been demonstrated to cause other detrimental effects such as post-traumatic stress disorder. Locked solitary seclusion is very different from timeout areas with unblocked egress designed to calm and comfort with appropriate staffing, which has been shown to effect behavior change.

When we talk about physical restraint, we have to acknowledge that emergency interventions limited to protecting someone from immediate harm is sometimes necessary, but physical restraint should be limited to the least duration and the least risky method and must be accomplished only by specially trained personnel. Planned physical restraint for a treatment to reduce negative behavior has not been shown to be effective. For example, according to one researcher, a review of over 109 articles spanning 35 years between 1965 and 2000 on restraint and seclusion on children and adolescents found that the techniques have only questionable efficacy. It is hard to find any therapeutical value in the practices or in the research.

As many of you from the Services Subcommittee heard from Kevin Huckshorn in the meeting last year, solutions that have been effective in some systems include: leaders who set an organizational cultural change agenda. I can't stress this enough. This is a cultural and attitudinal change. Systemic collection of seclusion and restraint data makes a tremendous difference, and then using that data to inform the staff and evaluate the incidents. Improvement in the environmental conditions and providing other ways to manage behavior in the environment. Ensuring staff are trained in de-escalation as well as positive behavior supports. Individualized approaches, including functional behavior analysis and the development of individualized positive behavior support plans based on those assessments. When restraint events are utilized, debriefing to both analyze the event and to mitigate the adverse effect. And of course, we always come back to staff training. At the heart of all the change that must occur, regardless of setting, is an understanding and an attitudinal shift that restrictive behavioral interventions such as restraint and seclusion will not change behavioral outcomes and should be reduced to the greatest degree possible, if not eliminated. I look forward to hearing from our various presenters. Thank you.

Dr. Daniels: Thank you, Sharon.

Ms. Blackwell: And welcome, Alexa. Sharon, that was great, also, I extend my thanks. That was really a wonderful discussion of where we've come and where we haven't gone in the past, what, 150 years, 200 years? It's a little overwhelming, so I guess since we have time reserved for discussion later today we should probably just move on.

And Alexa is here. There is time for questions? Great. So with that, would people like to discuss what Sharon just spoke about?

One thing I heard you say, Sharon, that I thought was really moving, is Dr. Connolly's comment that in a properly constructed building -- I would go further and say that in any setting -- of course, that was probably an artifact of the time that people were secluded in residential settings that were institutional in nature. But isn't it interesting that he had these progressive ideas so long ago?

Dr. Huang: Ellen, can I just build on that? It is interesting in terms of the environmental pieces to that. We had a meeting a couple of years ago and we were talking about, you know, how do you create an environment, both the physical environment that is conducive to non-use of seclusion and restraint, and it was really interesting because, on architectural plans for building hospitals they include -- they think there's a requirement for a seclusion room. You know, so there are other policies and other jurisdictions or in other disciplines that have not caught up to date with where we are in our thinking around what really is therapeutic care. So that's -- and so we thought well, we really need to work with the, you know, American Architecture Association, to say that's not really a requirement for hospital construction.

Ms. Lewis: I think that's right and I think that that's part of what we've seen in the educational setting, right? If you build it they will use it. If there is an inappropriate locked timeout -- I mean locked seclusion setting, in lieu of a carefully thought and constructed timeout setting in which egress is not blocked, individuals have the opportunity to be comforted by trained staff and there is an opportunity for individuals to cool down in an environment that's conducive to that. It does not need to be seclusion.

I also think what's interesting is there are several individuals at this point who are doing some very interesting work about the effect of the environment and how to use architectural materials, setting, et cetera, on helping individuals manage behavior. And I think that that's an area that, you know, kind of -- we might want to explore at a future time, not necessarily specifically in this context, but there's some really great work going on out there.

Dr. Shore: This is Stephen Shore. I think we definitely should do that. But as you mentioned, there's no support -- there's no research supporting seclusion and restraint, as you described. And I think the more we can bring out research showing that when we do things more positively, managing the environment in a broad sense, you know, let's bring out what happens, the positive effects.

Dr. Strickland: Sharon, thank you very much. That was very informative. I have a question. You mentioned that in the DD Act, that the DD Act addresses seclusion and restraint but that there's no provision for enforcement. Part of the question is, do provisions for enforcement exist elsewhere, and where they do, are they coupled with the positive strategies that you and Larke just referred to?

Ms. Lewis: Well, I will actually defer to Ellen and Larke a little bit on this, but yes. I mean, we do have very explicit references that were established in the Children's Health Act of 2000 that address the issue in medical settings. We do not have Federal legislation that addresses the issue in school and educational settings, and so it is difficult to come up with a policy structure that addresses it consistently across environments under the current law.

Mr. Ne'eman: Sharon, this is Ari. With respect to the Children's Health Act standards and implementation, what have we learned from implementation of that in the context of adult service provision settings? Where has it been most effective and where have there been the most challenges?

Ms. Lewis: I don't know that I'm the most qualified person to answer that. I don't know if, Ellen or Larke, you want to jump in, in terms of what we know from the research base, you know, since 2000 and what data we have in terms of the effectiveness of those provisions.

Ms. Blackwell: Ari, this is Ellen. I'm actually going to talk about that a little bit later today after having several conversations with our survey and certification group and CMS. So if you could just hold off for a little bit, that would be great.

Mr. Ne'eman: Sure. I look

forward to it. Thank you so much.

Ms. Blackwell: Sharon, I have a question for you. I know that you worked on what is now known as the Keeping All Students Safe Act, when you worked for Congressman Miller. Can you talk a little bit about the genesis of that proposed legislation and how we got to where we are today with the current bill?

Ms. Lewis: Oh, absolutely. Actually, the very, very beginnings of that bill reside prior to the Children's Health Act in terms of -- as many of you may know, the Hartford Courant in Connecticut ran a fairly extensive expose on the utilization of seclusion and restraint in residential settings, which then resulted in the language that we've been talking about in the Children's Health Act. Subsequent to that, we started to see additional reports of seclusion and restraint becoming an issue in school settings. And when, prior to my work with

Chairman Miller, I worked in Senator Dodd's office, who had taken a keen interest in this and had been the member who had really led the charge on the Children's Health Act. His comment was, we thought we had addressed this problem when we passed the Children's Health Act and had looked at non-medical community-based settings, but, as we know, without the hook back into the educational system there's really not a way to address the issue. We saw increasing anecdotal evidence of seclusion and restraint in the schools and Chairman Miller, having heard from several constituents on this issue, then the National Disability Rights Network report came out and it piqued his interest. He decided that what we really needed to do was a GAO study on what we knew about seclusion and restraint. They did an investigation, which I believe is in the background materials provided here, in which, you know, they analyzed state policies and procedures on seclusion and restraint in the schools, found that the vast majority of states did not have a consistent set of policies and procedures at the state level applicable to both seclusion and restraint. And so, from there, we then worked with the community stakeholders, as well as a bipartisan group of members, to begin to address -- and the Department of Education, to begin to address what a policy might look like, you know, really frankly crafted on the backbone of what the Children's Health Act lays out in terms of definitional issues, but acknowledging the distinction between a medical or health setting and the schools, which I think is critically important in the conversation, because the staffing level, the staffing training opportunities and knowledge are very, very different in the different facilities. And so the legislation tried to acknowledge the distinctions but also set a very, very specific bar in acknowledging that seclusion and restraint should only be used in emergency circumstances when there is imminent danger and by trained staff, and really pushed it to the states to establish the standards around which seclusion and restraint should be used.

Dr. Rice: Hi, this is Cathy Rice. Sharon, thank you for that wonderful overview, very helpful, particularly the solutions that you mentioned. And you talked first of all about the cultural change which is so vital. Are there -- we saw a wonderful presentation on that back at the November meeting that we had. But are there any documented guidelines that would help facilities that are interested in doing such a cultural change, you know, in terms of best practices to implement that, to reach the full level of the organization? Are there any resources for that?

Ms. Lewis: There's a fair amount of literature at this point but they are small studies. We don't have a strong national body of work. I know that Alexa will address some of the data collection challenges particular to the schools. And we -- there are several researchers out of actually both Nebraska as well as -- where is Joe Ryan? -- down in North Carolina, looking at the efficacy of various training protocol and you know, I think we're getting there and I think that we have a fair evidence body out of the mental health system when we're talking about medical or residential facilities. The challenge really is in the educational context at this point, in terms of a strong evidence-based practice and what kind of training and staffing levels consistently can allow you to significantly reduce or eliminate seclusion and restraint.

Dr. Rice: Just as a follow-up, it may be helpful for committee members to keep in mind, in the event that this committee continues to exist and there's another iteration of the Strategic Research Plan, thinking not only now in terms of practice recommendations but research recommendations that are needed along this issue as well would be really helpful.

Dr. Huang: Ellen, can I -- and Cathy. In the mental health field, we do have some of those in terms of what are effective practices and we did have a grant program that I'll speak about a little bit later where we did an evaluation of certain interventions to see whether they could be implemented facility-wise and what the outcomes were. So we have that some in mental health and to a certain extent some of that can generalize to other settings but then, I think, keeping in mind what Sharon's saying about the distinction between schools and mental health, both inpatient as well as community-based facilities.

Ms. Blackwell: Okay. Any other questions from our colleagues on the telephone? All right. Go ahead.

Mr. Grossman: Yes, I'm going to kind of harp back to my opening statement here. We're, the subcommittees are to make recommendations. IACC, in our advisory capacity as a FACA committee, we can only make recommendations to the Secretary. So what specifically should we be asking of her? And with that said, it's going to come up as we go through today. There's other agencies such as Department of Justice and Department of Education that need to be engaged in this process. And I'm not really sure how we do that and on what we advise the Secretary, but I'm open to any suggestions you may have on how we get those other groups involved, if we have to do it through the Secretary, or if we reach beyond our own advisory capacity to try and bring those other groups in. So I'd like your thoughts on that.

Ms. Lewis: Well, I think as Alison laid out in her initial comments, within the Safety Subcommittee we did have a fairly robust conversation about whether or not the IACC might want to take up the issues of the regulations related to the Children's Health Act as something that we might want to get a status update on and I'm hoping that Larke and Ellen will be able to speak to that a little bit. And if not, I think it's certainly something that we should investigate and potentially think about how we might suggest that that's something that, you know, dependent upon the status that may need to be pursued. You know, in terms of the Department of Ed, I will defer to my colleague Alexa. It's certainly something that we've had multiple conversations about and I think getting an update on where we are with the data collection and Department of Ed efforts. As I said before, I think one of the most difficult things from the Federal level, in terms of the Department of Education, is, absent legislation, there is very little that the Department of Education can pursue. IDEA does not provide the authority to address seclusion or restraint without additional legislative action.

Ms. Blackwell: Okay, thank you, Sharon. I actually think that's a nice segue into our next speaker. Alexa Posny is the Assistant Secretary of the Office of Special Education and Rehabilitation Services for the Department of Education. Alexa, thank you so much for coming today. I think of Alexa as the special ed director of the United States and sort of the rehabilitative services director of the United States. She's the chief of the special ed directors, so Alexa has a world of experience in this area. She's really the only person who can give us this update. So thank you so much for coming.

Dr. Posny: Thank you. And I wish I could have been here the whole time to hear Sharon but we had talked about it. But I have a feeling you're going to hear pretty much the same refrain in terms of seclusion and restraint. We know that we've been working on this as, you know, a concerted issue since at least 2009 and what I want to do is just kind of give you a timeline of the activity that we have pursued over this. And I'm sure you have this in all your background material, but we know it started with the GAO report in 2009 where the findings actually, you know, gave us a lot of information and Sharon has said it very well and over and over again: there are no Federal regulations that exist. And as a result of that it makes it very difficult for us as the Department of Ed to go out and basically say you can and cannot do this.

We know that the GAO report also talked about the hundreds of cases of alleged abuse that included deaths and everything else, and that is not something any of us can allow and we don't want to see that happen. However, what they concluded in the report is that there are presently no reliable national data on when and how often restraint and seclusion are being used in schools or on the extent of the abuse. So we really have no data and what we needed is documentation of the abuse of restraint or seclusion in a sample of 10 closed cases that resulted in criminal conviction. However, they further observed that problems with untrained or poorly trained staff were often related to the many instances of alleged abuse. Of course, following that report there was a hearing that was held on restraint and seclusion on May 19, 2009 and testimony at this and other hearings together with the related work of the committee led to the drafting of the proposed Federal legislation.

Arne has been very clear that as education leaders in the letter that he wrote, he wrote two different letters, one to the chief state school officers and one to the Congress. And what he said, our first responsibility should be to make sure that schools foster learning in a safe environment for all of our children and teachers. This -- the letter that was written to the chief state school officers was done July 31, 2009. Interesting, at the time I was a chief state school officer and paid very close attention to the letter that Arne had sent. And what he did in the letter is he urged each state to review its current policies and guidelines regarding the use of restraint and seclusion and if appropriate to revise or develop them to ensure the safety of students. It also highlighted as a major piece what we refer to as positive behavioral interventions and supports, PBIS. That is absolutely what we are promoting across the whole country to the point where we have a Technical Assistance Center that just is for PBIS. It also provided examples of states that had successfully implemented PBIS programs and we have scaled that across the United States which has been great. It also explained that the Office of Elementary and Secondary Education would be contacting each state to discuss the state's plans to ensure the proper use of restraint and seclusion to protect the safety.

Another one is the letter that -- delivered to the chairman of the congressional committees and he said very clearly in that, I applaud your interest in addressing this very serious issue. However, what we did mention is the fact that the Federal legislation without statutory authority, we as a department are not authorized to perform any other function than data collection. And it makes this very difficult because we have no role in enforcement at this point. The other -- what he acknowledged in the letter was the national need for Federal legislation and pledged the department's support for the new legislation. What's interesting and one of the reasons that I was late is because I was on the Hill talking with people in Senator Harkin's office, talking about the proposed restraint and seclusion bill exactly in terms of what we wanted to do.

Now, what was articulated also within that letter were nine principles that Arne believes would be useful for Congress to consider in the context of any legislation. The letter also informed Congress that the Department of Ed was collecting, reviewing and publicizing information about the current use of restraint and seclusion in every state and every territory. What we know is that there is tremendous variance across the states. What we did in February of 2010, we released a summary of state policies that were related to restraint and seclusion. We also have the regional comprehensive technical assistance centers which collected state policies and procedures on restraint andF seclusion across the United States. What we do know is that the oversight of restraint and seclusion varies depending upon which state you happen to be in. Also, the scope and impact of the laws differ across the United States as well as any of the restrictions. Some states do have some restrictions and many states have nothing and are silent on it. And of course, training is the number one.

What I want to share with you is just some of the data that we have. In terms of the states in the oversight of restraint and seclusion in schools, 31 states have legally regulated on restraint and seclusion. However, 19 states have no laws or regulations related to the use of these practices. And having just come from the state of Kansas I can very clearly tell you the state of Kansas does not have any regulation on restraint and seclusion. They could not come to agreement on what it was. And it's not because they didn't think it was important, they just didn't know what to do. The second one, when we talk about the scope and impact of the 31 states, the laws vary greatly. Five states place some restrictions just on the use of restraints but do not regulate seclusion. One state regulates the use of seclusion without regulating restraint, and only eight states specifically prohibit the use of prone restraint, face-down which of course can impede a child's ability to breathe. So again, we have variance depending upon where you happen to live. They also have varied policies regulating the training of school staff on the use of restraint and seclusion. Thirteen states require that certain staff members receive the training before they're allowed to use it. Eight states offer training and technical assistance to local education agencies and providing training to school staff, but again, the type of training and the methods that are used vary across every different community in which it happens.

In spring of 2011 we asked about publishing data. The state table was published in February 2010 and many states were in the process of developing, reviewing and if appropriate, revising their state policies and guidelines. And the PBIS center, our Positive Behavioral Interventions and Support Center, conducted an update of the state summary this spring. This update should be available on the center's website in fall of 2011. So we'll have new data. The other thing is when we initially -- and I can just share this with you -- when we collect the data for the very first time, the data are very suspect because of misunderstandings about even what the definitions are their cases may or may not have been reported. As we go through, and I usually look at about the third data point is about the point in time when you can probably rely on the data and know that people have some common understandings about it. When you look at the civil rights data collection, the Office for Civil Rights has also begun collecting more information about seclusion and restraint. Now, it's not in every single district, it is in 7,000 school districts which are to provide a representational sample. And the CRDC now collects school- and district-level information on four different things: the number of students subjected to physical restraint, the number subjected to mechanical restraint, the number subjected to seclusion and the total number of incidents of physical restraint, mechanical restraint and seclusion. This data -- right now OCR is in the process of validating the data that has been collected. It will be released in fall of 2011 so we will have more information this fall.

One of the things is we were very clear, we hope, about the definitions, what physical restraint meant. It does not talk about and we -- it does not include the use of a physical escort which means a temporary touching or holding of the hand. We also clarified in terms of seclusion that it does not include timeout which is a behavior management technique that involves the monitored separation of the student in a nonlocked setting. So we were trying to make it very clear what it did or did not include because in school systems, they could automatically assume that any type of seclusion would mean timeout. And I don't know about you, but my son was behavioral challenged and I used timeout quite a bit and it was helpful to me, believe me.

In terms of the bills that Sharon has talked about. You know, the first one was we had two different ones that were offered last year, the House bill and the Senate bill, and this year we currently have the House bill. And what the -- the purposes of these measures included limiting the use of restraint and seclusion in schools to cases where there's an immediate risk to the physical safety of the child or others at the school. When I was at the Hill just shortly before I came here I talked about my first teaching job was teaching middle school emotionally disturbed kids and one of my students was a runner, and he would invariably run out into the street so I would have to restrain him and you know, there are just times -- now, I couldn't hurt a flea, but at least I could stop him from being hurt, and that's part of what we needed to talk about. It also talks about providing criteria and steps for the proper use of restraint and seclusion, promoting the use of positive reinforcement and of course PBIS, and authorizing support to states and localities in adopting more stringent oversight and establishing requirements for collecting data on the use of these practices. And currently there is not a bill that has been introduced in the Senate.

And again, what we stress over and over again is the use of PBIS and this has been highly effective. The data that I can tell you just in relationship to the state from which I came, the use in promoting behavioral interventions and supports not only has it reduced the use of restraints and seclusion, it has also in terms of expelling a student or suspending a student, that has almost gone down to nothing because we now are able to -- I think the biggest thing in terms of why seclusion and restraint doesn't work is the fact that we're not teaching them the appropriate behavior to use in place of it. All seclusion and restraint does is to stop the behavior, but it doesn't teach them what to do and how to behave. PBIS is -- that is exactly the intent behind it and that is why it works so much better.

Now, in terms of where we're headed and I know someone asked about is there any guidance that we have. The OSEP is working currently with the Substance Abuse and Mental Health Services Administration, otherwise known as SAMHSA, and we are working together to create a paper and it will be a guidance document about restraint and seclusion. The paper is going to be based on the nine principles plus a few added ones that we thought were very important. The nine principles outlined in Arne's letter that he sent last year. And what it will do, it will describe the principles that school and program staff members should use to consider if the use of restraint and seclusion is ever necessary and provide information on current policies and practices for using it in public schools. It's also going to have the -- the other effective practices that can and should be used.

What I want you to understand, the undergirding behind this paper is the premise that every effort should be made to prevent the need for ever using restraint and seclusion. That is the premise. The first is that any behavioral intervention must be consistent to have the child's right to be treated with dignity. No child should ever be subject to any abuse. And that is a major premise upon which this is built. The second one is talking about whenever, if it has to ever be used that it must be used to address only immediate risks to physical safety and should never be used as a form of punishment or discipline. The idea is to protect the safety of the child and anyone else around him or her. What we know is that these practices should not be used to discipline children for failing to follow expected rules. If used, it should be implemented in a way that no harm or anything occurs. The third principle is talking about that a child should be continuously observed and appropriately monitored to make sure that no harm is coming to any child. Another principle is talking about that school personnel need to learn how to use it appropriately if it ever has to be used at all. And the use of effective alternatives should also be provided to every single staff member and of course that includes positive behavioral interventions and supports.

The next principle is talking about keeping parents informed. Parents should absolutely be provided information about any policies that exist on restraint and seclusion at their child's school or other educational setting and also related to informing parents is that the details of any incident that occurs that required the use of restraint or seclusion should be documented in writing and discussed with the parents immediately. Prompt notification helps parents become informed team members who can work with their child's teachers and other school staff to prevent further incidences.

Next one is talking about states’ districts and schools should not only establish and publish policies and procedures, but should also periodically review and update them as appropriate. Reviews should consider all of the available data that they have. In terms of the legislation, what we need to keep in mind is the fact that this is not something that just applies to students with disabilities, it applies to all students, and we need to make sure that they develop policies and procedures that address situations for any child whose inappropriate behavior risks physical harm to themselves or others. And lastly, we know that each incidence of the use of restraint and seclusion should be properly documented. As I've indicated, that data can be used to evaluate any outcomes of using seclusion or restraint, whether the procedures are being applied with fidelity or whether staff need additional training among other things.

Other things that we're working on is, you know, the technical assistance document that we are jointly developing with SAMHSA. We are also going to do another document that goes along with it which also is slated to be completed this fall and we hope will be helpful. We also know that since about approximately 12 percent of the overall student population are students with disabilities, we can never forget that students with disabilities are a part of and not separate from all the rest of education. As such, we really are working very hard on making sure that students with disabilities are included in every single aspect of the Elementary and Secondary Education Act, holding them to the highest standards, the same as everyone else. We have seen tremendous progress among and between students with disabilities. We also know that the Individuals with Disabilities Education Act will follow on the heels of ESEA reauthorization and our goal is to align these two pieces of legislation to allow states the flexibility they need in order to truly reform their efforts and make sure that we have one educational system that takes care of everyone. We also know, though, that the funding will remain for the separate programs. And we continue to have that need through

IDEA, but we also know that the ESEA reauthorization will increase support for the inclusion and improved outcomes of students with disabilities. We are also preparing for the reauthorization of IDEA and we want this reauthorization to be informed by everyone across the United States. So I will be planning and organizing a listening tour across the United States and convening stakeholder groups to provide us with input. And we've also been working with the Department of Labor to provide technical assistance in working on the reauthorization of the Workforce Investment Act and the Rehab Act, no small -- well you know that better than I do. It's been an interesting proposition. The idea is the fact that when we continue to work together as we have, and especially in relationship to the restraint and seclusion issue along with so many others, we will be able to make sure that we progress towards our goals for our nation's children.

And what are our goals? That all students will acquire the same essential knowledge and skills, that all students learning will be carefully monitored and we'll let them know and give them multiple ways to let them show us what they know. And that any child, whenever he or she is struggling at any point in time will receive the extra time and support that he or she needs whenever they need it and that yes, as teachers we're going to let them in on the secret, and we're going to clarify the standards that we use to assess the quality of their work. And it's probably the last one that's the most important, that all students will be the beneficiaries of educators who have promised to work together collaboratively to use the practices that have the most positive impact on their achievement. And with that I'd like to turn it back to you and I'll be happy to take any questions.

Ms. Blackwell: Alexa, thank you so much, that was great. A lot of information to process in a short time. So people in the room, questions, comments? Go ahead.

Ms. Singer: This is Alison. I have a question. Actually I have two questions.

Ms. Blackwell: Okay, go ahead. We're having a little trouble hearing you, Alison.

Ms. Singer: Okay. Is that better?

Ms. Blackwell: Yes.

Ms. Singer: All right. Alexa, thank you so much for bringing these data to our attention. I think we've been waiting for a long time to see what these data would look like and frankly they are scarier than I think many of us even anticipated. I think it's great that based on these data DOE is putting together recommendations for schools. My question is really whether in addition you are able to put together some sample guidelines or sample legislation for the state legislators to try to close that gap with regard to the number of states that have protections in place.

Dr. Posny: That's a great question. Now, we are developing a guidance document and we have not drafted anything in terms of, you know, proposed state legislation. But I know what we can do is to take a look at what is, what has been crafted across the United States. It differs. I mean, it is -- it's like an open -- I don't know, it'd be hard to characterize it. But you know, we would be more than happy to take a look at it. And I really believe the guidance document that we're developing I think could be a good basis for what the states could or should do as well as what's proposed at the Federal level, the legislation that's already been written for the Senate and the House. Because those are two, those two were very much alike and I think the language has been pretty much crafted, and I think that would be a great example.

Mr. Grossman: This is Lee, and Alexa I want to thank you. Actually I want to say bravo, that was excellent. Appreciate the information you provided. I guess one comment I'd like to make is those working principles certainly rocked in my opinion. The comment is that I'm not -- for the life of me I can't understand why those just aren't -- haven't been incorporated to this point and why they have to be just brought up now. But I'm glad that they are being brought up now and we're working towards that.

Could you explain a little bit more about the Workforce Investment Act and how that plays into this? Because as part of what we're trying to do here also we're looking at life-span issues regarding seclusion and restraint and how to address that. Is that something that will be able to help us beyond the school years?

Dr. Posny: Well, I certainly hope

so. I mean, when I think, you know, it's very unusual. OSERS is the only, you know, we're the only -- known as the principal office or whatever that really works with people with disabilities from birth to the end of life. There isn't anyone else in the agency so sometimes the adult part of this kind of gets lost, but that's why the Workforce Investment Act I think is so critically important. It's also one of the reasons we're doing the paper jointly with SAMHSA because we need to span the whole -- because restraint and seclusion should, you know, shouldn't be used with adults either. And I think sometimes, and I know they've worked very hard in making sure that the institutions or whatever, but that may not necessarily be the case. In terms of the Workforce Investment Act it's more towards making sure that people are self-sufficient so that they can live on their own and specifically we have probably not addressed like any of the behavioral issues or whatever.

However, it's a critically important skill if we really are going to have gainful employment for every adult. So it's probably something we should address. And you know, I'll go back and take a look but it's critically important.

Ms. Blackwell: Anyone else on the phone have questions?

Ms. Singer: I have another question if --

Ms. Blackwell: Okay, go ahead, Alison.

Ms. Singer: Alexa, what can we do as the IACC, as the subcommittees to support your drafting of guidelines for schools and state legislatures based on these, the new database principles?

Dr. Posny: You know there's a part of me, I could be facetious and say help us write it, but that's not going to help. I know we can't do that. What would be helpful is once the document does go all the way through clearance and we have everything done, it would be great if you would take a look at it and I will try to get you a copy as early as I can before it could -- might possibly be released and see if you could come out in support of what the document is. I certainly hope so. That would be extremely helpful, you know, in terms of promoting it. And I hope that it will be a tremendous resource for everyone with the idea that because it's going to be based upon the principles that, you know, I just reiterated with a few more that have been added. So I just think it would be helpful if we can begin as a collective group to say yes, we can get behind this and we can agree because I think sometimes they think we don't even agree with each other and sometimes that sends out a mixed message. And if there's something in terms of what we can embrace together that would be extremely helpful.

Ms. Singer: And what's the timetable for the preparation of this document?

Dr. Posny: Well, we're in the midst of writing it right now so we're just working on it internally, we're working with SAMHSA to get this through. So we just need to do the internal clearance. I am -- I'm not sure at this point if it has to go through OMB clearance. If it does it just means that it will just be a longer process. So I will keep you apprised. If it does go to OMB you will know that, okay, because they list in there what documents they do receive. If not, we're still hoping, we want this document to be out and be able to be used before the start of the next school year, you know, so that we can begin to get everyone revved up and make sure. The other thing is that, you know, with any of our discretionary dollars we want to see more professional development that goes into PBIS and the other types of supports that we can do. So timing is critically important.

Ms. Blackwell: Alexa, the next

meeting is in July so if you could possibly update us prior to that time it'd be very helpful.

Dr. Posny: That would be great if I could. See, that gives me the impetus to go back and say let's move a little faster, guys. I'll try, thank you.

Mr. Ne'eman: Alexa, this is Ari. Thank you so much for sharing with us today. My question is with regards to the guidance to school districts, I know one of the issues that's been discussed quite often in these conversations is if restraint and seclusion is to be truly viewed as it should be as solely an emergency intervention then districts really, you know, should not plan for its use with respect to individual students. Is this something that you anticipate the guidance will provide districts instruction around or do you anticipate it will remain silent on that point?

Dr. Posny: That's a great

question, Ari. And you know, it was part of the discussion that we just had with the Hill. You know, corporal punishment, this is the interesting part. Corporal punishment we know is outlawed in many states, but do we have to actually say that in terms of our guidance? And yet I know exactly what you're trying to get at, Ari, and I'm not exactly sure at this point in time. But I know that when you see the guidance you'll know very well what side of the issue we're standing on, that it should be used only if there's potential harm to the child or to others. I mean, that is the tenor behind what we're saying. So whether we have to come out and say, you know, we can't say you can never use it and I think that's the biggest issue because there are times for the safety of others that we may have to. And I'm talking more about the restraint, not the seclusion.

Mr. Ne'eman: I just -- I'm sorry, I didn't mean to interrupt.

Dr. Posny: That's okay, go right ahead, Ari.

Mr. Ne'eman: Well, I definitely understand that. I think all of the discussions have recognized that in emergencies, you know, there's some role for that.

Dr. Posny: Right.

Mr. Ne'eman: My question was more along the lines of, you know, what is the guidance going to say with respect to whether or not schools are going to be advised as to whether they should or should not plan for the use of restraint and seclusion with individual students, say, through the IEP process or other documents attached to individual students.

Dr. Posny: Yes, okay, I know. You asked me this question the last time I was here too, Ari, and this one, this one is the toughest one to give a definitive answer because there are pros and cons on whether it should or should not be in the IEP. And this is a tough one. You know, the whole idea about not having it in the IEP, believe me, I completely understand because by having it and allowing it in the IEP it's almost as if we're giving permission and saying this is an okay and I don't even want to say a technique, this is something okay to use. The issue is no, it's not and that's not what we're trying to say. However, if we go back to the intent behind the IEP we have never restricted anything from being included in the IEP. The IEP, you know, gives -- it makes sure that FAPE is provided. And you know, a blanket prohibition really goes against the concept of individualized services according to the needs of a particular child. You know, I was talking about the child that I had when I was teaching and the use of restraint was included in that child's IEP. The mother wanted to make sure I used it to stop him from harming himself.

So can I give you a definitive answer, Ari? I can't. We have never restricted or put any restrictions on what can and cannot be in the IEP, and yet there's a part of me saying I agree with you. Should it be in the IEP? No, because it does give permission and that's what everyone is wrestling with. And you know, I know the Hill is wrestling with it as well.

Mr. Ne'eman: Thanks so much.

Dr. Posny: Thank you, Ari.

Dr. Rice: Hi, this is Cathy. You had mentioned that there is a House version of the Keeping All Students Safe. Is there -- can you give any kind of read on whether there will be a Senate version and what may have -- were there in terms of implementation or technical issues that kept the two bills from being passed last time?

Dr. Posny: Yes, I think Sharon might want to address this one. Go right ahead.

Ms. Lewis: So just to be clear on the legislation, the legislation did pass the House in the last Congress and then the Senate drafted a bill that was essentially modeled on the House bill with a few minor changes. The biggest sticking point in the committee at the time was this provision around whether or not to allow seclusion and restraint to be written into an IEP. The House bill did prohibit that inclusion. The revised Senate bill because there were actually two Senate bills that were dropped, the second Senate bill that was most likely to come up for consideration would have allowed the inclusion of seclusion and restraint in an IEP. I think it was -- was it only restraint? I think it may have only been restraint -- in an IEP given a set of requirements prior to utilization. So a student would have had to had a functional behavior assessment. There needed to be a positive behavior plan in place and several other precursors prior to inclusion. And there was a lot of debate and back and forth among the community and frankly I think the clock ran out. And the sponsor of the legislation was Senator Dodd who is no longer in the Senate and so sometimes one of the things that happens is it takes a little bit longer to get going the next time around in terms of new staff, new member taking up the issue. It is my understanding, and not to speak on behalf of Senator Harkin, but it is my understanding that both Senator Harkin and Representative Miller are very interested in including components of this issue in the reauthorization of the Elementary and Secondary Act because they do see this as an all-students issue and so I think that part of the legislative conversation at this point is around is there a way to craft this in the context of there's a part of ESEA, I think it's currently Title 4, around safe schools. And is there a way to address the issue in the context of safe schools. And again, without, you know, without going any further in terms of the assumptions around legislative negotiations. I think that's kind of where things stand.

Dr. Huang: Alexa, thanks very much. I'm SAMHSA and we've been working together and we are on some fast deadlines and clearance processes for this guidance paper. Sharon, I just want to really also highlight that, you know, if we look at it as an all-students issue as opposed to students with disabilities or students who have IEPs I think we can get around the IEP piece. Because I'd be curious of what's in the data that's being collected by OCR. If they look at that by are these students with IEPs or not IEPs. Because I have a feeling that it's probably students without IEPs because we have the population that we -- that's of concern to us, children with various emotional and behavioral disorders, many do not have IEPs and many of them are the -- sort of the key population that is subjected to seclusion or restraint. So that might be a critical piece to look at in that OCR data. I don't know if it can be looked at that way, but I think -- and our approach is really preventing the use of. And so I think that gets around -- our concern with it being an IEP is that it then looks like it's a therapeutic intervention and we're really backing away from that, when it may be -- actually, even hundreds of years ago it wasn't a therapeutic intervention, but we're really moving away from thinking about this as -- that it's therapeutic in any way. So that might be another way to look at it and look at the data there too.

Dr. Posny: The data is being broken out by students with or without disabilities. It's also being broken out depending upon whether they have an IEP or a 504. So we will be able to -- we'll have a much better idea.

Dr. Huang: Okay.

Dr. Posny: Which I think will be very helpful. And Larke, I just want to say thank you. You guys have been great to work with. Yes.

Dr. Huang: I think it was Sharon -- when that hearing, the congressional hearing and said well, why doesn't Education talk to SAMHSA, what they've done and we've actually followed through on that so that's -- that's been good.

Mr. Grossman: That seems to be a great segue way to our next speakers which are Ellen talking about what's happening at CMS in regards to this and then Larke presenting from SAMHSA's perspective.

Ms. Blackwell: Okay, thanks. Actually, I feel like I'm going to be talking more about what happened at CMS and not so much what's happening. And I'm doing that basically because I think there are a lot of people who may not understand, you know, Medicaid is very complex in the first place but where we got to where we are today at CMS with seclusion and restraint. This was actually the first issue I ever worked on when I joined the Federal service 10 years ago so it's a little bit close to my heart and it was interesting to go back in time and look at some of these things. So if I'm boring historically I apologize, but I think these are really important things that happened.

And as you heard Sharon and Alexa say, certainly for government to do something we have to have a law to hang our hat on and this is the big one here, the Children's Health Act of 2000. I think it's good that we start with this. It's on the website, Susan put it up as a link. This is a really important piece of legislation that President Clinton signed. It looked at children who have a variety of different disabilities including autism. Parts H and I of the Children's Health Act are directly related to seclusion and restraint, and Title 1, some of the people on the phone, certainly Gail would recall that it created the Interagency Autism Coordinating Committee. So a little interesting fact there. So what does Section 3207 do? Any facility that receives Federal funds must follow these rules. And I'll talk a little bit in a few minutes about what those facilities would be, but these were embedded in the Children's Health Act. Section 3208 discusses public and private non-medical facilities and what they must do to protect the seclusion and restraint rates of children. So I would urge everyone to take a look at these sections of the Children's Health Act. Again, I think it's really important to understand where regulations and policies stem from.

And how did we get to the Children's Health Act in the first place? You heard Sharon talk about the Hartford Courant articles. This happened a long time ago, but I think it is important to revisit what happened here. In late 1998 and early 1999 this newspaper published a series of articles about children who had died in various community settings for the most part, some institutional settings, related to seclusion and restraint. And these articles are still available online, if you look for them you can find them, and I think they're still relevant today in terms of how we got here. So the articles, the Hartford Courant actually got the Harvard Center for Risk Analysis to do a survey and the survey revealed that at the tip of the iceberg 50 to 150 children were dying each year, looked mostly at facilities that serve people with mental disorders or intellectual disabilities and really, I think they extrapolated in the article that those were just the ones that they could track. So that's quite a number of children and people dying. They also revealed that seclusion and restraint was mostly used for these reasons: discipline, punishment and staff convenience.

Again, not a surprise to any of us who are familiar with reasons why seclusion and restraint might be used. The children died related to asphyxia, cardiac complications, drug overdoses and interactions, blunt force trauma, strangulation, choking, fire-smoke inhalation and aspiration. So that's what the Hartford Courant article said.

And they were pretty horrifying articles. They certainly got the attention of a lot of people in the Congress. So as Congress is wont to do it asked for an investigation, it asked the GAO to go and look at what was really happening and that's what the GAO did. Especially -- the focus at that point was to look at how Federal funds were being used to fund facilities that might be using these procedures. So in 1999 the GAO published this report. It's on the IACC website and I put a link here. I think it's still relevant. Again, the report looked at people with mental disorders and intellectual disabilities. The report did not look at schools, outpatient treatment, sheltered workshops, drug programs or correctional facilities. At the time, the Centers for Medicare and Medicaid Services was known as the Health Care Financing Administration and the report recommended that HCFA, now CMS, issue some policies that would apply to facilities that are funded with Federal funds, Medicare and Medicaid being the biggest public payers of health services in the world. One of the biggest recommendations of the report was that HCFA improve requirements for staff training and I think that we've heard several people mention that today. So again, I think that this report is still relevant and I hope that everybody, if you haven't had a chance to review it, takes a look at it.

So what did CMS do? CMS did a couple of things. It issued patients’ rights conditions of participation in facilities that CMS surveys and then it also issued an interim final rule on the use of restraint and seclusion in what we call psychiatric residential treatment facilities, psych under 21 facilities, and thirdly there was a clarification on the regulation that we did issue. So the hospital COPs, I've given you the citation here, if you want to read them you can certainly do that. These were issued in July of '99. We also conducted research on seclusion and restraint in adults that we believed -- sorry, I left the one off of there -- but HCFA believed that the research that it did on seclusion and restraint translated to children and that children might in fact be much more vulnerable to these procedures than adults. Advocates also sent CMS a number of comments indicating that children were a population of special interest and HCFA said that it would certainly issue a regulation looking in particular at kids. So a lot of things started to happen in 1999 and 2000.

In 2001, in January, this was

about the time that I came to CMS. We issued a regulation on -- an interim final regulation on how seclusion and restraint could be used in these facilities that we call PRTFs. And this is basically a summary of that regulation. Quite a few things that you heard Alexa mention today. The really -- the similar principles that seclusion and restraint can only be used to ensure the safety of the person or other people in emergencies. It must terminate when the situation concludes irrespective of the time that might be remaining on a medical order that's been issued. The least emergency intervention must be used. As-needed seclusion and restraint orders, physician orders are prohibited. Seclusion and restraint can't be used at the same time. So you know, this was a big deal and I remember it quite well. So again, I would urge everyone to take a look at this reg. This interim final is still in place.

So what is a PRTF? It's a facility that exists in Medicaid pretty much primarily as a result of all these changes. It's a non-hospital facility that provides an inpatient psych benefit to children. It has to be accredited by JCAHO or another respectable accrediting organization. It has to comply with the one Medicaid condition of participation regarding seclusion and restraint, and it requires that these PRTFs have to report serious occurrences to the state Medicaid agency and also to the state protection and advocacy agency.

So there were some other additional provisions in this interim final rule. It defines seclusion and restraint. It talks about who can order seclusion and restraint. It talked about time limits. It required a one-hour face to face assessment and ongoing monitoring. Parents and guardians had to be notified. The facility had to get together with the parents for two immediate debriefing sessions after an occurrence of seclusion and restraint. The regulation talks about reporting requirements and it also talks about staff education and training competencies. This was a big deal at CMS and to this day it's really the bedrock of seclusion and restraint rules.

So we got a lot of comments after we issued this interim final regulation and we issued a clarification on May 22nd which was -- in 2001 which was when this rule became effective. A lot of commenters were concerned that there was a lack of nurse and psychiatrist shortages to order seclusion and restraint. We also clarified exactly which facilities are subject to the rule, in other words, which facilities qualify as PRTFs. And we did make an amendment. I think as you heard Alexa say, restraint, we talked about touching on the hand and you know, leading someone to another area, so there was a lot of confusion about how that fit into this idea of personal restraint. So that's where CMS left the PRTF reg and it is still in place. And I happen to believe it's a pretty good regulation.

We followed it up with a state Medicaid director letter which is really just an official policy clarification and also issued guidance to the state survey agency directors. CMS survey function is the entity that actually monitors these facilities. And here is the condition of participation, the one condition of participation for the use of seclusion and restraint in PRTFs. It's at 42 Code of Federal Regulations 483.350-76, Subpart G. It basically says that the Children's Health Act reporting and training requirements apply and it also defines certain terms that you heard others talk about today. So that's it, that's what states and these facilities have to tell CMS.

So what happened after we issued this regulation? I think that's pretty interesting. PRTFs have to report all deaths to CMS, not just seclusion and restraint related deaths. Since 2001 there have been four deaths reported in these facilities and one death occurred after an individual struggled with staff in a protective hold. So I actually think that's, you know, I don't want to say that one person's death is a success story, but based on what we heard in the late 1990s I think this is a success story. It shows that putting these rules in place can make a big difference. Now, of course we, you know, that's based on the data that we get like everything else, but it's a positive step.

So what providers in CMS do we regulate that have seclusion and restraint related regulations? We regulate hospitals including psychiatric hospitals. I actually made a mistake. Yesterday I was afraid that I had forgotten ICFs/MRs so I put it on here twice. We regulate nursing facility use of seclusion and restraint and also as I said earlier the PRTF facilities.

So where are PRTFs in Medicaid? They actually fall under our mandatory benefit rubric under the early periodic screening diagnostic and treatment benefit, kind of a mouthful, EPSDT. This is a benefit that went into the statute early on in the 1960s when Medicaid first was established as a program and it essentially says that children can receive Medicaid -- children are entitled to receive any benefit under Section 1905(a) of the Social Security Act. The PRTF benefit is Section 1905(a)(16). However, states are not required to use PRTFs to provide psychiatric services to children. So although certain protections are afforded to children who are in PRTFs, states may also use other facilities to provide the services that are not regulated by the Medicaid program. And I'll talk about those in a minute. We don't really know how many states use the PRTF benefit. I can't even hazard a guess but many states over the past 10 years have used this benefit. It has one really big draw which is that in PRTF states can receive reimbursement for room and board which isn't traditional in Medicaid programs so that is an incentive for states to use this.

So where are ICFs/MR in Medicaid? This benefit was added the Congress in 1967. Congress was concerned about really terrible conditions in large institutions so it created another facility that CMS regulates. There are more than 6,000 of them in the United States. Most of them are actually quite small, less than nine beds. However, most clients are still served in large ICFs/MR. Those would be the ones that have more than nine people living in them. These are very expensive. The average cost is more than $118,000 a year. Some states like Alaska no longer operate any ICFs. But I think there is a distinction to be made here. Although here in my home state Maryland, Maryland's never operated anything but very large ICFs but some states use these facilities very effectively to provide services to people with developmental disabilities and there is a distinct set of rules governing the use of seclusion and restraint in ICFs. Although it is older than the PRTF regs it's located at 42 CFR 483.450. It's under the section called Client Behavior and Facility Practices. And again, this is an older law, it probably -- when I looked at it yesterday I have to say I really do not feel that this is as up to date as some of the other items that we're discussing in terms of the new school legislation or even the PRTF regs. Again, you can see that it says that behavior management can't be used for discipline, staff convenience or as a substitute for active treatment. Timeout rooms are approved and they're actually called timeout rooms in this condition of participation. Physical restraints can be put in a person's plan or they can be used as an emergency order -- as an emergency measure. So there's more room here I think in a person's plan, there's already embedded in this legislation a way to put in physical restraints. It does require that there be a record of how they're used, that the individual be checked and that they be released as quickly as possible from any kind of physical restraint. And there are some other requirements surrounding the use of chemical restraints or drugs used to control behaviors.

So there are also regulations in Medicare and Medicaid that discuss how seclusion and restraint can be used in hospitals, and in 2006 the OIG issued a report, and again I would urge everyone to take a look at this. I can't remember if, Susan, you put it up on the website. I think you did.

Dr. Daniels: Yes. It’s on the

website.

Ms. Blackwell: The hospital OIG report. CMS essentially concurred with this report that talked about hospital deaths and we sent out a letter reminding state survey agencies of their responsibilities associated with the patient's rights, COP, and in the meantime we have increased our capacity to monitor and triage the findings that are reported to us from hospitals across the United States. Our survey and certification staff is presently using a contractor to gather more statistics on seclusion and restraint in hospital settings. We're looking at what they're finding and we are developing tools for follow-up on seclusion and restraint.

So I thought we should take a second to look at settings that are funded by the Medicaid program that CMS doesn't monitor. And this is kind of a long list. The first is home and community-based settings which could be the home where a person lives, a group home, a residential care facility, an adult care home, adult foster care, child foster care, facilities, these are called residential treatment facilities or residential treatment centers for children. I would have to say that that's the alternative that a lot of states us in lieu of PRTFs. We do not regulate assisted living facilities and although we do regulate nursing homes I think what we're seeing in the service arena now is more states and more people using assisted living facilities as a bridge before they end up in nursing facilities. So to me that's sort of a growing area where, again, we don't regulate these facilities. And then other places, for example day habilitation programs where a person with a developmental disability might go during the day or adult day programs where an older adult might go during the day. And then lastly schools that we heard a lot about from Alexa.

So in talking about schools I think it is important to mention that the Medicaid program has more than a foothold in school world. In 1965 as I said EPSDT was added to the statute. These three laws really support Medicaid's involvement in schools: IDEA which started in 1975 as the Education for All Handicapped Children Act and then lastly in 1988 an artifact of a law that was later sunsetted or retracted, Section 1903(c) of the Social Security Act and that's really the place where the foot goes through the door in Medicaid. And what it says is that Medicaid is the first payer for services that are covered in Medicaid under Section 1905(a) if they are included in a child's IEP or IFSP and might alternatively be paid for by education funds. But those services have to be services that are included in that part of the Medicaid statute. For example, speech therapy, occupational therapy, rehabilitative services, and the services have to be described according to Medicaid requirements not necessarily education requirements. So Medicaid is paying for a lot of services that are considered to be Medicaid services before education if they're included in a child's IEP or IFSP. So a lot of people may not realize that CMS has a huge presence in school settings.

So where are home and community-based services in Medicaid? Probably the one that most people are familiar with are these Section 1915(c) home and community-based services waivers. Home and community-based services in Medicaid also fall under the state plan now in Section 1915(i). There are some other new places in the statute. Section 1905(a), that's kind of the bedrock of Medicaid. A lot of states are now using the Section 1115 authority to provide Medicaid services, and then some states use contracts under Section 1915(a) to provide HCBS. So there are a number of places in our statute.

As I said, the first one is probably the one most people are familiar with.

So how do we actually go about looking at seclusion and restraint and safety and these waivers? States have to tell us under the rubric of health and welfare what they're doing in the realm of these six quality assurances. The one I put the star next to is the big one. And when states apply to CMS to provide these optional home and community-based services they have to tell us that there are safeguards in place to protect the health and welfare of the people that are enrolled in the waiver. Under that piece they have to tell us what their response is to critical events and incidents, what safeguards are in place directly relating to restraints and restrictive interventions, and then what they do so far as medication management and administration. Now again, we don't monitor what states do but we do ask them to tell us what they're doing when we approve their waivers. And halfway through the life -- generally it's about five years -- of these waivers we go in and monitor how states are doing in these six areas including health and welfare, and we make decisions about whether or not a waiver might be re-approved by the Secretary based on how states are doing.

So in what we call Appendix G-2 the states have to tell CMS about their incident management system, oversight procedures that the operating agency might be using. In most waivers that serve people with autism the state developmental disabilities agency is usually the operating agency, but they are really operating under the umbrella of the state Medicaid agency who is CMS's partner. And they have to tell us how they manage their incident management system and a lot of things about what happens. So what do they have to tell us specifically regarding seclusion and restraint? They have to tell us what restrictive interventions they permit and the circumstances under which they are permitted, and then they have to tell us the protocols and the methods they use to detect the use of these. So there are a lot of questions in these waivers that states have to answer, and all of this is public information. I'm going to give you a link in a second here, but if a family member is enrolled in one of these waivers I always say that I think the best thing to really understand the services your family member receives is to actually read the waiver, not necessarily guidance that might be given out by the state developmental disabilities agency because this is really where it's at, this is the document that -- where it begins.

So what do we do under Section 1915(i)? This is a newer piece of coverage that was added to the Medicaid statute through the Deficit Reduction Act. And we ask states question about their state plan coverage regarding health and welfare. Specifically we ask that the state tell us how it identifies, addresses and seeks to prevent incidents of abuse, neglect, exploitation, including the use of restraints. So far as I know this is the only place in the Medicaid state plan where we ask this sort of question. So if states are providing home and community-based services under the state plan and not under a home and community-based waiver the state does have to tell CMS what it's doing.

So what's on the docket now? There's a piece of the Affordable Care Act, Section 2402, Sharon is well-versed in this area, that directs the Health and Human Services Secretary to write regulations that talk about how home and community-based services resources will be allocated. They focus on how people will lead individualized, self-directed lives and essentially how provider coordination will be increased, and these apply to the United States and HHS programs in general. So Section 2402(a)(3) mentions oversight and monitoring of service system functions. And again, I would emphasize that for government to do anything there has to be a piece of the statute that leads us to that place so perhaps there's potential here for additional regulations to come forth on seclusion and restraint. CMS is part of a cross-HHS work group that is working on this provision now. Henry Claypool, another member, Rosaly is here today is working on this Section 2402 group so we will see what comes of this.

So if you go to this link, this is a link where you can actually look at the home and community-based waivers that are approved in your state. It's up to date and again, I urge everyone to take a look at these programs and specifically what your state has said insofar as what seclusion and restraint provisions will be permissible in its home and community-based services programs.

And then also I always think it's

a good idea to be familiar with what CMS regional offices oversee the activities that are taking place in particular states. So here's a list of our 10 regional offices. They are much closer to what happens in the states than we are at the central office in Baltimore although we work very closely with our regional office partners. So if beneficiaries have issues I always urge them to talk with our regional office counterparts who will usually get in touch with us. And we do often work with beneficiaries on individual problems or issues.

So that's all I have. That was a lot. Questions?

Dr. Strickland: This is Bonnie. Thank you, Ellen, that's terrific. The regulations are very comprehensive. I mean, clearly it begs the issue on to what extent could these regulations inform regulations for other agencies and states as they develop their own regulatory guidance around seclusion and restraint.

I want to go back to the issue of enforcement of regulations. And you touched on it a little, but it sounded as if the enforcement side might be a little -- not as strong as the regulatory side. I just want to be sure I'm clear on that. I don't quite understand how CMS actually enforces this very comprehensive set of regulations.

Ms. Blackwell: Well, because our state survey agencies are required to go out and as I said, PRTFs are required to report so we have a couple of individuals for example who look at the hospital reporting, and we have one individual who looks at the PRTF reporting. But the reports do go to the state P&A agencies and also to the state survey agencies who are required to report to us.

Dr. Strickland: Are those just deaths, or are they also --

Ms. Blackwell: Just deaths.

Dr. Strickland: Well right, I get

that, but how about just the incidents of seclusion and restraint in general? Is there any reporting mechanism built in for -- I guess I'm not really sure what I'm asking but death seems to be --

Ms. Lewis: Correct me if I'm wrong, Ellen, but I'm not aware of any requirement that the individual states are required to report incidents.

Ms. Blackwell: No, they're required to report deaths, that's all.

Dr. Strickland: And is there -- do you know of any other mechanism in states around facilities where individuals or families would report that kind of information and it would be gathered and used by agencies or?

Ms. Blackwell: Well most states for example in developmental disabilities world, and Sharon is probably better prepared to answer this than I am, have a mechanism for people to file complaints. So for example in

Maryland it's the Office of Health Care Quality and people can usually file a complaint, it could be a medication error, it could be a seclusion and restraint issue, it could be an abuse issue to their state survey agency. And the states are responsible for going out and looking at those incidents. Every state so far as I know has that sort of system in place.

Ms. Lewis: I think that's right. I think that, however, it does -- it's important to acknowledge that the ability to monitor and provide oversight in particular when there are not family members or other advocates involved creates a unique set of challenges around identifying those incidents. You know, we do have a long history of difficulties in monitoring individuals receiving services in particular in larger congregate provider institutions and you know, even just recently we had a report in The New York Times just you know two months ago about state-operated facilities and what was happening with abuse among the staff, and restraint is certainly a component of that. So while it is the responsibility of the states to monitor their systems and how much is tied back into data collection that would allow CMS to have a sense of how well these regulations are being implemented, I don't know that we have that information.

Mr. Grossman: And Bonnie, I think that's an excellent point that you're raising. I'm going to ask you to kind of put that in the parking space for right now. I think that'd be a great conversation that we should have with Curt Decker this afternoon because he would -- I'm sure he has some recommendations along those lines.

Ms. Blackwell: And I think -- I mean I said this previously, but over the past 30 years we've seen more and more, happily, services move into home and community-based settings which is what we all agree is the right thing. But as you can see, CMS really doesn't have the authority to regulate the kinds -- I mean, we have a little piece of the statute that talks about health and welfare so we do look at it in these waiver applications but we don't have these sorts of rules. It's a state-designated function. So now we have the services sector moving more and more in the right direction and we've got the institutional side that has these rules but you know, as you heard Alexa say, there's not really a piece in schools and there's not really a piece in home and community-based services. So maybe there's an opportunity there.

Ms. Lewis: I would agree. I mean, under the current proposed regulations for home and community-based services these issues have not been addressed. I think that the focus has really been on what do we need to be doing from a positive perspective and I think that there is some opportunity in terms of the NPRM does address extensively the need for person-centered planning. And I think that as we see home and community-based providers implement those components of the CMS regs we will see that individualized approach and the need to address these things on an individual basis which we also know reduces the incidents. I mean, a big piece of this just comes down to are you prepared for the behavioral incident and are you addressing the behaviors at the front end prior to getting to an incident, and we believe that person-centered planning is a critical component of that.

Dr. Huang: Just one other comment on that, Bonnie, is I think that is in some ways the crux of the issue, our data. You know, what data do we collect systematically across states. I know I've looked at some of that data and oftentimes I think there's probably under-reporting as well. I think that you might get deaths that are to a heart attack, but maybe the triggering thing was a restraint, or an injury, or a fall. But so when you look at some of that, I remember years ago looking at it and there was no deaths in California, huge state, you know, and then there were like 25 deaths in Iowa. You know, so how they collect, how they interpret it, how they report it, who makes the determination of the cause of death at the time of the death is really quite variable I think across states. So we don't have it consistently. In my presentation I'll show you some of the data we have but that is really, it's I think a very big challenge. And we're not even done with all the regs yet from the Children's Health Act. And so the issue of enforcement, I know that there's a piece where SAMHSA is supposed to do the enforcement, but we have no funding to do the enforcement. The reg's not completed yet because we haven't got concurrence across -- just within our department. We're not even talking about cross-department issues. So those are still really outstanding questions.

Ms. Blackwell: Christine.

Ms. McKee: Ellen, I have a question. You talked about the state waivers having to specify the types of circumstances under which they would use restraint. I haven't taken a look at those. How do they parallel the ideals that Alexa talked about this morning? Are they that progressive or are they?

Ms. Blackwell: It depends on the state. I mean, we -- when we look -- when CMS reviews these waivers we have an individual in our regional office. As I said, we have a strong partnership with these people. And then someone in our central office who looks at the waiver application. We ask questions and states answer them. So I would venture to say that when you look at a home and community-based waiver you're going to see a pretty good description of what they do. And then we ask the state to tell us, as I said, how they monitor what they're doing midway through the waiver. If something goes awry we usually go in and ask for a corrective action plan if we see things, you know, aren't happening the way that the state said they would. But you know, that's about it, that's where we are right now.

Ms. McKee: I just wondered if there was language in there that we might borrow for something but it sounds like they might be a step behind.

Ms. Blackwell: You'd have to look -- well, some states are further ahead than others.

Ms. McKee: Are they? Okay.

Ms. Lewis: Well, and I think that if we're looking for places -- and I'm looking forward to hearing Larke's presentation. I think if we're looking for probably the places where we're going to see the most progressive existing policy it is in the work that SAMHSA has done specifically because they have had an initiative to reduce and I think it's to reduce and eliminate or to reduce restraint and seclusion across multiple states. And I think that that's a part -- it's a really good question and where are their models and examples that we can look to.

Ms. Blackwell: That's a very nice segue way to introducing Larke. Thank you, Sharon.

Dr. Huang: Okay. Well, I know that we're kind of behind schedule here and I think we have a lunch scheduled and I have a meeting scheduled at 1:30 that I have to leave, so I'm going to go through this fairly quickly but some of it, some of the discussion I think has already addressed some of the information in my slides.

So I'm at SAMHSA, the Substance Abuse Mental Health Services Administration, and we have had an initiative to really look at the efforts to reduce and eliminate the use of seclusion and restraint, and now we're also moving into more of an approach to preventing the use, that we really want to even move further upstream, what do you have to do in a facility, in the training of the workforce staff. Involvement very much of consumers and families to prevent this type of practice from occurring in mental health facilities.

Again, you've heard before, Ellen mentioned the Harvard Center for Risk Analysis, anywhere from 50 to 150 Americans die annually from the use of seclusion and restraint, that we are increasingly viewing it as a treatment failure. And I have to say that probably about 28 to 30 years ago when I was working in mental health facilities, state facilities and community crisis units that that was part of the practice. I mean, that was part, we had seclusion rooms, we routinely -- this was in San Francisco and also the period of drug-induced psychoses. We consistently and thought about restraint across the life span as a therapeutic process. And so when I think about where we've come but I also look at Sharon's history and you know, that in some ways we have come some far but not as far as we really should. It's kind of like you look at, think you know it's like leeches, we were using leeches for treatment? And when I think about what we were doing, you know, in a fairly progressive medical setting around seclusion and restraint and that's what I was trained in. I really think it is really changing practice, changing values around it, understanding better client-centered care and the real key issues of safety and respect.

We also know that the use of these practices may be detrimental to the recovery of persons with a mental illness and also re-traumatizing. We're increasingly looking at the role of trauma in -- for across the life span of people, and children and youth with mental health and addiction disorders and seeing increasingly more trauma in their histories and trauma histories. We also know that use of these practices can actually also be traumatizing for the staff who engage in these practices. We also know given the two cohorts of a grant program and funding of a technical assistance center that in fact you can reduce and in some places completely eliminate the use of seclusion and restraint in mental health treatment facilities and also in forensic facilities. We've had a number of jail-oriented forensic facilities that have really eradicated the use of seclusion and restraint. So if you think about that being a high risk environment where there are a lot of behavioral health issues and challenges and some of those facilities have actually eliminated the use of.

So we also really want to focus more on the prevention of the use of seclusion and restraint. And now we're also looking at it from a slightly different strategy. We've looked at it from the clinical impact, we've looked at it from the organizational program impact and now we're also looking at it, what is the economic impact of the use of seclusion and restraint. We're trying to look at how do we need to talk to different people who are in decision-making capacities to realize that if you take an economic or a business case to this it really speaks to people who are in different positions or power to say I don't want this going on in my facility, that in fact there are opportunity costs because when you're doing this you're not doing treatment, tremendous numbers of liability injuries among staff as well as clients and patients.

Ongoing, you heard about the Hartford Courant. Well, very sadly those things aren't -- they haven't stopped. In fact, I just got another email. Every day I get an email of somebody who's injured in a treatment facility, in a place that's supposed to be taking care of someone or in a school facility where a teacher has sat on a child and caused asphyxiation. You know, so the Hartford Courant stimulated a lot of the work around it, but sadly these things are not -- they're not stopping.

We need to get clear on the definitions of seclusion and restraint. As you heard Alexa say, that there are definitions that might be used in schools that are definitions that are used in other kinds of treatment, whether they're home and community-based treatment facilities or hospital facilities. We tend to use the CMS definition and that's the definition that we tend to promote in our work. We feel that there has been good consensus derived around that definition and that has cross-sector applicability as well.

The piece around seclusion that is really critical and that is really differentiating it from timeout rooms is that a person is physically prevented from leaving, okay? In terms of restraint people say well how do you differentiate drugs and medications from chemical restraint. Well, we really try to differentiate what are medications used as part of a treatment plan versus those that are used for patient or individual control. Looking at restraint, there are different types of restraint. Some places where SAMHSA has gotten in a position of non-concurring with some regs is really making clear what's in the definition around what we mean by restraint. In some places prone restraint has been totally prohibited because that's probably one of the most dangerous types of restraint that most often leads to serious injury as well as deaths. Okay.

So based on that we have had a series of different initiatives at SAMHSA, again, stimulated by the Hartford Courant series, the Children's Health Act which Ellen did a very nice delineation of provisions in that act, along with NASMHPD which is our National Association of State Mental Health

Program Directors -- it's the national arm for all the state mental health offices and commissioners -- issued a call really to look at how do we eliminate the use of seclusion and restraint in behavioral health care. Came up in 2003 with a national action plan which led to some funding opportunities, some data collection efforts and to really beginning to look at guidelines. A key piece of the way we do work at SAMHSA is very much including the consumer and family voice. That is very much a guiding principle not just in this work but in our grant-making program we have that. We do block granting to states around mental health and addictions treatment. We are a major source of funding for addictions work. In all of those in those states that receive our funds, and they all receive funds, we require a state mental health planning council with a majority representation of consumers and users of services in the states. So we really actually put into our policies the role of consumers and families in treatment development, policies and initiatives.

So our approach to looking at seclusion and restraint is that it's viewed as a safety intervention of last resort. It is not a treatment modality. We often look at it as a treatment failure when this is needing to be invoked. We want to provide training, technical assistance and other support to states, providers, facilities, consumers and families in order to reduce and ultimately eliminate seclusion and restraint in mental health and substance abuse treatment, both in terms of state-funded treatments, in terms of inpatient, in CMS-regulated facilities as well as in our home and community-based services of which we are re-balancing the work in states from more inpatient work to more home and community-based treatment supports. And to really implement changes regarding seclusion and restraint at the clinical, the programmatic and the organizational level. So we want to work with providers and practitioners to know alternatives to using seclusion and restraint, and we want that to be done also in the programmatic and an organizational level. I think you heard from Kevin Huckshorn who we've supported to develop our training and Technical Assistance Center and do a lot of the trainings for us, that we're really looking at changes in -- at the organizational level, at the culture of the organization. We feel that that needs to be done in order to support better individual clinical treatment approaches. So think about it as a multi-tiered process which means that as you look at regulations and policy that also needs to be done at a multi-level process.

I wanted to just share with you there have been a number of questions that come up around data. Data is a very challenging area to penetrate here. Through JCAHO they are -- JCAHO-funded inpatient hospitals are required to do reporting around seclusion and restraint so that reporting goes to NASMHPD, the national research institute which is the research arm of the National Association of State Mental Health Programs. And I wanted to just show you some of the data. It's very hard to actually get this data. It's very hard to know -- the house facilities are actually systematically collecting it, but it gives you a snapshot of where we're going.

This is 2008 data and this is broken out by age. I don't have it. It's in your handout. These are, I'm sorry, difficult to read but it's over 2002 to 2007 quarterly reports of the use of hours of restraint by age. So this is broken out by clients in inpatient treatment facilities 12 years and under, clients ages 18 to 24, 13 to 17 years, 25 to 44 years. You can see a decrease in the hours of restraint over time, over that period from 2002 to 2007. You'll see that there is variability in terms of higher rates of hours of restraint among the 18 to 24-year-olds. As we get older you see less time of hours in restraint. I want to say that this does not necessarily include nursing home data. We do hear quite a bit around elderly abuse or uses of restraints, probably less seclusion but uses of restraints. This is not nursing home data. This is percent of clients restrained. So while you saw the percent of time in restraints among children 12 years and under we see a slight uptick in the percentage of children restrained. So it's really important to look at the time in restraints, the time in seclusion, the percentage of people in restraints, the percentage of people in seclusion because we really want to look at is a little bit more disaggregated to know really what's going on.

Okay, so you have this. I'm going to go through this really quickly for the sake of time. This again is seclusion hours and then again you see a little bit more higher rates of that among children and the 18- to 24-year-olds, less in the older populations and then what percent of clients secluded. When you break it out by children about 20 percent of children in mental health facilities are subjected to seclusion. So that's why it's really important to break it out by age over time by percentage of those who are secluded and time in seclusion.

Okay, so just sort of a summary of this because I know you're straining to read the data. Unfortunately this is PDF data. We have little opportunity to really play with the graphs, that's why it's very hard to read. So that the hours of restraint per 1,000 inpatient hours really varies significantly by age group. Twelve years and under in this particular time period the hours of restraint decreased but the percentage of clients restrained actually increased. In the 18- to 24-years you'll see they exhibit the highest percent of time in restraint, yet the percent of clients restrained remained level. The hours of seclusion decreased for all age groups except for the 18- to 24-year-olds. The percent of clients secluded remained level in all age groups except the 12 years and under, and that's where we saw the highest rates of percent of clients secluded.

This is more recent data. We asked to get the 2010 data. You'll see restraint hours going down. This is not disaggregated by age group. You'll see the percent of clients restrained fairly even, much variability in seclusion hours and percent of clients secluded slightly downward with sort of a plateauing.

Okay. So what are our key activities to begin to address this? We have had two cohorts of a grant program to states. We also fund the PAIMI grants where the Protection and Advocacy for Individuals with Mental Illnesses. Those are grants that go to states. They are formula grants related to the size of population of states. And we fund -- two percent of that funding goes to NDRN to do technical assistance to the protection and advocacy agencies in states. We tried to look at this issue also in terms of the addictions area. We've done some addictions round table. But if you think about detox agencies, the coercive care that's often given in substance abuse treatment agencies, it's very much a challenge to even get this to be a discussion at the table there. We are looking at how we can do more in terms of Federal regulations around seclusion and restraint, and beginning to look at in our surveys of facilities, looking at data elements we want to collect there around the use of seclusion and restraint.

This is what has been our seclusion-related budget. You'll see it's a very small piece of SAMHSA's budget. We are a $3 billion agency so we've had two-plus million dollars for our grant programs, $36 million which has pretty much remained level for our PAIMI funding. We also are moving that -- we have funded 16 states to address the seclusion and restraint. We are no longer doing state-funded grants and taking the learnings from -- the lessons from those state grants to now move it into technical assistance and training to be able to reach a broader audience of states. A key part of this reduction is really workforce development, it's really training and technical assistance. So through our Training and TA Grant Program we funded two cohorts, a total of about 16 states to put in place interventions to reduce this. And there was guidance around what those interventions might look like and guidance around who should be at the table. Consumers and families were very much a part of the planning that states needed to do to roll this out to their different state hospitals. We have a national evaluation of that effort and a coordinating center that has continually to -- pulled out the lessons learned, looked at the evidence-based interventions at the clinical level as well as the organizational programmatic level to begin to train more broadly across the country using those interventions.

These are the states that were funded. We also had another transformation grant going to some of these states. We looked at when there was -- when they got both of those grants because part of the transformation grants were really to look at how we're transforming services in states. And a key piece of that transformation was a consumer voice, a very strong consumer family advocacy voice, and those transformations looking at trauma in those states and looking at re-traumatization of people with various behavioral health issues. So we wanted them to bring those efforts together. So we looked at -- these were the states that had those grants.

The National Technical Assistance Center, the coordinating center for seclusion and restraint alternatives, continues to push out the six core strategies which is the intervention that many of the states have used as well as individual treatment facilities have used to reduce and prevent seclusion and restraint. That strategy really looks at de-escalation, crisis plans, identifying triggers, changing organizational cultures, reducing coercive care and also looking at some other models like the sanctuary model, the restorative relationship or reconnecting models that are really very much patient- and client-focused models to look at a very different type of interventions in these facilities. We also developed with -- by consumer groups developed a roadmap training curriculum from the eyes of consumers and people who are in recovery from various mental health issues. Put together a curriculum that is consumer- and family-focused for really how best to identify triggers, involve consumers in advocacy positions in programs, in facilities, in the planning to be advocates and navigators for clients in these facilities. They also developed a training video on seclusion and restraint alternatives. We fund the National Disability Rights Network -- you'll hear from Curt later -- to do some of the TA to the protection and advocacy agencies around specifically their seclusion and restraint investigations in states. We also fund a National Center for Trauma-Informed Care which is working with organizations, facilities to implement non-coercive patient- and client-centered trauma-informed treatment and sort of whole-scale cultural change in organizational treatment settings.

This is a sample intervention. These are the six core strategies. They focused on leadership for organizational change, rigorous debriefing following any seclusion and restraint incidents, use of data. The data piece is very critical, it was really teaching facilities how to define and track and monitor their data and then to use their data in terms of their organizational change process. This data piece was very, very critical because it also allowed a director of a facility or a director of a unit to see how frequently clients were being restrained or secluded. And they could also see at what times of the day, what times in a facility, is it usually around transitions, is it the movement to lunch, is it the movement when a person is returning -- is getting ready to go on leave or getting to go for a home visit. They could better understand what were the triggers both environmentally in their facilities as well as the particular personal triggers for any individual and client. So understanding that data really helped client treatment planners as well as directors of different units to better understand how can we prevent this by understanding what's going on and what the data is telling us.

Workforce development is a key piece, training, and this is where we have actually not reached internally within HHS movement on some of our regulations because of the training pieces. We get tremendous turnover in many of our mental health facilities, in home and community-based as well as state facilities, larger inpatient, so we feel very strongly at SAMHSA that we need a standard for training and a regular periodicity of training, that we can't have regulations that say "and training will occur on a regular basis." We want to know what that regular basis means. The use of seclusion and restraint prevention tools, we're calling these prevention now, crisis plans for a unit, individualized crisis plans. Better knowing, you know, we have had horrendous stories of young people who have been sexually abused and they have real difficulty at night, you know, have difficulty going to sleep at night. We've seen facilities where because of their difficulties and their behavior issues around going to sleep they're put in seclusion rooms and locked. So if you think about someone who's been sexually molested who's now in a locked seclusion room in the dark, you know, if you think about that as a re-traumatizing, and that's certainly not therapeutic for an individual who's already dealing with trauma. So really understanding the triggers.

We have had a number of facilities that have changed seclusion rooms, and if you look at some of these seclusion rooms in some of these older facilities they are -- they look like -- they're huge, bolted metal doors with big locks that slide across and you hear that click, very much as you're going into a jail or a prison. These are not, you know, nice, comfortable hospital bedrooms you're going into. So in a number of our facilities we actually changed those into comfort rooms or sensory rooms where the whole environment is changed and there's, depending -- we know that people have different areas in which they can do self-comforting and self-regulation related to then that ability to self-comfort. So looked at multiple types of comfort, whether it's music, whether it's soft toys, whether it's comfortable, safe couches, but facilities have been very creative in changing over these harsh seclusion rooms into now comfort rooms. And that clients can also have their own comfort packages that they decide what supports them when they're going to feel a triggering coming on and what can they actually put in their own comfort package which are packages they actually carry around with them. So there's a real -- lots of very innovative strategies to prevent and identify triggers, and prevent needs for conflict that occur that lead to seclusion and restraint.

And very much a part of this is the full inclusion of consumers and families in this effort.

So results we find, and we have -- we've developed a set of issue briefs that are just sort of very quickly looking at some of these policies and looking at some of the findings. So we find that facilities can successfully implement these interventions such as the six core strategies. It results in significant reduction in use of seclusion and restraint to the point of some facilities have actually eliminated it. It's no longer a part of their organizational culture and it's reduced conflict in treatment settings. I'm going to go skip over that.

You heard a lot about the regulations from Ellen related to the Children's Health Act. We are still stuck on some of these regulations. When Lee and others ask well, what can this group do, you can get some of these unstuck. We are stuck internally around Part I which is the regulation for non-medical children's residential settings. We're stuck in what facilities that actually covers, we're not sure if that covers school educational facilities as well or alternative school facilities. We have -- there's something around SAMHSA implementing that. We have no budget for implementing this. We are stuck in terms of a number of things, in terms of the degree, the time for regular monitoring, who should be doing the monitoring. We have a lot of challenges around the training for -- that relates to this particular Part I of the Children's Health Act. So this is a reg that has been stuck in the department for years. We're not even talking one year, several months, we're talking multiple years. I think we're in a very different position of working with CMS around some of this work now too so I think it'd be something that would be really might be useful to bring to the Secretary's attention, that we have a reg that's been stuck in the department for years now, and to then bring us all back to the table to really look at where we have come since 2006, you know, in terms of what we've learned about this and what should go into a regulation for looking at -- and this really addresses some of what was saying -- some of the home and community-based services and the children's community residential settings. So that's a real concrete recommendation I could put out to this work group. We're looking at data elements in terms of our survey studies. We want to know do institutions, do different facilities have a policy around seclusion and restraint, do they have a policy to reduce the use of that.

Making the business case, we're really trying to look at this on multiple strategies. What is the organizational cost? If you look at staff time for managing seclusion and restraint procedures. We had one study that did a time motion task analysis and found that one hour restraint involved 25 different activities, claimed approximately 12 hours of staff time to manage and process the whole event, from paperwork processing to debriefing to staff debriefing to being in contact with the families. We looked at restraint claims about 23 percent of staff time, 50 percent of nursing resources to just manage seclusion restraint. If you think about opportunity cost or opportunities lost that's time that could be going towards treatment, it's time that treatment is not being provided. If you look at client injuries, liability and legal costs as well as staff injuries, workforce compensation issues, turnover, absenteeism, workforce instability and dissatisfaction, where we've actually been able to reduce or eliminate the use of seclusion and restraint in treatment settings we actually see an increase in work staff satisfaction. So that if they're not having to do these coercive treatments, coercive interventions or practices, we actually find that they have more greater job satisfaction.

Client consumer costs, serious consumer costs. Death we see coming from restraint. From seclusions that are not monitored properly we also see deaths. Tremendous range of physical injuries, trauma, re-traumatizing, disruption of therapeutic relationships, then an ongoing mistrust of the caregivers who are there to actually provide care and treatment and support the individuals. And the lost time for quality care and treatment.

Benefits associated with, we see fewer injuries. We see actually shorter lengths of stay in treatment facilities, decreased rehospitalizations, less use of medications and higher levels of functioning at time of discharge. So there are real clear benefits that we need to better articulate and get out to people who are still not sure if this should be part of a treatment modality.

Our challenges are we still have tremendous data challenges. We have challenges with the uptake of effective approaches reducing and eliminating seclusion and restraint. For children we're getting now a proliferation of unlicensed, un-regulated residential treatment centers that kind of move, float around across state boundaries and tend to use very coercive techniques. We have the challenge of expanding this into schools where actually more mental health services are funded in schools than in the mental health specialty service sector for kids, and look at working with our Federal partners. We need more coordination with CMS around some of the regulatory actions and strengthen the linkage with our trauma-informed care approaches.

We have recent briefs that have come out last year around our national strategy, another one on some of the findings from the two cohorts of grant programs that were used to reduce the use of seclusion and restraint, and a recent document, a brief and a monograph on making the business case. And we also have very compelling stories from families who are willing to share their stories who have lost children to the use of restraint in facilities they thought were designed to take care of their children and to work on healing processes for their children.

We are in, as Alexa mentioned, we are in working with them around a guidance document around looking at seclusion and restraint in schools. We are working with them on some of the guidance principles. We're -- I think it's really good that we're in discussions around that now. We want to see that go out. It's a little -- it's challenging for us as SAMHSA because we're a Substance Abuse Mental Health Services Agency. Schools are not our direct lane, it's not where we have authority, but in fact it's where most of our children are on a regular basis. We strongly support the PBIS approach but we also feel that there's a very critical role for schools to play in looking at what we've been able to do in the mental health treatment setting. Some of those interventions have been used in school settings and we would like to really be in a dialogue with the Education Department around how we can better transfer some of those practices we've seen that have been successful in mental health treatment facilities move to schools.

I think that's it. These are just screenshots of some of the briefs that have come out. We have one, two, making the business case four because we are still working on three, the one that addresses seclusion and restraint in schools. Okay, that's it for me.

Ms. Blackwell: Wow, thank you, Larke. That was great.

Dr. Huang: I want to say that

what you have in my handout is not the final version of my slides so this is a more updated version.

Ms. Blackwell: Well, I hope everyone will -- I know that Susan will put some of this information up on the IACC website.

Dr. Daniels: Yes Ellen, a lot of it already is up on the website. On the Meetings and Events page if you click on Meeting Materials many of the items that Alexa mentioned, that Larke mentioned, that Ellen mentioned are already up and we will add some of these. This issue brief is one of the items that's up on the website now.

Ms. Blackwell: Okay. Questions from people in the room? Lyn?

Ms. Redwood: Yes, Larke, I just want to thank you for such a wonderful presentation. I sat here writing notes and I'd write down a question and the next slide you would answer it. So it was just a really detailed presentation. I did want to mention that some of the slides in here, especially on making the business case are missing, but I assume those are in the links that you just showed in the last slide.

Dr. Huang: You can actually get the issue brief and we have it in a monograph as well as in a four-pager. We wanted to make these easy use for policymakers too. So yes, you can get them on the link there, you can just download them. They're all available.

Ms. Redwood: That's great. And I really appreciate the perspective that this can be completely prevented. And I think there is somewhat of a disconnect between your agency and then what we were hearing from the Department of Education that it cannot be completely prevented. So I hope that this afternoon we have time to have discussion around that. But one of the questions that I had was the percent of children -- you made the comment that this is where our children are. So I'm just curious what percent of the ASD, of the population that you're serving actually have a ASD diagnosis?

Dr. Huang: The population that we serve in our major children's grant program is probably about 5 percent and that's a very small percentage of that Children's Mental Health Initiative. And I think it's because the way the legislation is written around that, it's children, it's focused on children with serious emotional disorders. Now, in our block grant program there -- and we don't necessarily track that. And so I can't tell you the specific percentage in all that we fund that are children or adults with ASD. That's not a specified population for us in our -- so if they are children or youth that also have emotional, behavioral or addiction disorders then they'll come into our purview as well. But -- and I guess that's why, given the public health crisis around this and the high percentage, and that they are going to be showing up more and more in our treatment facilities and in schools, and that's why I think this safety issue is really critical.

Dr. Strickland: Larke, thank you. Wonderful, wonderful presentation. I was surprised I guess to see the percent of children under 12, 12 and under, restrained and secluded. I thought it wouldn't be so high. I would have thought that 13 to 17, that percentage would be higher. Any insight into why younger children would -- higher percentages of younger children would be restrained and secluded?

Dr. Huang: You know, that data is always very interesting to me. I -- I don't know why. We -- and I don't know, you know, I don't know what kinds of facilities. We don't have the numbers on those either. We don't know if adolescents might be more in some of the home and community-based or residential treatment facilities or if the adolescents are going to be restrained. I mean, one of the problems with the mental health system is we're kind of a poorly funded system so many of our youth are being diverted into other sectors like child welfare, foster care, and very sadly, juvenile justice. So that oftentimes there is more funding in states for treatment in juvenile justice than there is in the mental health specialty sector. So it might be the nature of the population that we're actually getting in our treatment facilities versus justice-supported facilities too. So we see a lot of services for mental health actually funded in child welfare and juvenile justice and education than in this much smaller funded specialty. And if you think about the state funding, state funding, the big items in state funding are schools and corrections. So we're always vying for part of that piece of the state budget.

Ms. Lewis: I'd actually like to add a thought to that, however. When we looked at the anecdotal data that we do have in the schools, the prevalence was much, much higher among the younger children regardless of the placement issue. And a couple of the researchers -- this actually was a question that came up when we had the hearing -- espoused the theory that some of that is really related to a teacher and aide in the school settings willingness to intervene physically when the child is smaller, and that the data that we have, which is very limited indicates that this again in the educational context, the vast majority of the children that were restrained were actually between the ages, shockingly, of three and nine. And so it is -- it goes back to my initial comment about the cultural piece.

Dr. Strickland: Did that hold true for seclusion as well? Because here it seems to be very high for seclusion of younger children.

Ms. Lewis: Yes.

Dr. Huang: These are not

education. This is not schools -- what I showed you is not school data.

Dr. Strickland: Right, I understand that. But I'm -- well, not to belabor --

Ms. Lewis: Yes, we were -- we were all surprised by that. And the -- but yes, the utilization of physical interventions was much higher with the younger kids.

Dr. Rice: A follow-up question. This is Cathy. So, Larke, you mentioned those data were from inpatient facilities, is that correct? Hospitals? And you said they were required to report. So under what authority are they required to report and would it be a possible recommendation of this committee to suggest more specificity in that requirement of reporting?

Dr. Huang: That's Joint Commission on Accreditation of Hospitals. They are required to report under JCAHO.

Ms. McKee: I was shocked too by

the age group of the kids being restrained. And it struck me in all this that there might be another partner that we might be talking to and we have SAMHSA and we have the Department of Education, but a lot of parents have BCBA people running their home behavioral interventions, and they're the ones who are going to be putting the language into the IEP documents and the behavioral interventions that they're utilizing in their homes. And I don't know if maybe that community voice should be heard as well, if their recommendations would be different. I don't know if this training video is available and if there would be a perspective. I don't know of any BCBA who would ever recommend seclusion and restraint, but certainly they have behavioral interventions and they're advising parents what to do in the homes, so.

Dr. Huang: Yes, all those resources are available on the website and if there's questions they can always kind of contact us and we can, you know, maybe set up a training around it or something as well. But we do think of -- as families, parents, as the really critical part of the planning process for this too.

Mr. Grossman: And that's another good parking space question for this afternoon. You can ask Bob Putnam about that who'll be talking -- who is BCBA and is talking about PBIS.

Ms. Redwood: Larke, are you also seeing an increase in the number of young children being served through your programs? I know that you broke it out by client hours, but I'm just curious if since say 2003 or so, or early 2000s you've seen an uptick also in children with other mental health disorders being served?

Dr. Huang: Actually we have. We have more. And the way we provide services is often through grants or block grants. So we put out an RFA, I'm thinking particularly of our Children's Mental Health Initiative and we're seeing more applications coming in that are focusing on young children, on early childhood pieces.

Now, I think there is also -- there's also a little bit of an increased focus I think in our department around young children. So I think in the Affordable Care Act there is some major provisions around home visiting. I think the Early Learning Challenge Fund which is with us and Department of Education was cited in there and now I think has funding. So I think there is generally increased recognition that children, young children, young children and their families, if you can intervene earlier that they may have better trajectories developmentally. So we are seeing an increase in the focus on young children.

We have some flexibility in designing our grant program. Sometimes we get real specificity from a legislator around what we should focus on. We've often seen a little bit more around a focus on young children. So we have a grant program that is specifically focused on birth to 8, children.

Ms. Lewis: I guess I would just add that ACF, the Administration on Children and Families, has also been working with the Department of Education on looking at mental health and behavioral support and wraparound issues through -- from starting in early childhood all the way up through high school, and the implications in terms of academic performance. Because what we know and I think Alexa kind of touched on this a little bit, but all of these issues actually have a fairly significant correlation in terms of in children's outcomes and school in terms of the educational component. And so there have been multiple conversations at multiple levels across ACF, the early childhood folks at Department of Ed as well as the Office of Special Education and the elementary and secondary education folks around how do we look at this more holistically for these students at risk.

Ms. Blackwell: Does anyone on the phone have questions for Larke or comments?

Dr. Koroshetz: Yes, this is Dr. Koroshetz. Can you hear me?

Ms. Blackwell: Go ahead.

Dr. Koroshetz: Can you hear me?

Ms. Blackwell: Yes, we can hear you.

Dr. Koroshetz: Oh, okay. Yes, I was wondering just from some work that I've done in institutions with people who have difficulty with control and sometimes violence that the reporting requirement led many institutions to basically start to cull out people who were, you know, the most problematic. And so I'm wondering if anyone's been tracking whether or not an access problem has developed over the same time period, or maybe more in the beginning when new reporting requirements were instituted. Did that lead institutions to kind of stop taking the most difficult cases?

Dr. Huang: I don't know of anybody that's really tracked that and the data that I presented there are from state facilities. They don't get to pick necessarily who they treat or can't treat, don't want to treat. Now it might be a different -- it might be a different picture in private facilities, but I didn't present that data. But I do want to say that in terms of the facilities, including correctional facilities, and forensic facilities with mental health patients on there, that they have done amazing, remarkable things to really change the culture around really coercive practices. So, and I'd be happy to give you examples of that or we have sort of a community practice, a group of directors who continue to sort of work as a community practice to reinforce each other and also to work with other agency or facility directors to kind of move these practices forward. So it's just remarkable I think how you can really change a culture of an organization so that you really don't have to use these really injurious, non-therapeutic practices.

Dr. Koroshetz: No, I agree. In my experience that was also the case and the professionals I think realized that the new system was much more effective and people felt more comfortable with it. It was more the administrators of the institutions that became nervous with the reporting requirements. So I think that somehow, you know, changing the culture, unfortunately it's not just the caregivers but it's -- at least in the private facilities it's the people who are making decisions about the finances and the -- and their culpability also that have to kind of be educated.

Dr. Huang: That's why we did the business case monograph. We thought that would really appeal to some of the --

Dr. Koroshetz: Yes.

Dr. Huang: -- people in decision-making. I just also want to say I am really sorry I can't be here this afternoon. So if there are other questions that come up, you know, I'd be happy to be in touch with people or you know, have another dialogue.

Ms. Blackwell: Thank you, Larke. So this is our lunch break and we have had such a stimulating discussion that we are about 45 minutes late. What we're going to be doing for this is we will have all the IACC members please go downstairs and place a lunch order and we will have to have the lunch delivered to you here in order for you to be able to eat lunch during the presentations for the afternoon session because we need to stay on time and start at 1 o'clock. So I'd like for you all to do that and then bring your lunch back here so that we can make sure that we start on time with our next presentation.

Thanks so much.

(Whereupon, the subcommittees recessed for lunch at 12:46 p.m. and resumed at 1:19 p.m.)

Ms. Blackwell: Okay, I think we're ready to get started again we have. We have our next speaker and I'm very pleased he can be with us today. Chas Moseley is the associate executive director -- Chas, I can never say this perfectly -- the National Association of State Directors of Developmental Disability Services, NASDDDS. And NASDDDS is essentially the group of state developmental disabilities directors who run a lot of the programs that serve children and adults in this country through state systems. So with that Chas is going to talk with us this afternoon a little bit about that perspective. So thank you, Chas.

Dr. Moseley: Great. Thank you very much. It's great to be here and to have a chance to talk to you all. I want to talk a little bit about seclusion and restraint and this is going to be a very brief look at some of the state DD agencies and practices. Some of the -- let's see -- some of what's going on in the field of adult developmental disability services, not educational services.

First some background. State DD agencies serve people with intellectual and developmental disabilities who have a number of complex and challenging conditions as you all know.

Approximately a million people receiving some type of support nationwide. We've got -- the association in collaboration with our research partners the Human Services Research Institute in 25 states annually conducts the National Core Indicators Performance Measure System. And the data that I'm going to be sharing right now are from valid, reliable samples that are done in those states across the country. And they line up pretty well with the other data sources that are done by Charlie Lakin and Dave Braddock and his crew. Of the about 12,000 people who were reviewed by the Adult Consumer Survey last year in the 2009-2010 year approximately 36 percent had co-occurring developmental disabilities and mental illness, and that number has been pretty consistent over the years. Above 30 generally it kind of goes up and down. We've got one state that has some really high numbers in this area and that kind of brings up the overall average. Approximately 11 percent have diagnoses of autism. That number has also been creeping up and it ranges from about 4 percent in Wyoming to just under 20 percent in New Jersey. About 15 percent have cerebral palsy, about 31 percent seizures or neurological conditions, about 5 percent have TBI and other larger percents, less than 5, have behavioral disorders, communication disorders and a whole number of other co-occurring conditions.

People live in a wide variety of

both specialized and typical homes in the community. The specialized institution facilities numbers are about 20 percent of this sample and that's ICF/MRs. As you know, some of the ICFs are relatively small 4- to 6-bed facilities in the community. Group homes, about 26 percent, apartment programs, around 5, independent homes, around 11 percent, parents' and families' homes are about 27 percent and you can see the rest there with foster care, group home, nursing facilities and others.

The numbers are interesting. We have been watching the data that Charlie Lakin gathers in the residential services and trends and he identifies that about 57 percent of all people with intellectual and developmental disabilities that are receiving publicly financed supports live in the home of a family member. These numbers are a little bit lower than that but they certainly identify kind of a very strong trend of where people are living. And in talking to our members due to budget -- the budgetary situation we actually expect to see a greater proportion of people receiving supports to receive those in the home of a family member.

As far as characteristics go, individual characteristics, about 29 percent, about one-third of the people use non-verbal communication. Fifty-one percent of the people -- now before I mentioned there was around, what, 35 percent of people had co-occurring developmental disabilities and mental illness. It's interesting that about 51 percent of people take medications for mood disorders, anxiety, behavioral disorders, or psychotic disorders. Now, if we drill down a little bit to look at people with autism, the column on the left, Diagnosis of Mental Illness, the group of folks with autism, a fewer number have mental illness, about 30 percent of those folks have mental illness versus about 35 percent of the broader population. But as you can see with the -- what color is that -- yellow bars they consistently receive -- a higher percentage of them receive drugs for a whole range of conditions including mood disorder, anxiety, behavior problems, and psychotic disorder. In fact, people with autism receive about -- excuse me, about twice as many people with autism receive psychotropic medication for behavior problems than do people in the regular DD population that are served by state agencies.

And people with autism as you can see are more prone to self-injury, disruptive behavior and destructive behavior. And as a result they're really more vulnerable to seclusion and restraint and other kinds of approaches that put people at risk for being hurt. Improving supports for people with challenging conditions is a real focus of NASDDDS activities. And I should just sort of step off the queue a little bit to say that it's also a personal concern of mine and the staff at the association. I was telling Sharon over the break when I got my start in this business in the very early '70s, I developed a shelter workshop for a group of folks who were coming out of institutions. And after we got going we put together a timeout room because people were -- well, we had a -- somewhat of a reputation of taking people who were like the most challenging of the groups that came out of the institutions that other agencies wouldn't serve. And so we had a timeout room and we were using it and it got used, and it was getting used more, and every time it was a fight to get somebody to go there because as you might imagine people didn't want to go there. One of the counselors said, you know, we don't need this, let's get rid of it. So I said sure, let's do it because it was creating a mess. We converted it to a library and it was really interesting, from that moment on, from the moment that we took the door -- changed the door, put books in there and chairs it never became an issue. We just -- staff acted differently, the rest of us acted differently and the timeout room was essentially never talked about again and that was a key learning experience for me. It really underscored the fact that when you have that kind of alternative that's around people use it. And when you don't have it people come up with other ways to respond to crises and other issues.

Okay, back to the slides. The association is very concerned about supports to people with coexisting conditions and with challenging conditions. We have regular features in our newsletters, our conferences and symposiums. A couple of years ago we had one focusing on autism. Some of you folks were there. Several of our meetings have addressed very specifically people who present challenging conditions, people who are offenders and have other needs. Our research on state strategies for supporting these folks have covered restrictive procedures, dual diagnosis and challenging behaviors. Because the idea of restrictive procedures and frankly because of the restraint and seclusion things that we're reading about that were going on in the educational system, we wanted to get our members thinking about this area and to become aware that they really needed to examine their own restrictive procedures. We sent out a call to all the 51 state agencies asking if they would send us copies of their policies and procedures and regulations and guidelines and reports on the use of restrictive procedures in their state. And we got a response from all 51 states, it was amazing. I think we send out our queries and we get 35 out of 50, 45 out of 50, but in this case we got all 51. We posted them on our website. There is a clickable map so that if you want to find out what's going on in Arizona or Ohio you can click on that and you'll see a list of that state's policies and procedures, and they're pretty up to date. We've tried to go after them and make sure that states send us new ones when they're there. So if you're interested they're all there and they're all available for review.

The use, reduction, and elimination of restraint and seclusion in services as I mentioned is really a significant concern. And as we have looked into it in more detail I think as a field we're really learning about -- learning to recognize the impact of trauma in the lives of folks with DD. I came to the meeting a little bit later and I know the person from SAMHSA -- I believe she was? -- was talking about trauma-informed care. And we have been reviewing the information from -- that NASMHPD put together. I think it's really good data. And also coming from clinicians working in all of our various member state agencies, over the past, gosh, 15 years or so more and more people have been talking about the fact that what they were seeing in -- while caring for people with dual diagnosis was more akin to post-traumatic stress syndrome than it was to any kind of major mental illness per se. Folks were really traumatized by the kinds of services that they had received and as you can see here, some of the data certainly supports that. More than 90 percent of people with DD will experience sexual abuse in their lifetimes from the ARC. People with DD are 4 to 10 times more likely to be victims of crime than those without DD. Assault is 3 times higher, sexual assault about 11 times higher, robbery about 13 times higher. Over 5 million crimes are committed against people with developmental disabilities each year. You folks know this, I realize that, but I think it's good to kind of come back and revisit that we are working with a very vulnerable group and we really need to figure out ways to structure services, but also ways to get to the staff who provide the minute to minute support to the individuals in our service delivery systems. Because really, protection from abuse and mistreatment, restraint and seclusion, it really comes down to the decisions that are made, many times, by a staff person late in the afternoon, early in the morning, at different times during the day between their personal relationship with the person that they're supporting.

Restraint and seclusion, in the past it was really seen as a therapeutic response. The rationale was that it keeps people receiving support safe, it keeps people, other folks in the sheltered workshop who may be getting hit by someone who's throwing a hammer across the room, safe, it helps people regain control, that there's clinical evidence and knowledge behind it, and it's used only when necessary. Well, I think when you look into this you find out that it's really not true, that it doesn't keep people safe, it does not help people regain control. It's -- the clinical evidence is pretty shaky. In fact, if anything the opposite information is there. And it's frequently used when it is not necessary. It's used as a crutch. Restraint can be a source of trauma and experience. Restraint can re-trigger the experience of trauma and restraint can be part of the original trauma that kind of got the person into that place to begin with. And I know many of you who have worked directly as direct support staff know, the experiences of having worked with somebody who came out of an institution and -- well, I'm beating around the bush. I can tell you of my own experience working with Ernie who came out of an institution and when Ernie got pressed by staff and when he had three or four people around him he would tell us that his mind went right back to that institution and he was fighting for his life. And many people were in that kind of situation, many people had kind of put boundaries around them to protect themselves. And when you're relying on restraint and seclusion as a way to respond to behaviors or a way to treat behaviors you're really making things worse.

Let's see. Restraint has been used for the wrong reasons, failure of other treatment methods, staff convenience and power struggles. A lot of state directors acknowledge the fact that if you're using restraint it's because you have not designed the appropriate positive behavioral support program to enable a person to get around a particular problem, and restraint is really an indication of a failure. There's also a lot of power struggles, as I mentioned, that can happen between individuals and certainly between staff and the people receiving support. Unwanted outcomes including coma, broken bones, bruises, cuts requiring stitches, deaths due to asphyxiation, strangulation, cardiac arrest, blunt trauma and probably as important as any of these is it really undermines the ability to develop the positive relationships that are really necessary to help people that have challenging conditions achieve a full life in the community.

The notion of trauma-informed care has really gained a lot of support in our field. During our last -- the association's last annual meeting we had a couple of presentations from some of the folks at NASMHPD on this and they were rated among the highest that we had ever received. It recognizes the significant amount of trauma that people with ID and DD experience in institutions, in schools, in services and in the community. The personal experience of interpersonal violence including sexual abuse, physical abuse, severe neglect, loss and/or witnessing of violence, terrorism and disasters can really have a very traumatic impact on all of us actually. And that naturally includes verbal and psychological abuse. And for people who have difficulty expressing themselves with language or by other means it can be even more frustrating and even more damaging.

Understanding leads to change. As people began to recognize this they began to realize that they needed to take another look at their current service delivery system and the current rules and regulations for permitting and regulating restraint and seclusion. Most states across the country have instituted programs to really improve the use and understanding of positive behavioral support strategies for the people receiving services. Some states have performed an in-depth review and reassessment of the way they do business and I'll be talking about a couple of those in just a second. And others have done some broad-based systems change to really change the way they look at it, to institute a positive culture and to get everyone in the service delivery system to think differently about the issue.

I'm going to talk about three states briefly, Vermont, Maryland, and Ohio. Vermont I can -- myself, I was the state director in Vermont. I can talk about a little -- a few of the things that we did there in full disclosure here. We closed the state institution in '93 and moved all services out into the community. And as that was happening, in the last year of that process we realized that the statutory framework in the state was designed around the anchor of the institution. The institution had been there since 1915, it had the lights on 24 hours, 7 days a week, it was always there. We realized that if we were going to shift to a community-based service delivery system we need to have a statutory framework that would give people the same confidence, give the legislature the same confidence that somebody was going to be there to respond to the needs of people who are the most vulnerable, the needs of people with intellectual and developmental disabilities. And we looked at the regulations in particular around restraint and there were several of us at the time that wanted to make sure that we didn't have a situation where an out-of-state provider who perhaps was structuring their system around a very tight behavioral framework that engaged in restrictive procedures or aversive stimuli would come into the state, and we wanted to make sure that door was closed. So we put together a series of clear regulations and system expectations around what people would receive that addressed restraints and restriction of rights, prohibits seclusion in any form and prohibits the use of any kind of restraints other than to protect people directly. There was a recognition that sometimes if somebody's coming after you then you might need to do something.

The behavioral support guidelines kind of lay it all out in some very clear detail. It was written with the understanding that the main audience was going to be support staff and at a level that is pretty straightforward. It's on the Vermont DD website, easy to pull down, and I can certainly forward that to you if you're interested. In this case there was not much going on at the time and there wasn't a need to really go out and work with agencies about changing their practices. Basically the state had for years taken a pretty strict role on what staff could do in terms of restraint, and seclusion had been already outlawed.

Maryland. In 2008 Michael Chapman who was the director at the time instituted the Maryland DDA Restraint Elimination Initiative. The goal was to eliminate restraint and they took a number of steps. They established a joint task force with 18 members from government, from provider agencies and advocacy groups and they reviewed the situation and put together a final report that was disseminated in July that provided specific recommendations to the management team of the state with respect to how they should do things differently. The system's change strategy was organized around the six or seven key systems change bullets that Kevin Huckshorn from NASMHPD had put together. They provide a really nice framework I think for looking at this at a systems level. Excuse me.

It begins with leadership towards organizational change, articulating a vision, values and philosophy that expects reduction in restraint and seclusion, developing and implementing a performance-based improvement action plan that people could actually see and measure and look at over the course of time, and holding people accountable to achieving the goals of that plan.

You know, the association, NASDDDS has engaged in a number of different activities with states and one of the ones that we're most excited about and have been kind of impressed ourselves I think about is the State Employment Leadership Network. We now have about 21 states that are engaged in changing the way they offer services to improve employment outcomes. What has come out of that is the important role that leadership plays. It's really clear that unless you have the top people in the agency, and I don't mean only the executive director or the director, you've got to have the key staff. Everybody has got to be out in the field carrying the message, talking about it, looking out for it, bringing it up, and really providing that kind of focused leadership to make the change happen.

The use of data to inform practice. Most state DD agencies I would say across the country are data poor. They do not have the data that they want, they don't have the data that they need. And it makes it very difficult if you don't have a system, an IT system in place to really put things together in a way that allows you to capture the outcomes, to talk about them, to measure them and to go back and check on them over time. Maryland's system put together some data to inform practice and to really look at their performance over time.

Workforce development, treatment environment, creating a treatment environment that is less likely to be coercive or to trigger conflicts and to include intensive staff training and education. A couple of years ago the association did a series of research articles and presentations and group presentations with our members around serving people with dual diagnosis. We had an all-day symposium and brought together the technical experts as well as key administrative tasks to talk about what works and what doesn't work.

And one of the things that people kept coming back to time and time again was the treatment environment. The environment created by the staff. You've got to enable people to develop relationships and have a system that really works that piece of it. You can't expect to get positive outcomes from a strict behavioral approach that does not recognize that people want to be part of their communities, that people want to have friends and that people want to interact with others in their town.

Maryland used restraint prevention tools which included individualized approaches, person-centered approaches, and trauma and risk assessment strategies. And these are kind of the three things that I think stand out among any of the states that are -- all the state I should say that are working to reduce restraint is really focusing on the person, individualized approaches, person-centered supports. And that doesn't mean a quick 20-minute person-centered plan, it really means sitting down with the person and going back to the very beginning and saying what's important to you, what's important for you, what works, what doesn't work, what's a good day, what's a bad day, all of the very specific tools which can lead a conversation around to enabling a person to really talk about their lives.

Full inclusion and self-advocates. As we move forward and whether it's this initiative or whatever initiative we're moving on to, it's really clear that you must include the people who are going to be impacted by that initiative. Self-advocates need to be part of the whole process. Maryland it was in oversight monitoring and peer support. And debriefing activities to analyze every single event that takes place, to not let anything go by but to stop and do an analysis of what caused it and what -- how it could be prevented in the future.

Ohio statewide initiative was

launched by Director John Martin and I'm sorry that John couldn't be here today. He I think is a real light in Ohio and thought about this himself and really came to the conclusion that they really needed to make some change. And they wanted to bring about lasting change in the DD system that wasn't going to be a flash in the pan and go away after a few years, but really to figure out how they could shift their thinking about behavior change away from aversive measures and towards the development and support of good lives, of the lives that any of us would want to live, and to shift away from behavior management to new conversations with people about what they want and what they need, to shift away from focusing exclusively on challenging behavior to a focus on building a culture and practices that support good lives. Rather than going in to the provider agency or the county agency in Ohio and saying here's how you need to do this, you're not doing it right, their approach is to say how can we learn about this together, how can we both figure out how to remediate this problem and figure out a better way to do business. Rather than importing outside experts that are typically 500 miles away that come in and spend two days with you and then leave, we wanted to identify the capacity within their states. And believe me, each state has real centers of capacity. There are those experts in every single state who really get it about how to work with people, the naturals that we all wish that made up all of the support staff. And rather than being directed by the Department of DD really wanted the initiative to be owned by a diverse group of individuals, really by everybody.

The initial focus was on shifting people's belief through training tools and resources, giving people information about how to do it right. They provided an overview of the positive culture initiative and a description of Ohio's positive culture initiative and a write-up of the program is on our website. If you just go and click on Ohio you'll see all the information there.

Gentle teaching. A lot of states have gone back to John McGee's original approach a hundred thousand years ago about gentle teaching and realizing that it is a really good approach, it really sets a stage to do most anything that you want to do. Helping people really understand the dangers of restraint and seclusion because these are very dangerous practices, and to institute an overall program of trauma-informed care. The components of the initiatives are a conveners group that kind of directs the overall state, the overall work. A collaboration with other systems and supporters, local network groups that kind of expand up to regional behavior support committees and statewide behavioral support committees, setting a number of layers where people can really connect at all levels of the system.

The Behavioral Support Advisory Committee was one that advised the department on the directions to head and the strategies to employ. In 2008 they recommended a ban on all prone restraints. 2009 they created a crisis intervention and prevention assessment tool to be used for people in crisis. They developed training curriculum, 2009 and '10 collected data on the use of restraint and seclusion to assess progress towards their positive practices. And in 2011 they're developing currently a guidebook to outline Ohio's approach to a positive culture. And as soon as we get a copy of this we're certainly going to send it out to all of our members and see if we can stick it on our website as well. The state is moving forward in a very positive way. I'm not sure how my time is going.

But some final thoughts. State DD agency directors are really very committed to reducing the use of restraints and seclusion and we're going to be reminding them that if they don't appear to be as committed from whatever we can do from far away by urging them forward, by demonstrating new practices and positive practices. And by the way, if any of you come across something that is new or interesting or innovative by all means shoot me a copy of it. I'm always looking to receive and to share that kind of information. Several other states are implementing programs, but it's really a work in progress and I don't think anyone would say that they're there. That's just, that's kind of our system is a system that has a lot of strengths and still has a lot of weaknesses and something that we have to be very aware of and continue to focus on.

I just wanted to conclude with a quote from Herb Lovett. "I think any approach that enhances a person's sense of values and dignity is worth a lifetime of trying. Behavior change should be seen as a growth rather than a series of defeats and surrenders." And I think so many times we have created systems with the best interests in mind that really created situations where in order for a person to move forward they had to admit defeat, they had to lose face in order to somehow rebuild it down the road. And what we need to do is to figure out ways to enable people to feel good about themselves and good about their growing ability to interact with others in the community. So there it is. Does anyone have any questions?

Ms. Blackwell: Questions in the room first. Anyone? Chas I have a question.

Dr. Moseley: Yes.

Ms. Blackwell: We talked earlier today about the migration over the past 20 years towards community-based settings versus institutional settings and certainly that's something we can all applaud. And you referenced Charlie's work which we've actually had Charlie talk with us. He came in November and referenced the fact that especially as budgets, state budgets shrink, and that's where I'm trying to get with this, more and more people will be living at home longer. So how does the budgetary and fiscal situation impact training which you identified as so important? How are the state DD directors dealing with the training issues and specifically those related to seclusion and restraint in home and community-based services?

Dr. Moseley: In one word, devastating. Training has always been difficult for state agencies to hold in their budget. It's the first thing that state budget officers look for. The second thing is any other non-direct support services. And it frequently gets vacuumed right out of budgets and it has for the past 25 years. Over the past five years as the recession has got larger and then maybe a little bit smaller state agencies have lost significant numbers of staff. One state agency went from having about 14 -- state DD agency went from having about 14 people in their quality assurance program and a program that engaged not only people who would do the compliance piece and come in and talk to folks, but it also had a remediation component that had resources to provide training to providers with poor kids, for adults and for a whole series of other -- in a whole series of other areas. That has now been shrunk to two individuals and you know that the focus in that particular state is no longer on looking to identify areas of need and work towards addressing those areas of need, it's really on compliance. And we are very concerned that states are losing valuable staff in their quality assurance areas as well as valuable staff in their training areas and just don't have the capacity that they had before. And as I mentioned, it's always been a struggle. Some states, a couple have set up separate nonprofit organizations that after they set them up are off on their own and they can kind of work through to push dollars that way to training so it's not in their budget and vulnerable. But for many others it's very difficult to do.

Now I do want to say that the College of Direct Support is providing a lot of work. Several states have contracted with them and the last time I talked to them they were still seeing a lot of participation which is wonderful. I think that that's not enough. I think that especially around restraint and seclusion and people with really challenging conditions there really needs to be a focused effort to train the first-level supervisors so that they really understand what to look for and how to guide their direct support staff and how to help them really conceptualize challenging issues in different ways.

Ms. Blackwell: So it sounds like there might be opportunity even in the private sector to provide that sort of thing, or you know, with the loss of just the state agency staff and what's happening at the ground level.

Dr. Moseley: There's some opportunities but to go more to the dark side, states are cutting provider reimbursement rates by 10-15 percent, and that's pretty standard. We're doing -- in the process of gathering information on our state agency budget-cutting activities across the country. And you know, 10-15 percent or 5-15 percent is pretty normal. What I'm seeing just in what's coming by, I haven't done the analysis yet, but it's going to have an impact.

Ms. Singer: This is Alison. Can I follow up on something that you just said regarding kids with the most challenging behaviors? You know, of course for most individuals I think the policies that you described in your presentation that eliminate the need for restraint make sense, but you really haven't addressed the issue of that small segment of the population of people with autism who have the most challenging behaviors, by which I really mean self-injurious behaviors. And we have some specialized schools and experienced school directors and BCBAs who say that sometimes some form of restraint to protect children from self-injurious behaviors is necessary in order to prevent them from having to be moved to more restrictive environments. So I was hoping that you could speak to that issue a little bit.

Dr. Moseley: Well, most of our members serve adults. Some do serve kids. Personally I would not say that planned restraint is necessary or appropriate or as, in my former life as a counselor and someone who worked directly with folks who had challenging conditions I would feel personally that that was unethical. I would not use that. That's strong, I don't mean to be impugning another professional's focus, but it's just not for me. I've seen it work without restraints, I've seen people make significant changes in their lives and I guess all I can say is what I know and I think there's alternatives.

Ms. Blackwell: Thank you, Chas. Is there anyone else on the phone who has questions for Chas? Okay. Thank you so much. That was great.

Dr. Moseley: Thank you.

Ms. Blackwell: It's really important to hear the perspective of the state developmental disabilities directors in respect to seclusion and restraint.

So I believe our next speaker is Curt Decker. Hi Curt. Thank you so much for coming. Curt has a long history of -- I hate to say a long history of seclusion and restraint but I know that you do, Curt.

(Laughter)

Mr. Decker: Not nearly enough.

I'd like to seclude and restrain a few Federal bureaucrats that --

Ms. Blackwell: I think Curt has been in this --

Ms. Lewis: We would like to do the same.

Ms. Blackwell: He has lived in the seclusion and restraint world for a long time. Curt is with the National Disability Rights Network and again is a national expert on this issue. So I'm so glad that you could join us today and talk a little bit about what's happening in school settings, Curt.

Mr. Decker: Well thank you, and thank you for inviting me. I'm glad to be here. I'm Curt Decker, I'm the executive director of the National Disability Rights Network and that's the membership association of the protection and advocacy programs that are Federally funded from eight different sources of funding from the major -- from the many agencies represented here, funding from the Administration on Developmental Disabilities, Center for Mental Health Services, HRSA, Social Security Administration and the Rehabilitation Services Administration. We're comprehensive, every state and territory, and we provide legally-based advocacy services to anyone with a disability on any issue affected by their disability. And we've been around for 30 years starting out with people with developmental disabilities and over the last 30 years cobbling together this network of different agencies to try to be able to provide the kind of services, legally-based services that we think are so critical to this population.

We have been, as you said, involved in seclusion and restraint for many years, initially in institutions and facilities, especially children's residential facilities, and we were very active back in 2000 with the passage of the Children's Health

Act as a result of the Hartford Courant exposes in Connecticut about what was happening to children in residential facilities. And frankly, when you think about this it's sort of like well yes, that's where it happens, those big congregate facilities that hopefully we are closing slowly. Now these -- all these other children's residential facilities that are away and stuck away and children being sent, you know, thousands of miles under the theory that they can't be served in their own home school and so we kind of, you know, while we work very hard to change that we sort of I think thought that that was sort of the way it worked. And we've worked very closely with Kevin Huckshorn and Joan Gillece and the NASMHPD contract to try to address these issues in institutions. And I think some of the things that were said in the previous speaker is true. They've made some progress in some places.

In the early 2000s we started

getting some anecdotal stories. I remember having a little woman -- a woman with a little girl who was Native American and had Down syndrome who was found to be restrained in a chair at her school on the reservation and we were so horrified and the P&A and the Native American P&A worked on that case. We brought that little girl to our annual meeting and she was in her little Native American costume and we thought you know, my God, this horrible situation. And then we began to get I think more examples popping up and eventually what we did is we pulled together our membership and said who -- what are we seeing here in schools. Because again, this happens in facilities and congregate places, but it probably doesn't happen in schools. And to our shock and dismay almost every single P&A in the country had two, three, fix, six cases, kids who were abused, who were injured and killed in some cases. And I think you all have a copy. And that led to the publication of this report that we did a couple of years ago that tried to pull together our experience. Now again, remember, we are sort of the tip of the iceberg. We're seeing, you know, small numbers of cases compared to the number of children that are in schools, but it was such a large number of cases coming to us. We were pretty confident in releasing this report. Now of course immediately we were attacked by some of the school groups that this was anecdotal. The good news was that Congressman Miller pulled together both a press conference and then a hearing and asked for a GAO study and several months later GAO came back and said not only are they right they didn't get them all. We found more dead kids in schools.

And so the point of the report was to say, you know, we can't think of this as just a problem in institutions and residential facilities, but it's happening in that school down the street from your house and it's happening as an epidemic in this country. And maybe we can talk for a minute about maybe why it's happening, but as a result -- and the good news about -- we don't issue reports very often and I'm not a big report person because I certainly know about the hundreds and hundreds of reports that are sitting on shelves gathering dust. So the point of the report was to get some action. And initially, and I think this is somewhat of a sad story and I hope it's something that you as the IACC can work on is that we got a lot of action right away. We had a meeting at the White House and lots of people came to the White House for a meeting. And then we had the hearing and the GAO study and a bill introduced in the House and it passed. And Sharon Lewis, in another iteration, was very instrumental in all that. And then of course it got to the Senate and basically has ran into lots of problems and died last December at the end of the last session and so we have nothing as a result. And it also raises some interesting issues about how we as a disability community try to come together to try to move an agenda forward. And you know, I think there's a lot of disagreement right now about -- I think we got caught up, is the perfect the enemy of the good, and as a result have now nothing at a Federal level.

We also have very little at the Federal administrative agency level. I know you had Larke here earlier and you had Alexa, but frankly I think nothing has happened since those initial meetings. We took those wonderful principles that Kevin and Joan created for institutional settings on how to reduce seclusion and restraint and Larke funded a small project. We put together what we thought was a pretty simple little thing saying gee, if it worked over here let's change it a little bit and make it, put it in the education language and maybe this will be a guide to education people about how they can restrain seclusion and restraint. And so we put that together and we sent it over. It was a guide. And then it went over to the Department of Education General Counsel where it has sat for two years because it had a policy recommendation in it, God forbid. And so despite my constant phone calls to the White House, to the Department of Education, to SAMHSA to get this little stinky recommendation out that might help a few, you know, education folks think about how to deal, how to change the behavior in their schools we cannot get out of this administration and I think it is outrageous. We then even went back and said okay, we can't get it out of here, we'll go back and we'll take all of Secretary Duncan's statements about this and we'll compare them to our report, and lo and behold, about 90 percent of the things we were recommending he had said in some other iteration. So what's the big deal about being able to get this report. So I guess my point being is that if we can't get this out under this administration, a simple six principles of how to change the behavior at a school, what are we really doing about this epidemic? The White House seems to be very concerned about bullying as am I and they've had an all-day conference on bullying and it's a serious problem with children being injured, and I think it's part of the whole concept of how are we making schools safe for kids with disabilities because the kid I brought to that bullying conference was a kid with cerebral palsy who was bullied by virtue of his disability and so it's all related. But we can't just treat these things, you know, in little pockets but we have to have some kind of a comprehensive approach.

In our report we recommended several things. I mean, we first of all have to have notification of parents. Parents don't even know this is happening. What we found out were parents were telling us, especially with kids who were non-verbal and so are many of these kids -- and by the way, the vast majority of our cases were children with autism -- that they just knew that their kid didn't want to go to school anymore but they couldn't tell why. And it wasn't until they found out that their child had been restrained 60, 70, 80 times over the course of the year and that's why they didn't want to go to school. So we need to have notification of parents. We have to have data, I agree with data, and when we've had a little bit of data -- I think Providence, Rhode Island actually requires reporting of incidences of seclusion and restraint in their schools -- we get like 300 examples of this happening. So when we require the data and we can actually get it we actually can document that this is a serious, serious problem.

We need to try to ban it but that is very politically hard to do. And you know, as soon as you try to ban prone restraint you get like the comment on the phone about oh my God, what's going to happen to the staff, how are we going to be able to handle these difficult children. Now remember, these difficult children, the one on the cover of our report, she was blowing bubbles in her milk in the school and the teacher sat on her and killed her. So I don't think that was a behavior that couldn't have been addressed in some other way. But just to know that that I think is an excuse that a lot of administrators use, that these are such seriously dangerous children that we've got to be able to use these techniques. And what we've gotten in a couple of places of course is you cannot use banning seclusion and restraint, except. Well, as soon as you have an "except" then you've allowed it and then of course it's left to every, you know, all the myriad of people in those schools around the country defining what "except" is. So it is a tough issue to deal with in terms of trying to ban it. And then of course we have tried to be positive in saying that we really do have to provide support and training and education to the teachers and I would, Chas, you said a lot of things about the staff. I feel this is serious about leadership and the principal and the entire setup in the school. Because we know in special ed especially that there's a divine right of principals. So principals really need to be able to suspend and expel children. They have to do it, it's in their genetic makeup. And when you try to stop that through using IDEA to say gee, this child -- it's not the child's fault that they're acting out, it's the system and the program that is the fault, you know, you cannot expel that kid for it and they'd go berserk. So there is a constant tension I think in those schools about, you know, the fact that they want to have the ability to control their school environment and so seclusion and restraint become one of these aspects. And it's not seen as you said, Chas, about how dangerous it is. You know, as I sat in that hearing that Congressman Miller had and the mother whose child was killed, sat on, crushed that day, and it was horrible and people were crying, but I couldn't help thinking about the other 30 kids in the classroom. I mean, can you imagine, you know, hi dear, what did you do in school today? Oh, they killed Johnny who was sitting next to me in my classroom. So this idea that it's not only the child that's being injured or killed, it's all the other kids in the school who are being affected by this kind of -- and talking about post-traumatic stress syndrome, I think we've got lots and lots of kids in those schools who may not even have disabilities, you know, experiencing this kind of behavior in what is supposed to be a safe setting.

Again, you know, it's great that people are concerned, it's great that people are talking about this, but what are we doing about it? We haven't got the regs yet out of the 2000 Children's Health Act, seclusion and restraint in facilities. It's 2011 and we still haven't seen those regulations. So you can imagine what's going to happen if we try to get something out on seclusion and restraint in schools. So we've got to, I think, pretty quickly move beyond concern and talking and recommendations. And my challenge to Alexa who's not here has been where is the Department of Education, where is OSERS' policy, where is the summit, you know, where is the meeting to come out with saying this is behavior that we are not going to tolerate in our schools. We're left in the P&A system to be slogging around every single individual school. My North Carolina program has managed to get it banned in three counties in North Carolina. My Texas P&A has 1,200 school districts to deal with. So the fact that if you're going to do it school district by school district, it's going to be a really long haul before we do that. You know, we try to go to the county or city level to try to get this, you know, we might have a little more systemic change. The problem with special education, with OSERS is they say we don't -- we deal with the state education agencies. We have no control over the LEAs, it's only the SEAs, and so we can't tell LEAs what to do. So we need to be thinking about how they can develop some strong policies to the SEAs and then through their monitoring process make sure that the SEAs are making sure this is getting down to the LEAs. The problem is, and frankly and Stuart just asked me this question, I mean forget Federal legislation. It is not going to happen. And if we sit back and think that we'll just get it solved by an act of Congress it will not happen. What we've been told so far is that the House won't even entertain the bill. Congressman Miller reintroduced his bill just the other day. He has 19 cosponsors. He doesn't have Congressman McMorris Rodgers who was one of the original cosponsors because I'm sure the caucus jumped on her fairly quickly for breaking ranks and actually supporting something that was, you know, positive. So Senator Harkin's going to introduce a bill that's not going to have the IEP provision in it which means he won't get any Republican cosponsors which means that bill will die.

Now, the whole IEP issue has gotten very controversial and it's been really problematic. It's been a really divisive issue. I don't know if you know what that is, but there's many of us, many people who believe, and I agree, that the IEP, individual education plan, is a therapeutic document. It should not be a document that contains how you discipline and how you use various seclusion and restraints. The problems is that the only way we'll get a bill out of the Senate is if there is -- they allow to have this in the IEP. Now, my organization struggled with this mightily and we had some pretty nasty knock-down drag-out fights because in some states where they had a couple of -- some state law, they felt that this was really a terrible thing. In the other 45 states where we don't have anything they felt that as bad as it would be to bring the IEP into this kind of a setting at least it gave us a document to work with and there's due process protections for parents under the IEP, and there's attorney's fees that could be gotten. So we might have at least a vehicle to deal with this issue through the IEP. But you know, we never got really to that decision because Senator Dodd, seeing the disagreement in the disability community just threw up his hands and said forget it, I'm not working on this, I'm retiring, goodbye. And so we're pretty much I think at a standstill on Federal legislation, which then brings it back down to the administration level, to the state level and to the local level. And so we're going to have to put our efforts at all those levels and I wish we could see some real activity here at the Federal level. I can't get our little paper out from SAMHSA and Department of Education, it doesn't sound like that's going to -- if we can't do that how are we going to get really strong policy guidance with some enforcement and some teeth. We've got to, as I said, to get past the whole idea of concern. I'm glad people are concerned, I'm glad people are talking but I want to start seeing some real action and some development of policies and procedures and enforcement and follow-up to make sure that this epidemic that's, you know, hurting kids in the name of providing them with an education.

I think, you know, trying to think about why is this happening, you know, what we're being told, again this is anecdotal, so I can't guarantee you, but clearly the pressure on schools to keep kids up to tests and keep everything calm I think is putting a lot of pressure on schools to make sure that the kids who are not sitting quietly in their classrooms be dealt with. We know that some schools are telling parents, as was said earlier, if you don't allow us to do this we'll put the child in a more restrictive setting, so they're basically blackmailing, for lack of a better word to put a fine point on it. You know, coercing parents into accepting these kinds of things rather than something more restrictive or out of town or worse. And so these are the kinds of things that are going on in schools in the name of serving kids with disabilities. So we are working with the Office of Civil Rights at Department of Education. They too have a problem. We discovered that the regional offices, if we file a complaint at the regional office at the Office of Civil Rights there's no review at the national office so we have to -- we get a bad ruling, we have to appeal it so that the people at the Federal --

at the national OCR office get to know that one of their regional people did something that we didn't like. So it's, you know, not very clear, good, comprehensive enforcement system.

We are working, you know, we brought together the director of the Center for Mental Health Services with the director of the Office of Special Education and some people from OSERS to say is there a way we can get -- develop some programs that will really address the issue of safety of kids in schools. And we'll look at seclusion and restraint, we'll look at bullying and we'll try to involve my folks at the local level to be available out there to work with parents and to, you know, push these schools and enforce the few laws that are there but really try to use the IEP process to make sure that these kids are not -- that the program is changed and developed rather than just resorting to the easy way out which they think is seclusion or restraint.

So I'm going to stop there and maybe we could have a couple of questions. I think everyone has a copy of our reports. We're not letting go, we're going to keep pursuing this issue both in schools and in the institutional setting.

Ms. Blackwell: Yes and Curt, the publication you're referring to is also linked on the IACC website for people who aren't here in the room who don't have a printed copy.

Mr. Decker: Great.

Ms. Blackwell: Do we have questions from folks in the room?

Mr. Decker: And there's extra copies for your audience if people in the audience don't have it.

Ms. Blackwell: Oh, great.

Mr. Decker: I know the committee got it but so there's extra ones back out there.

Ms. Blackwell: Thank you. I know

Alison had asked a question earlier. There are some school providers, and I think you alluded to this, that really believe strongly that they should have a way to use these mechanisms. So could you sort of address their argument and your response a little bit, in a little more detail?

Mr. Decker: Well, I think it is similar to what happens in the institutional setting. People think this is the only thing they can do, they think they're protecting staff and of course one of the things I think that the NASMHPD people have done so successfully is show that what you -- you can lower the workman's compensation of your staff. Because someone else -- the staff get hurt when they're using seclusion and restraint techniques. I mean, what I didn't -- what I wanted to mention is the other way we sort of started to get wind of this problem was when we were doing all the work on the institutional side some of the folks who train people on how to use, you know, techniques of seclusion and restraint safely came to us and talked about you know their concern with our position, we wanted to ban seclusion and restraint in institutions. And as the guy was leaving out the door he said, we were talking and we talked about our position, his position, and as he left he said you know, what's interesting, I'm getting a lot of calls from schools. A lot of our training sessions for institutional staff, schools are coming, want to come. And we're like gee, what's that about. And of course five years later we know exactly what that's about because now schools are sending their staff to be trained on how to use seclusion and restraint techniques. So that is not -- doesn't sound good for principals and the leadership in these school systems to be trying to create the positive behavior supports and other techniques that would actually change the environment of the whole school. And frankly if we're successful

I think we'll be able to, through the disability filter, maybe improve conditions for all kids in schools because it's not just kids with disabilities are getting secluded and restrained as well. So I think we have an ability to really make a really major shift in how schools treat kids.

Ms. Lewis: So Curt, you mentioned the issue of the providers and the training. Can you speak a little bit to some of the things that we learned in the process of developing the legislation and the hearing about what we know about the training protocols that are available and how school systems are making their decisions to participate in -- with various providers. And what kinds of standards if any are out there related to training.

Mr. Decker: Well, I don't think there's very much at all in terms of -- I think it's very much left -- it's all recommendations and you know, reports saying gee, you ought to think about this. I don't really, I've not really seen any real strong standards, number one. Number two, what we've been told is that if the principal -- it starts at the top. If the principal adopts, says there's going to be, we're going to use these techniques in our school and it's going to go down through the entire network not only the teachers, but the janitors and the school security people, I mean all of these folks you know because schools use different personnel to restrain. Sometimes it's a janitor, sometimes it's the security officer, sometimes it's the teacher, and if the message goes down that this is not the way we're going to do it we're told that it really makes a major significant change in the attitude in the whole school. But it seems very voluntary. I don't see much in the way of certainly cross-school district. I think there's a lot of autonomy you know that people are given, the autonomy and again, back to this idea that principals have the ability to run their schools as they see fit. And so I think you know we're a long way from standards, we're a long way from any kind of absolute requirement and again, if, you know, just anecdotal but if they have a choice from going PBIS or sending their teachers to a class on how to use restraints I think you get a picture of we haven't changed that many minds yet. So we're going to have -- I mean I do think we have to have these -- some strong statements coming out of the Federal agencies. We recommended some kind of a summit on seclusion and restraint similar to what they did with bullying. Again, I don't want to -- I think that's a very serious issue and probably frankly they're connected. I would think that lots of kids with disabilities who experience bullying then end up acting out which then leads to the need to, you know, do some kind of behavior control or they leave. And you know, I think we have to pay as much attention to this as we do to bullying. I hope that answers your question. Things are -- I'm obviously very unhappy at the state of things and I think it's, you know, people come here today and told you things are good and things are great and people are making all these wonderful changes. Don't believe it. I think it's as bad as it is today as it was two years ago when we did this report because I've seen very little in the way of change.

Ms. Lewis: I was going to say, so I know that you're here to talk about schools but given that you guys also have a significant responsibility in terms of other settings can you talk at all about -- one of the things that has come up and when Ellen ran through kind of where we are in terms of regulatory framework and where we are overall, clearly most of the efforts have been focused upon institutional settings and not home and community-based settings. And so one of the questions that I think some of us are grappling with is how do we begin to address this issue similar to the question that we asked Chas, within the home and community-based context, you know, as soon as we start moving out of the more congregate facilities and you know, and training becomes more and more difficult and staffing becomes more and more difficult. And do you expect -- I mean, I know again we don't have data but based on what you hear from P&As do you anticipate or expect that we have a problem out in other settings, non-institutional settings?

Mr. Decker: Well, absolutely. I think two things are happening. It is great, the Lakin data, to see us downsizing these facilities and moving people into the community, whatever the community is. I see two things happening. Either in order to be able to do that the states are cutting deals with the unions to bring the institutional staff into the community, so the staff that were restraining and secluding you know in institutions are now going to be working in the community, or we're hiring people at such a low wage and untrained that we have people you know, you can make more money at McDonald's than working in a group home. And so you know the whole College of Direct Support people who are trying to get a better wage for group home workers. So we've either had totally untrained people who are inexperienced or people who've experienced using restraint and seclusion as a natural part of their job who are coming into these communities. So I'm very nervous. We've had two major pieces of litigation, one in Illinois that's going to probably close down 6,000 beds over the next several years and then Department of Justice which we worked with closely in Georgia where they're going to downsize huge numbers of DD and MI beds. But what experience does Illinois or Georgia have in developing good quality community programs and what is the monitoring system to make sure that as we move people from those places into smaller places, scattered all over the countryside, that we're going to put these people in a better place? Now obviously I support that litigation but I have no faith that the state of Georgia knows how to develop good quality community programs. And then to the extent that it affects kids in schools as well eventually. So I think it's, you know, we've got to make sure that we just -- I think one of our roles in the P&A system, you know, often lawyers just fight a lawsuit and then walk away. If we win, hey we won, great. I mean, one nice thing about my system is we just don't walk away, we now are going to follow these people into the community and try with our limited resources to make sure there's something in place so that person doesn't just languish in a small institution as opposed to a big institution. And we heard certainly at some of the hearings that Sharon held that parents say my kid lives in the community but no one talked to her, there's no transportation, nothing for her to do. You know, what's so great about this. And she's also now subject to whatever, to people sort of molesting her and you walk across the street. If you're in an institution you don't get hit by a car. If you're in the community you walk across the street you can get hit by a car. So there, you know, we've got to really make sure that it isn't just you know size but actually quality and I think we're a long way from that. Now hopefully you know we're, you know, we're going to be forcing, but you know given the budget cuts I think states do think that they can save money by downsizing these large facilities and there may be some but I'm not comfortable arguing. If they really pay people a good living wage to work in these places, how cheap would they really be. And so, yes. We have a lot of work to do in terms of trying to make sure that we go into the institutions and investigate abuse, we try to go in the community to make sure they're safe there, we try to go in schools. There's a lot to do. Yes, Lee.

Mr. Grossman: Thank you for your excellent presentation. I love your enthusiasm, I love what you're saying because it, as you said, really things haven't changed that much and their recent period even though there's been quite a bit of discussion around this topic. So I'm trying to get a sense of really what needs to be done. We've had some presenters earlier talk about organizational change, cultural change, and seems as though that has to come from the top. In our case dealing with this issue Secretary Duncan has made some very, very profound and pretty important comments regarding restraint and seclusion in support of it and how we need to change. But it doesn't seem like that's enough. Or I'm asking you is that enough, or what else needs to happen to make this change occur? Is it strictly through regulation? Is it strictly through legislation or is it basically enforcement? Or just sending out a team of attorneys out there to start suing all over the place? How do you remedy this?

Mr. Decker: Well, it's all of the above and more. I mean, I -- you know, I'm not going to -- no, unfortunately it won't work. I don't think -- a Federal statute could pass tomorrow and I don't know we'd have a significant change. Regulations based on that Federal statute could come a year from now and I don't know we'd have that change. A direct guidance to the state SEAs saying you need to make this a central part of your oversight of the LEAs, you know, strong regulations at the state level, enforcement from informed parents, you know, it's all of those things have to be together working in synergy or you're not going to get it. You know, you have to have the policy, you have to have the strong law and then you have to have the enforcement because you know, we all know laws are only as good as -- they're not self-enforcing laws. Every law that we've passed on behalf of people with disabilities, IDEA, ADA, if there isn't enforcement it doesn't happen. But you have to have a law, and then you have to have everything in between. So there has to be this multi-layer approach. And I think what the IACC can do, I hope, is to keep pressure on the Federal agencies to do their part of it which is to make sure that there's policy guideline and oversight there. My job is then to get out there and represent individuals and hopefully take those individual cases and try to raise them up to some kind of systemic level. And you know, maybe if Congress changes over the next couple of years we can go back in and get some Federal law. I've got my people at various state legislatures trying to get state law. But we're up against some very, very powerful interests who are quite active, unions, teachers' unions. We have this interesting relationship with unions. At the national level they're very progressive and they're up there with us on ADA and lobbying, et cetera, et cetera, but at the local level they're representing institutional workers, they're representing teachers, they're pushing back on a lot of these kinds of legislative attempts that we're making at the state level because that's where they do their work. And suddenly they're not as friendly to us on these issues. So.

So I mean I know that's -- it really is all of the above. And I think just the P&A system won't do it, just a Federal law won't do it. It's got to be this continuum of things and I think they're out there and there's little pieces here and there but to try to make all of that happen, I really hope there would be some kind of -- you know, I think getting CMS to get their regulations out on seclusion and restraint, you know, to get some action out of OSERS on something. Again, they don't have the legislative backing but they certainly could I think put out some guidance and make this a part of their monitoring system.

The one piece of good news, we finally after 20 years, I've been asking OSEP, the Office of Special Education to call us before they come to the state. You know, I believe for good or ill the P&A does an incredible amount of special education work. That wasn't why we were originally created but it's what has landed in our lap. Something like 60 percent of our DD funds go to special education work. And it could all go to special education work if we didn't stop it. And you know, we've now worked out a deal, we're like come talk to us before your monitoring team comes out. We think we can point you in the right direction to where there are some school districts that we think are particularly bad on a variety of issues so work with us. And they finally, Melody Musgrove, the new OSEP director, said yes. And so the answer is stick around long enough and things you've been working on for 20-25 years sometimes happen. So that's my goal, just keep -- live forever and then I can maybe see some of these things come to fruition.

Ms. Blackwell: Curt, I have a question.

Mr. Decker: That's a good strategy but it may not work.

Ms. Blackwell: I don't know if I want to live forever, but okay. So I heard you mention a couple of times the final CHA reg which is in CMS's court and has been there for a while. But --

Mr. Decker: A decade.

Ms. Blackwell: -- right, about home and community-based services. Is there something else that you think CMS could do with the -- with what's on the books now to strengthen its role in the area of seclusion and restraint in home and community-based settings? I'm curious to hear your thoughts.

Mr. Decker: I mean, while I think obviously the Department of Education has a huge, huge role here. I mean, we are using EPSDT out of CMS you know as a way of providing supports to kids in schools and I'm told a lot of places around the country in the classrooms are aides with individual children with disabilities funded by CMS. And we know that CMS is a huge funder of education services because schools have been clever about how they can bill Medicaid for transportation. So it seems to me they have a major role in schools. Now, I love CMS because they tell me they don't support sheltered employment, they don't do education, yes they do, they do a lot, a bazillion dollars going into all of those things and they can tell me they don't do it but they do. So there really is I think something for CMS to look at. And if nothing else just the cross-walking, couldn't we have some consistent policies about seclusion and restraint, whether it's institutions, residential facilities for children or regular education in schools. Why isn't there a consistent policy about all the things that we've been hearing today about how bad this is, how it doesn't work, it's not necessary, it hurts kids, it hurts other kids, it hurts the workers, and it doesn't accomplish what we want. So it seems to me there ought to be -- there could be some cross CMS-Department of Education work and again, I think SAMHSA has done some really good work. Now, those were demonstration projects, you know, six states you know over a couple of years and they did have really good results but that's six states. How about 50 states and the territories. So I think there's a lot of cross-fertilization that can go between these agencies and should.

Ms. Blackwell: Thank you. Other

questions? Anyone on the phone? Curt, thank you so much.

Mr. Decker: Sure.

Ms. Blackwell: It was really great to hear your perspective and we really appreciate it.

Mr. Decker: I didn't bring slides but I wore a really good suit.

Ms. Blackwell: Well and you brought your report too so let's not forget that. So thanks again. And do we have a break or do we go with our next speaker, Susan? All right, no, we're going to go on with our next speaker who is Bob Putnam. And we've actually heard a lot today about PBIS so I think it'll be wonderful to hear from Bob who actually runs the National Autism Center and is going to talk to us about PBIS. And Bob, thank you so much for coming and we look forward to hearing what you have to say.

Dr. Putnam: Thank you for having me. I'm very excited to be here on behalf of the National Technical Assistance Center for Positive Behavior Interventions and Supports. And I also have a couple of other hats. I work at the May Institute which is a program that serves children with autism and adults as well in schools. My primary job is to provide technical assistance in public schools and agencies serving individuals with challenging behavior and I've done that for too many years, about 30 years at this particular point in time. I also work at National Autism Center which is -- which under Susan Wilczynski's direction has completed an exhaustive study of looking at what works in the area of autism. Looked at 850 articles, manuscripts, coded them for evidence so that we really know what works in terms of that. I'm also here because I have three cousins who have children with autism as well so that it's not only something I deal with on a daily basis but I experience that as well having family members.

So I want to really thank Rob Horner and George Sugai who are the co-directors of the Technical Assistance Center. And probably some of the things I've learned from George and Rob is really how do we do this on a scaled-up basis. We're now in about 14,000 schools across 44 states doing school-wide PBS and it's just not saying that. There's treatment integrity data that supports that, so that how do you really do this so it's not an experimental study done here and there, that it's really scaling it up in terms of that and I'll go over some of the data that we have.

So what I was asked to do today is really talk about what school-wide positive behavior supports is. So it's really a systems approach we're looking at in terms of how do we work with districts, states, schools in terms of implementing evidence-based systems. And really the focus is on proactive and preventative. What can we do in terms of developing proactive and preventative interventions. How do we go about in terms of when we're working with students with autism, they have significant communication deficits. What are the strategies we can do to improve communication because oftentimes communication is linked to behavior and how do we develop competencies along those lines. How do we look at in terms of how to come up with acknowledgment systems that really work in terms of teaching those skills and really building fluency in terms of those skills so that we can look at in terms of minimizing problem behavior across all kids. So the school-wide PBS has been adopted in high schools and in middle schools and in preschools and in juvenile justice facilities, in mental health facilities, so it's pretty -- it's a system along those lines that's pretty comprehensive. And the data we have shows that schools that do implement school-wide PBS with integrity also improve academic scores as well because one of our goals is to have more kids in class and on task, and if they are then the reality is they're going to pick up more academic skills as well.

So it's not a specific curriculum, because people say well can you give us the book and there isn't necessarily a book. We have a process that we go through in terms of developing a school-wide positive behavior support plan and that our main goal is to have schools really select scientifically based interventions that they can apply that they look at in terms of what are the issues in their school and select the most appropriate interventions. Integrate them with a variety of other interventions they have in school and then successfully implement them. Because oftentimes what we see is schools adopt initiatives and they don't implement them with good treatment integrity so that this is what you're supposed to do and you can actually go in and see that they're actually doing that.

And so it's really a system again that we're looking at.

And we're looking at four integrated elements when we look at school-wide positive behavior support. We're looking at socially valued outcomes. So if we're looking at in terms of students with autism we would love to see students included with general ed students in the public schools. We would like to have them taught self-advocacy so that they're able to advocate for themselves, to be able to communicate effectively and that at the end of their educational experience get a good job, right? That's what we would really -- and that we would want to look at ways that we could actually measure those things and ways that we could track whether we're on the appropriate path. We have as I mentioned the selection of empirically validated and practical practices that schools can use to achieve these socially valid outcomes and that systems support data management, that they support good implementation, that they support good training with staff so that we really have good treatment integrity and that we have data that we can use to really look at in terms of are we progressing as a whole school in the right direction, are we progressing on an individual basis with students in terms of that direction.

So our goal really is that in multi-tiered prevention logic that we're really looking at it is in a school universal interventions, that would be one. We've talked about the administrator commitment where when we work with a school we have to have an administrator that's committed to implementing school-wide positive behavior support or it really doesn't work well. And they have to be committed to proactive and preventative discipline. That's what we're looking at, that everyone's interested in terms of doing that. And then we're really looking at in terms of do we have three to five expectations. So if in a school there's problems with aggression, one simple way -- and I'm doing this pretty simply -- would be to have the students taught to keep their hands and feet to themselves, right? That simple way, that we have fluency in terms of students being taught how to basically behave in this school, behave in the cafeteria, behave on the bus, that we really have fluency. And there's active teaching of that, and you can see that active teaching and there's measurement of students for having acquisition in terms of those skills. And then on the other hand there's some acknowledgment, that we have some way to reinforce and acknowledge students who are actually following those roles as a tier one, right? So that's really emphasis on teaching and acknowledging. If we look at tier two which is the next tier down we're looking at more intensive interventions along those lines and then at tier three we're looking at a good, functional behavioral assessment that would lead to a very good behavior support plan. So it's tiered and the more effective we have the interventions at the first tier and the second tier, the less number of students we see that are in tier three, the much more proactive the school is, the much more effective the interventions are at the third level.

So our guiding principle is really to invest first in prevention. We're looking at prevention at an early level, prevention in terms of when you look across the entire school what can we do to prevent problem behaviors from occurring. And we're not really just looking at seclusion and restraint, we're looking at bullying. George Sugai was invited to the White House about a month ago to talk to the White House staff around school-wide PBS and bullying. We're looking at disproportionality in terms of special education, we're really looking at across the board and we're looking at that those behaviors that result in restraint just don't happen overnight and oftentimes there are predictors in terms of what those behaviors or there are precursor behaviors and the reality is we want to be able to make sure that we don't have to use those procedures for safety reasons because basically we've come up with more effective procedures in the beginning. So there's really a lot of emphasis on teaching and we're not just saying this. We asked schools to show us, right? Show us your data, show us your data around treatment integrity. And that way we really clearly want to be identifying those students who need intensive support as early as possible. I have one student at age two, a child with autism that already had three major psychiatric drugs that he was being prescribed because of his challenging behavior. This is age two. The reality is to the extent that we really can develop effective behavior support interventions at age two we're not dealing with the situation going down the line. So our goal is really to look at can we do it early.

And that we have a continuum of interventions across the tier in terms of what we would want to do for early prevention in terms of where a child has more serious behavior problems that we have clearly interventions along those lines just like we would do for academics, right. We would want to look at in terms of tiered interventions. And that there's clear progress monitoring with fidelity. So that we're looking at you know if there's a plan is it implemented with treatment fidelity, if there's a behavior support plan is it implemented with treatment fidelity as well. And that we're looking at does this plan impact upon the academic and social outcomes for these students.

All right, now the reason why I

went all through that is because we really think it makes a difference as we get to this in terms of the use of seclusion and restraint. And we have preliminary data that shows it makes a huge difference along those lines in terms of the use of particularly restraint. We're looking at restraint as a safety issue and the goal would be there's a lot of things we can do not to get to that point in time.

So many people have talked about this this morning, I don't really need to go over in terms of what it is, right. And many people have also indicated that the procedures are prone to misapplication. In some cases you see that as a result students were at more risk by the use of these procedures than they are in terms of what their problem behavior is. That they're selected as a treatment approach and we're, again, suggesting this is really only a safety issue, that they shouldn't be implemented as a treatment approach. And that they're used for behaviors that do not place. I think the previous speaker actually had a situation where it was a minor behavior problem, not a major issue, and they were using restraint. And that you see people that are physically hurt or injured during attempts to conduct. We have research relative to that. And that clearly around the training, if in fact it's going to be used, if people aren't well-trained in terms of the use it puts people at more risk as well.

We also have research that indicates that it actually can serve as a reinforcer, that in fact using these procedures can actually increase the behavior rather than necessarily change the behavior. And probably the biggest thing is it's implemented independent of a comprehensive function-based behavior intervention plan. That it's used -- when you go in and look at it there isn't a good plan that's addressing the particular issues that are either precursors or antecedents in terms of the problem behavior, that it's in some cases jumping right to the restraint.

So what kind of research do we have relative to school-wide positive behavior supports? We've implemented school-wide positive behavior support in 14,000 schools across 44 states. So this is not something that's kind of a little experiment that's put in two or three schools, there's 14,000 schools. And when we say 14,000 schools we're looking at treatment integrity data as well. It's just not they signed up and said gee, we're doing school-wide positive behavior support. And we have a lot of data at this point that indicates reductions in problem behavior across the board, bullying, disruptive, defiance, aggression and also those schools that implement school-wide PBS show improved academic outcomes as compared to those schools that basically do not.

We also have some preliminary data

that indicates that more intensive student behavior support is perceived as more effective when school-wide behavior support is implemented, that that is basically that the intensive behavior support plans are more -- implemented with more integrity and that staff has much more knowledge in terms of why they're doing what they're doing. And that we also have some really evaluation but not experimental data that shows reduction in the number of instances in terms of the use of restraint, the effectiveness of comprehensive interventions and also the maintenance. So let me just give you an example. This is a public middle school, alternative school that serves students with EBD and also with ASD. And we were called in to provide some technical assistance around improving the whole behavioral climate. And one of the things we were really looking at is the number of restraints. So just like I've described we worked with the school around coming up with a school-wide plan that had clear expectations and the staff really actively taught those expectations to fluency, there's a clear reinforcement system in terms of tier one and that we begin to work on some individual interventions. And so you can see this is average of restraints per month which was six and a little -- we extended six for the two years previously and then in the first two years we had a significant reduction in terms of restraints in that particular school. This is the same set of data but on a month-to-month basis. The handout I gave you to the committee, this is updated information along those lines. So you can see in about the last 15 months there was -- 10 of the 15 months there was not a single restraint used. And we're still working around not having those being used. But it's a whole lot easier to work on those few instances than to basically work on all the instances, right, and that's our goal with our tier one interventions, can we reduce that so you have a better chance in terms of working on those more intensive cases.

There was also another study done by George that looked at an alternative school and saw with the implementation 69 percent reduction in physical restraints, 77 percent reduction in seclusion which probably he means timeout rather than seclusion and only one instance of physical restraint was used in the last 40 days of school. One of the things we don't have is a lot of studies like this, experimental studies. One of the things we're doing is really to work when you go through the literature and look at restraint and seclusion and actually look for good empirical studies that are -- we don't have a lot at this particular point in time.

The other thing I'll mention is with schools that use -- we have a study that we did in Massachusetts as you can probably tell from my accent that we looked at districts that used positive behavior supports particularly with the individuals with -- at tier three with intensive problems and looked at the rate of private school use in terms of referring kids. I don't know how much it cost and this school district saved $2 million and had better quality services in their district, more inclusive services. They didn't give the $2 million back, they moved it into inclusive services, to develop more supports along those lines. But what we see basically in terms of from a cost basis rather than a few kids being served that in fact a number of kids could be served more effectively.

So in terms of individual positive behavior supports these are the questions where we're looking at doing a functional behavioral assessment. And to the extent that we really can answer these questions with data gives us a lot better way of looking at in terms of what our planning would be, right. If we can figure out in terms of where does the challenging behavior occur, it occurs in our class, that's where the problem is. If it occurs when they're given a challenging task or in fact there's a transition situation that the individual is not preferable, it occurs after lunch, it occurs with this particular individual and it's because it's an escape-motivated behavior or it's attention, if we can answer these things empirically we have a much better chance in terms of looking at what are our interventions in terms of that. So when we look at a functional behavioral assessment and I've seen some good ones and I've seen some not so hot ones, right. The goal would be we'd really want to look at in terms of does it answer those questions so it gives us really precise information relative to intervention. And that the -- what we would want to do is look at these are sources of information. We like to interview parents. Parents, we think it's a really important source of information in terms of where we're going. Students wherever we can with direct observation and really collection of information relative to that, that really we can precisely come up with a hypothesis and then we can develop much more effective teaching, right, and reinforcement interventions for the individuals that we work with.

This was actually on Alexa's slides as well, this exact, that first statement independently that we came up with. And I do want to thank her because she's been very supportive to our center. And again, our behavioral interventions we're looking at, we're looking at preventative. What we mean constructive is teaching, right? What are we going to teach this person how to handle this particular situation and positive. And that particularly with this -- with challenging behavior that may in fact result in some type of hands-on procedures, that the efficacy and the data that basically we'd want to have would be a lot more intense, right, and provide us a lot more information around the effectiveness and where it's effective, where it's not effective than we would in terms of other challenging behaviors. So from our perspective kind of the more challenging the issue the more information we need to have in order to make really good database decisions.

The behavioral intervention should be adapted to context, whether it's an inner-city school or whether it's a school with Native American students that it really needs to be adapted to that. So when we're designing behavioral school-wide behavior support plans we're sitting down with the whole school and saying how does this work in your school and they help design that plan. And then, and I think everybody's mentioned this over and over again, right? Is how do we train the staff in terms of actually following through with either the school-wide plan or the individual behavior support plan because the plan is only as good as somebody being able to implement that. How do we design those plans such that people can do them and on the other hand is how do we make sure that they actually happen.

So what do we have for research relative to the effectiveness of positive behavior supports? Ted Carr who just passed away a couple of years ago was one of the leaders in our field and several other folks actually did a comprehensive meta-analysis of the efficacy of positive behavior supports for individuals with developmental disabilities, with individuals with autism who engage in aggression, severe self-injurious behavior, those types of behaviors that really would put people at risk for these types of practices. And it was found effective for all those examined problem behaviors really across the wide variety of participants and settings, the effect sizes were large, associated reductions in problem behavior that usually exceeds 80 percent. And most importantly, it was most effective when we had a really good functional behavioral assessment that would lead us to developing those interventions. Also the National Autism Center, the National Standards Project as I mentioned, they reviewed well over 800 manuscripts and looked at in terms of quality of evidence and their well-controlled research came from positive behavior supports, applied behavior analysis and behavior psychology particularly relative to the types of challenging behaviors that we're looking at.

So what do we suggest for policy from our center's perspective? From our perspective the majority problem behaviors that are used to justify, right, knowing -- to justify, right -- could be prevented with early intervention, intensive early intervention. Following along the things that I've suggested relative to the presentation that oftentimes it's really a result of insufficient investment in prevention efforts. What can we do to prevent this problem behavior, how do we figure out a way to develop a more effective behavior support plan that's not just in name only and that the staff are adequately trained on the plan. That I've worked with too many folks where the choices were, you know, this person -- the physician is calling me and saying this person's going to lose their eye unless you do something about it and we're really in a difficult situation. That's a very, very small percentage of the population right, so that the question is that in terms of some type of protective equipment that may be needed in a small number of cases, but there really needs to be some type of intensive formal behavioral assessment that looks at accompanying that so that we can avoid those situations in any way we can.

All right, so in summary that

we're looking at it only as a safety measure in terms of that with those types of problem behaviors that really put people at extreme safety. Within a comprehensive behavior support plan by highly trained personnel with really public -- and I know people have mentioned that families need to be notified with public information, accurate continuous data that would look at, you know, the implementation of the interventions, and both the impact on behavioral outcomes which is increasing desired behavior in communication skills in a lot of cases and decreasing problem behaviors, just not looking at problem behaviors. Questions? I don't know how much time I have.

Ms. Blackwell: Bob, thank you, that was pretty much a wonderful explanation of how PBS can be used to succeed. I have a question. You talked a little bit about the cost savings associated with this sort of model. Could you get into that a little more?

Because as you know, Medicaid and education are fighting it out at the top of state budgets right now, so I think making an argument for PBIS as a cost-effective way of helping people improve in schools and succeed in life is an important discussion.

Dr. Putnam: What we did was we worked in a large urban school district that had 16,000 students and this school district was able to identify to us those students because of challenging behavior that were at risk of leaving the district and going to a much more expensive and restrictive type of facilities. And our goal was really to develop, just as I laid out here, effective behavior support plans such that the students could be maintained in the district, could be maintained in some cases in inclusion settings rather than going to restrictive settings. And what we did was then compare the out-of-district placement costs of this district which happens to be the fourth or fifth largest district in Massachusetts to the other districts that from what we could tell really didn't have that same type of interventions. And it was about 4 percent of their operating budget less than the other large urban district which turned into about $2 million that they were able to save on their out-of-district placements which they could then turn back to serve, you know, more special ed students in the district, they could turn back to serve more general ed students in the district with more comprehensive types of procedures.

So I happen to also work -- my agency runs private schools so that, you know, in some cases we have students that really absolutely need that and other cases with more effective interventions that these individuals could be served in more inclusive settings with typical peers. And from our perspective we think that's very, very important, that the more access we can have to general ed peers with effective interventions the better off because life outcomes are much better for those individuals who can be served in inclusive settings than in segregated settings. So from our perspective the more we can do that the better off in this -- you know, we just happen to see there is cost savings as well because they were able to save money on these more expensive, intensive settings.

Ms. Blackwell: Thank you.

Ms. Redwood: Has that been published?

Dr. Putnam: Yes. It's -- I can give you the references. It's Putnam, Luiselli, Sennett and Malonson, 2002, Journal of Special Education Leadership. I can send you the reference if you want.

Ms. Redwood: That would be great.

Dr. Putnam: Okay.

Dr. Strickland: So along that same line, that was 10 years ago.

Dr. Putnam: Correct.

Dr. Strickland: And any replication? I mean, that's amazing data and even cost savings. It's astounding. I'm just -- I mean, I would expect it would have been replicated.

Dr. Putnam: Well, we've worked in other school systems because that's what we do and we see similar types of situations. I don't have it -- the advantage of what we did is we took the 15 largest urban districts and we had a comparative group whereas if we work in a suburban district it's a little bit hard to be able to have a comparative school district. So that I can tell you without research per se but it works as a strategy in a number of other districts along those lines, yes.

Dr. Strickland: Thank you.

Ms. Lewis: Well, and just to follow up on that. I mean, because I guess I hear what you're saying and I think that's a phenomenal cost savings and I just wonder if when we look at it in the context of the general trend of school districts in many places in the country working hard to create savings related to bringing home out-of-district placements in general, that that cost savings has held true. And unfortunately sometimes with or without the good reinvestment of the funds back in the district. So I would just say to the IACC that I think it's a good point and I would use that information with caution in terms of not -- I think you have to look at it in the broader context of are you a district that has a significant investment in out-of-district placements because I think that it's a great example of what happens and when you can bring those resources home, but we've also seen districts bring everybody home and not reinvest the resources.

Dr. Putnam: Correct.

Ms. Lewis: And just accrue the

cost savings.

Dr. Putnam: No, this was a school district that said look, we want to build our inclusion services stronger and that's how they used their resources in terms of that, and actually built stronger academic curriculum with the resources. So they were a smart district.

Ms. Lewis: I wanted to ask you a different question along the lines of your last slide in the -- the assertion around inclusion of restraint and seclusion in a comprehensive behavior support plan. And while I appreciate the perspective that with a functional behavioral assessment and appropriate supports there may be incidents in which you want to be planful about what happens with restraint especially so that we can avoid situations where you're exacerbating trauma or hurting someone with a medical diagnosis. But I really wonder if you can speak to the evidence base about the inclusion of seclusion in any kind of behavior support plan because it is my understanding is that there is absolutely no evidence base.

Dr. Putnam: Correct. I would not disagree with you around the seclusion. From our perspective it's -- if we're going to use something where somebody's taken away it's timeout which is prescribed for a function of behavior along those lines, but it's not seclusion. And in fact, most of what I've talked about is relative to restraint and not seclusion.

Ms. Lewis: And we lumped these two things together and I think that that's -- it's a really important distinction. And I think that part of the reason, and I don't know if you were here for my original remarks, but part of the distinction I think that we end up in is that -- or the difficulty that we end up in is when seclusion is seen as a behavior management tool we see an increase in restraint. And so we see these two things lumped together. And I just wanted to get clarity on that, so thank you.

Dr. Putnam: That's a great question.

Dr. Strickland: That was my thought exactly and I sort of at the beginning sort of -- I do understand why you would put them together because they're both problematic, but it almost sounds like when we say restraint is okay sometimes that we're also saying seclusion is okay sometimes. And so I think it's sort of a --

Dr. Putnam: I probably should delete from the slides the seclusion and just say, you know, we often call it protective holds rather than restraint in terms of in the programs that I work in. It's really protective holds because it's -- we want to get that across to people that the issue is we're really talking about a protective hold and the only reason we would want to do this is to protect somebody from injury.

Ms. Lewis: And along those lines I want to ask you kind of the same question I asked Curt in terms of your perspective. I mean, so PBIS is a terrific approach and we also know that when you get to tier three and you start talking about very intensive behavior support plans and de-escalation there are some very specialized providers out there who are working in that field with great variability in terms of their approaches and certainly when we looked at it through the investigation with GAO it was something that was of great concern. And I just was wondering within the context of what you guys are doing at PBIS or within your institute whether there has been the opportunity to think about or look at specific standards related to those tier three and high-level intervention supports in terms of the providers and the training. And what advice or perspective would you provide to the school districts who are frequently making the decision about what kind of support to bring in around those trainings. If you could comment on that at all.

Dr. Putnam: Well, in our field in behavioral analysis there's what's called the BCBA, board certified behavioral analysis. Now, I think that's one start along those lines. For some of these more complex individuals you really need to have somebody that has even more skills than that along those lines. And so one is really having a qualified person in terms of designing the interventions and also, really have good progress monitoring information that you can really look at on really a moment-by-moment basis in terms of what's going on, where is this working and where is this not that you can look at. We in the -- for the TA Center have SWIS which is School-wide Information System, SWIS, which is an electronic for schools data information that they can put their referrals to the office in this. And you can go across the schools and say oh gee, where is this happening, and then you can drill down to an individual kid and say where is this happening, under what circumstances, and it really gives you really good, precise information. And I think part of the issue is schools don't have precise information in terms of looking at that. And so part of it is also giving them the information because oftentimes they fill out forms for the state and never see the information come back. SWIS is really designed for the local school folks to be able to go on with two or three clicks of the computer to be able to look at what's going on relative to the whole school, relative to this classroom, relative to the individual student. So one is really building a data system that's transparent if you want in terms of kind of looking at it because the issue is, as I mentioned is how do we get to those behaviors before they get to that severity, right? If it's disruptive behavior, how do we -- how do we work on the disruptive behavior before you're getting to behaviors that put everybody in a safety situation. What are the things we can do to prevent that? How do we work on that first and that behavioral change before it goes down the line? And that's one of the things we've worked hard on was trying to -- again, it's the prevention. How do we figure out -- and people have mentioned it's a failure when we have to engage in restraint. It's from our perspective the same way, it's a failure along those lines and that we have to go back and look at what can we do the next time to make sure we don't have to get in that position. And on the other hand is really coming up with the school culture or the agency culture saying that we're going to do everything we can to make sure we don't have to -- we're not doing this. Like what can we do along those lines and that really has to come from the administrator on down saying that's our direction. But if you go in that direction you also have to give staff tools to use and just say -- it's not a situation where you just say no. We have to give the staff tools to be able to problem-solve, and the consumers the tools as well to be able to problem-solve those situations.

Mr. Grossman: Yes, thank you, Bob. I've got a number of questions. First, let me clarify. When Alexa was talking about her PBIS Technical Assistance Center she never identified it so is that the May institute?

Dr. Putnam: No, we're one of nine organizations as part of -- it's not the May Institute.

Mr. Grossman: Okay.

Dr. Putnam: It's located at the University of Oregon, the University of Connecticut. If you want more information, pbis.org. I would definitely go on that site. The other site I talked about is SWIS, swis.org, which is the data management so you can see what I'm talking about. But that's the site there which is directed by George Sugai and Rob Horner. We're just all helping to support the effort.

Mr. Grossman: Yes, I'm real familiar with George's work and I didn't realize that there was the pbis.org which is a great -- should be a great resource. One of the questions that I did have was regarding what you were saying about for example that the school district that saved $2 million with that. SAMHSA has developed what Larke showed us earlier, this business case. Is that something that either the technical assistance centers are working on or the May Institute is working on? Because that seems like it would be pretty much a no-brainer and extremely helpful to what we're trying to do to reduce seclusion and restraint across the life span.

Dr. Putnam: Yes. I think what we've tried to do is look at what it costs the school to do this. In a lot of cases it's --

we have large states that are doing this and using their state resources to do training and coaching capacity along those lines. Such as Illinois has about I think it's 1,200 schools that it's doing this at this particular point in time. Maryland has I think 600 or 700 schools. And so when you just look at one school separately in terms of doing the training it's more expensive, but when you can have -- train 60-70 schools at one time it really comes down to be much more cost-effective.

One of the projects we have is looking at kind of the economies in terms of what are the outcomes. And we're not there yet in terms of -- in fact this study is probably one of the few studies that really looks at those economies in terms of looking at effective services producing efficient services. Our perspective is that if you have effective services then oftentimes they're efficient. Some cases are not. With some of the students who are very, very challenging, it's expensive no matter what you do, but oftentimes with other services if they're effective then they can be more efficient.

Ms. Blackwell: Any questions from our colleagues on the phone? Oh, I'm sorry, Christine.

Ms. McKee: Ellen doesn't like to look to her left. Okay. I have a question as an ABA parent. We have millions of parents who have ABA programs at home and they send their children to school in supposed ABA programs. And what they're doing in the schools doesn't look anything like ABA. You know, they're not doing differential reinforcement, they're not -- their ITI is too long, all of it. What confidence do you have that you can implement behavioral programs like this in a public school setting? Have you -- have they been receptive to it? Have they held on to the teaching that's been done? It seems like you've broken through a barrier that has not been well broken with the teaching methodologies behind ABA in the public schools.

Dr. Putnam: We've had a lot of success with public schools in terms of that. I mean, I can tell you public schools that haven't necessarily embraced it, but we've had a lot of success and I think it's been also the approach that we've taken, trying to look at in terms of what are the meaningful outcomes in terms of this. I think it also varies state by state. We do a lot of work in Massachusetts which had the first special education law before the Federal law, that we had maximum feasible benefit as our standard while the rest of the nation had free and appropriate education. So that I think is an advantage in terms of that. So I think we just have to keep pushing, that you know, we have to get the evidence out there in terms of what the differences it makes in terms of early intervention, in terms of what difference does it make. And there are some studies out there that have looked at the impact of early intervention on costs going up the line that have said if you invest, you spend less money and it should not come down to money, but the reality is if you invest early you're going to have cost savings in terms of the intensity of the services and the level of services. And probably we need to have more studies along those lines that demonstrate that. It, you know, can be a struggle, I understand that. We've had reasonable success in terms of trying to -- working with school systems.

Ms. Blackwell: Anyone else? Okay, thank you so much.

Dr. Putnam: Thanks for having me.

Ms. Blackwell: So we're going to take a break now. What, 15 minutes, Susan? And then we'll come back and discuss what we heard today. Okay, thanks.

(Whereupon, the subcommittee

members took a brief break starting at 3:13 p.m. and reconvening at 3:36 p.m.)

Ms. Blackwell: Okay, well here we are. This is the second part of our day. This is when we sort of discuss what we heard today which is an enormous amount of information to process from a lot of different quarters. So I don't know. I heard a couple action items but I think that might be the place to start. I mean, I don't even know where to start. Our starting point before we started today was a discussion of whether or not we would send our Secretary who is Secretary Sebelius a letter. I think that's where the Safety Subcommittee started and I don't know how people feel about that. But if our intent is to send a letter then I think we'd have to talk about what the HHS Secretary specifically could do in the area, in this area of seclusion and restraint in terms of the Federal agencies that she has regulatory authority over. So, and also you know, in terms of conversing with other Secretaries who might have authority in this area.

So I'll just -- I guess I'll start because I heard a couple of people make recommendations today. And one thing I heard a couple of times was that some individuals think that CMS should issue a final Children's Health Act regulation because we have had an interim final regulation for many years. So that's one thing that of course Secretary Sebelius could tell CMS and the FACA committee, the IACC, could recommend to the Secretary that she do that. I heard at least one person mention that the bullying conference at the White House was very successful and that perhaps our Secretary could urge convening a meeting of a White House conference that would look at seclusion and restraint and possibly include other agencies like the Department of Justice and the Department of Education and other OPDIVs even of HHS that aren't here today.

I think that Curt brought up something that I brought up this morning that I want to touch back on which is that the agency I work for, CMS, which is regulated by Secretary Sebelius funds a lot of services in schools. And because CMS doesn't look at services necessarily by the place where they originate we don't to my knowledge exactly know how many of our services are coming from school-based providers. However, that is a link at the hip to the Department of Education. So you know, maybe there's a relationship between CMS and OSEP that could be further explored or that we might want to think about what we could do in that arena.

And then lastly I know that I brought up this, that Section 2402 is sitting out there and maybe there's some room there to talk about recommendations that could be made in the area of seclusion and restraint as far as national home and community-based services. So that's what I sort of took away but I certainly could have missed many things. That was a lot of things that happened. So Bonnie, why don't we start with you since you're at the end. Do you have suggestions for what you heard today?

Dr. Strickland: Actually, they were the -- I didn't hear as many -- well now that you say it I heard them all, but I heard several references to the Children's Health Act and partial implementation of what's already there, and could we communicate to the Secretary our support for getting them unstuck as Larke said. I also, I was intrigued by what Curt said as well and wondered if an EPSDT service required that that service be provided within the guidelines established by the existing CMS regulations. And I don't know how you would monitor that, but as you say there might be some way to carve a hook into that.

Ms. Blackwell: Well, maybe. I mean, generally I can explain the way that CMS looks at this. As I said earlier, these are Medicaid services to us that just happen to be delivered in a particular setting. They could be delivered in a home setting or a school setting. So for schools to bill Medicaid we have to ask the same questions we would ask any provider: what are the qualifications of the provider and what is the billing methodology. But we wouldn't necessarily go deeper on the state plan side and we're being billed for a lot of EPSDT services that just fall under the rubric of EPSDT. So we don't always -- unfortunately we don't always know.

Ms. Lewis: And I think that one of the particular challenges when we start talking about the Medicaid in the schools issue is that as many of you may know schools have really struggled with Medicaid billing. It has been a bit of a hot potato issue in part because Medicaid is set up to -- understandably -- bill in a manner that is related to medical systems and coding and processes and procedures. And there has been, you know, a substantial amount of back and forth in terms of the issues related to Medicaid billing in the schools. And I think that the issue of trying to use the hook of Medicaid funding in the schools may be difficult and to some degree EPSDT the same way because it may be too granular for the information -- you know at the school level for that information to be connected in terms of the dots and where the billing is. Not every single school gets Medicaid billing, and that is one of the challenges in terms of addressing the school issue with the current Federal statutory authority. Even if you look at the Children's Health Act and even if you were able to read the current statute as including schools which some will argue that non-medical community-based facilities should include schools, then the difficulty is in the enforcement hook. Because the Children's Health Act applies to entities that are receiving funds under the Public Health Service Act which ends up creating a very piecemeal piece of regulation in terms of who it applies to. So it -- one of the challenges that I know we have heard in all of this in terms of what actually exists is a patchwork quilt when we look at what's happening in the schools. And so I just -- I think that the ideas around thinking about the Children's Health Act reg, I think we heard that pretty loudly and clearly and getting that out there at least to begin to address the community-based settings for children and youth is critical and then creates an opportunity in terms of those entities. And then I think that the fact that the Department of Ed and SAMHSA are working on some guidance to schools is encouraging and you know, to the questions this morning I wonder, you know, how much further that can go. Are there model policies that could be developed? It's not been unheard of. Are there tool kits that could be established for school districts that tie in the concepts of positive behavior support as well as policies and procedures related to seclusion and restraint that might be useful for school systems absent Federal legislation.

Ms. Redwood: Sharon, to follow up on that last comment about absent Federal legislation. I was asking Susan as a FACA committee if we're allowed to support legislation and we can express -- Susan, help me out here -- an opinion that we would support a comprehensive policy that would address these issues, these urgent safety issues of seclusion and restraint. Correct, Susan?

Dr. Daniels: Yes, you could do it as a statement. The Secretary cannot support legislation, but a FACA committee can and can make a statement about that if they wish.

Ms. Redwood: I think we should do that. I think that would be an important step forward and it could be used by some of the advocacy community to try to get a bill introduced in the Senate that addresses this issue and passed this year. Because I see that as being the most comprehensive way to deal with this issue.

Ms. Blackwell: I have a clarifying question, Lyn. Are you saying that we should support the Keeping All Students Safe Act or some other piece of new legislation?

Ms. Redwood: Is that House Bill 1381? Yes. And I guess the discussion we need to have though is over this issue of whether or not it's included in the IEP. You know, ideally I would like to see it not be allowed to be included in the IEP but again, you don't want to, you know, as you say, throw the baby out with the bath water and let the perfect get in the way of something that would be definitely a step forward. So I think that's a discussion we need to have with the committee in terms of -- or we could just avoid that altogether and say we support comprehensive legislation and not get down into that granularity of addressing the IEP.

Dr. Rice: So just to follow up on that, would that be a separate statement by this committee or is that in the letter to the Secretary? So one of my questions is if this is in the letter to the Secretary then that's just out there in the world but nothing that she can do to follow up on it. So should we have a two-prong approach where we're talking about supporting the legislation but then also making a recommendation for a coordinated HHS-level policy. You know, we've got SAMHSA developing guidelines, CMS has worked on this issue, have some coordination among the agencies within HHS at the policy level.

Ms. Redwood: As much as I hate to say this, I think white papers and policy position papers can sometimes be useful so maybe we should consider something that would be very summarized that would come directly from the IACC with all of the supporting evidence that we've heard today to back up why this is our position, that we could put on our website and people could reference.

Dr. Rice: And just to follow up -- this is Cathy, for those on the phone -- you know, maybe even what is the least common denominator type of things that we'd want to see emphasized, whether it's the six core values, or Sharon, in your talk you mentioned some very clear points in terms of what's needed in the general sense that then of course the devil's in the details of how you implement those. But at least to come up with maybe some agreement on some of those guiding principles from this committee would be helpful.

Ms. Blackwell: I think what Lyn said is really important because it piggybacks on what Susan said which is that as a committee we can make recommendations or as our mother committee, not actually our

Services Subcommittee, but HHS can’t support legislation. So the recommendation to support the proposed legislation and in particular the exclusion of such a plan from a child's IEP, that could come from a FACA committee. So maybe that's something that we want to recommend to our mother committee both. I mean, how do people feel around the table today? Should we make both of those recommendations?

Dr. Strickland: I'd like to just make a general comment. It's just for consideration. If -- how much of a balanced message do we communicate to the Secretary? I mean, the role of this committee I know is to advise the committee, it is the -- I mean the Secretary, it is the Secretary's committee. And there's a lot of support for supporting legislation and how it ought to be supported and the way it ought to be implemented. What we haven't really talked a lot about but I imagine that we should is cost. And what's on the other side of that benefit ledger. I can't even believe I'm saying this, but it is -- we are providing a message to the Secretary. And I'm wondering, I guess it's more a question, Susan. Is it the role of the committee to communicate what is right, more the scientific -- well, not even scientific, just what the feeling of the committee members are, or is it -- and/or to present both sides of an argument? I'd love to just say let's do the right thing, but do you understand my dilemma here? I'm a Federal agent, I'm representing the person that votes on behalf of the agency, so it's not really probably pertinent for a lot of people but it would be for the member, the Federal member that votes on this committee for me. It would mean whether we abstain.

Dr. Daniels: You can do either one. You can do recommendations, you could do statements that are not necessarily recommending any particular action but just saying that you are generally in support of something and you could frame more than one side of an issue if you'd like or you could say that you've come to a conclusion based on certain evidence that you've heard, that this is a particular direction. So you really have quite a lot of flexibility.

Dr. Strickland: Well, I heard today I mean certainly some compelling cost-benefit for doing it. But it made me think about we really hadn't heard were there cost issues on the other side. But I do -- I think a white paper one way or the other might be a good idea to help support the -- if it needs support, the recommendation coming from the committee.

Ms. Redwood: I feel as if -- if we sent a letter that says these are the pros, these are the cons, these are the issues, it doesn't get us down the road. It really doesn't move us anywhere. I think everybody is already aware of what the issues are and the pros and cons. I see us as an advisory committee to weigh those issues and come out with a recommendation. But again, I'm not a Federal employee so I'm not restrained in my thinking. I'm a parent advocate and I want to see this stop. And I'm just trying to think of the fastest way to accomplish that without -- and somehow work around the bureaucracy.

Mr. Grossman: I agree with Lyn. And I think that it's just been, from a historical perspective the way that the IACC has operated is that it's a committee that makes decision by consensus and then we move forward on it. The whole strategic plan was developed, not that we had 100 percent agreement on aspects of it, but we had consensus with the definitive plan. And certainly the crisis involved here, the reason why we're here today is based on the feeling from the community that this needs to be addressed. So I think that we should be acting with definitive advice to the

Secretary. And from my standpoint there's a few items that we should be looking forward to, one of which I think is this notion of doing a White House summit. And the reason is is that it became very clear in some of the comments that were made today if we're going to -- if we're going to affect some organization and cultural change along this idea of removing these abhorrent procedures in classrooms and in residential facilities it has to start at the top. We have to have leadership that are speaking loudly to that effect, that this is not going to be supported at any level and then from there I think that we can come up with some of the white papers and some of the supports to that. But it really needs to be a strong statement from the top that this has to change. Otherwise it's going to be pervasive and it's going to continue for quite some time.

Ms. Blackwell: I'd like to hear what other co-chairs have to say, Sharon and

Alison.

Ms. Lewis: Alison, are you on the phone?

Ms. Singer: Yes, no, I'm still here. I think it's -- if we want our advice to the Secretary to be valuable, I think on the issue of restraint and seclusion 90 percent of the material we all agree on. You know, the issue on the Keeping Children Safe Act has to do with the IEP issue. So if we want to really provide the Secretary with useful information I think what the committee could do is really dig deeper on that issue, try to come up with a consensus statement and I agree with Lee, not everyone will agree, but it'll be the consensus statement of the committee and I think that would be valuable to her because it would be useful in terms of pushing the legislation forward. So you know, to me that's where I would focus.

On the Department of Education data I was very happy to see that those data are finally being released. I think we need to move on Lyn's suggestion which is to schedule the Department of Education to present the new guidelines that are based on those data at the July IACC meeting. I don't know what has to happen in order for that to come about, but Alexa did say that as IACC members it would be valuable to the Department of Education if we provided input and helped to disseminate the new guidelines and she said she would have them by July so I would love to see that on the schedule if we could move that forward.

Another thing I heard today that I think is an important action item is that one of the real road blocks to implementing safer practices is that there's lack of money for professional development to train community-based staff and school-based staff to properly implement the guidelines that we have. So you know, I know it's not a climate for asking for more money but that is something. And then the other thing we heard a lot about today is the issue of enforcement of existing regulations. I was happy to see the regulations that are in place and that most of them are really good and would serve to protect our children if they were only enforced. When we look at that New York Times article that came out that was -- that Sharon brought up earlier, that was an abhorrent story but that to me was an issue of enforcement. I mean, the reason that situation kept happening is because there was no enforcement of regulations that prevented this particular employee from being reassigned, so he was just reassigned to new settings and new settings and continued to -- I can't even describe it because I had trouble getting through that article. But one thing that emerged to me today that is a clear area of need is to focus on how we can improve enforcement. And I do think that that is something that the Secretary can do. And so if we are going to also move forward with writing this letter I would really focus on how CMS can work to enforce the regulations that are already in place and improve their reporting requirements and try to work with what we already have in place. So those are the three areas that I jotted down.

Ms. Lewis: So what I would add to all of this is I think that as we're thinking about specific action items we should think about the audience. If what we want to address is the schools, I think that the IACC making -- whether it's a specific or a general statement I'm going to step into that Federal employee role for a minute and stay out of that territory because I am also not able to endorse any particular pieces of legislation. But if the IACC wanted to make a statement around the need for Federal legislation or the need to move something forward in terms of Congress I think that that would be very well received by the community certainly and would be helpful to those who are advocating for the legislation.

In terms of a letter to the Secretary, however, I just wonder about the utility of getting into the school issues when we're talking about a letter to Secretary Sebelius and are there ideas that we have that we may want to support in terms of for example the continued conversations between SAMHSA and the Department of Education, you know, and frankly using the expertise within SAMHSA and offering up the expertise within SAMHSA to get to some very concrete tools for educators that frankly don't exist right now. I mean, when you look at the six core strategies and the work that has come out of SAMHSA there are very explicit resources available to the provider community top to bottom that are not available to school staff. And I believe based on prior conversations that folks like Kevin Huckshorn do believe that things like the six core strategies could be adapted for other environments, acknowledging that difference between school systems and mental health or residential treatment facilities that would be of use to the school systems. And given Secretary Duncan's support of the general principles and the acknowledgment of the direction that he's encouraging schools to go I just wonder if, you know, beyond a guidance document whether there might be a way to encourage investment in resources to more concrete tools that were jointly developed across HHS and the Department of Education. As, you know, as another concrete piece that we might want to include in recommendations to the Secretary.

Ms. Redwood: Well, if we're talking about cost, not recreating the wheel when you have wonderful documents already I think would be hugely beneficial. So I would really support that, Sharon. And I think your question about including information about the legislation in the letter to the Secretary we should also discuss too.

Mr. Grossman: I think what you were saying, Sharon, as I was hearing you there are these -- already these relationships developed between CMS and Department of Education, SAMHSA and the Department of Education. I think that if we're addressing any issues with the Secretary not only we'd make her aware of that but I think that it -- the other particular emphasis should be that this goes beyond just her purview and that would again I think push to some extent the need for interagency partnerships here. Again, when we're talking about enforcement in my mind that's Department of Justice has to be very, very much at the table. And of course -- I mean, I look at these as human rights abuses. I mean, bottom line you can call them -- it's happening in the school, it's happening at CMS. These are criminal activities that are at some level happening and they should be addressed as such and it should be pushed to that point so that our heads, our leaders can begin to emphasize the fact that we can't tolerate this any longer. So I'm getting off on a little bit of a tangent here, but the point that I was trying to make initially was that there is a lot of cooperation going on. If we are going to address and make recommendations to the Secretary I think part of that recommendation pretty much is to say Secretary Sebelius, you can't handle this alone, we have to have these other agencies involved if we're going to be effective across the life span in addressing this important issue.

Ms. Singer: I think one agency that may need to be involved given that we've talked today about this being an enforcement issue is the Department of Justice and the Civil Rights Division at the Department of Justice. Maybe they need to take a more active role in prosecuting the criminals who perpetrate these crimes. Maybe it needs to be handled that way.

Ms. Blackwell: What I'm hearing -- I mean I heard a couple things. I heard one discussion about a letter, and then I think what I'm hearing is a second option which might be the development of a statement from the committee. Maybe a statement would have more meaning because it goes beyond Secretary Sebelius and so maybe a statement supporting legislation or other initiatives might be a more meaningful approach. And also more useful for various members of the committee.

Ms. Singer: I just want to add again that I think one piece of it has to be -- we heard a lot today about regulations that are in place. And the regulations that are in place are good. So we really have to address how we want to enforce the existing regulations, and if there are ways that the Secretary can help us out or if DOJ has to help us out or CMS. You know, whichever agency. I think that has to be a prong as well. Because there are good regulations in place.

Ms. Lewis: I think one of the questions though is within the existing regulations what do we know about violations. I mean, I think we don't know in terms of data because we have these silos between different types of settings that are regulated in different ways, and much of the information that we have is anecdotal out of individual systems tied into things like specific waiver approaches or specific state plans. I just wonder how we might get our arms around the data and research needs because I think we can talk about enforcement, but part of what I heard in Ellen's presentation is and to some degree in Larke's presentation is that when we start peeling things back, where we have regulated has generally been fairly effective. So I don't know how much of an -- I just, I mean literally I don't know how much of an enforcement issue we have in certain pieces of this puzzle. We certainly have what I heard today, you know, some significant concerns about how do we take the very broad perspective of the Medicaid rules in terms of home and community-based since there's really no tie directly back into 1915 related to seclusion and restraint. And if we're concerned about group homes and other community-based settings that's another matter.

Mr. Grossman: I'm not sure how much enforcement we can be -- can be dealt with at this point until we have better regulations. And that's part of this whole process is that we -- once it's convened, once we meet and once regulations and legislation is passed then there will be a greater ability to enforce. But Department of Justice probably should be involved from the get-go so that they're part of that process as well.

I did want to comment on the statement versus recommendations. I was thinking about what Curt said about all these white papers sitting on desks collecting dust and I think to a degree as much as the statement sounds like it could be more powerful it's -- I think when we're making recommendations then it demands a response versus a statement that we just put out there. A statement could be very, very powerful but nobody has to respond to it, but if it's recommendations somebody has to give us an answer and hopefully some action behind it. So I would go for recommendations versus just issuing a statement.

Ms. Blackwell: I would just add that we have to go back to our mother committee and that the entire committee would have to decide, you know, exactly how it would like to proceed. We're just two little subcommittees here today so you know, the committee itself would have to decide at some point. You know, we can advise what it wants to do.

Ms. Redwood: I also heard today that we need consistent policies across CMS and the Department of Education, and I think that's something we could call for too is some consistency and then that's going to make enforcement a lot easier.

Dr. Shore: I think consistency is really important whether it's fidelity of treatment or whether it's across programs, schools, whether it's across governmental organizations. Because when we're not consistent that's when we -- that's a result of having these silos that maybe Lee or whoever it was that brought that up. Easier said than done of course.

Dr. Strickland: I wonder about the -- I think it was Lyn's point, or maybe it was Lee, but if we're taking this -- when we take this back to the larger committee it might be beneficial to have a sample recommendation or two already crafted and a statement what it would consist of already crafted rather than to try build it in that larger committee. And be fairly clear about the scope of what we're communicating, whether it's this is a human rights issue, it should stop, or whether we're going to go even and it will be stopped by the Secretary doing this, this, this. Or whether it's going to be much more involved in terms of the strategies by which it gets stopped meaning Department of Education has to do this, and so-and-so has to do this. But the scope I think will make -- we should think about that too before it gets introduced to the larger committee.

Dr. Daniels: I would advise the two subcommittees to actually fully flesh out a draft before July 19th and take that to the full committee. As you know that we're scheduled to sunset in September, so if you just start working on something in July you'll probably never finish.

Ms. Blackwell: I think we need a volunteer to draft recommendations or a statement. Yes, I'm looking at Sharon because she's the expert in this area. I totally will say that I am not an expert in seclusion and restraint although several people did call me one yesterday, but Sharon is the real expert. So we could certainly work with Sharon, Lee is the other co-chair and with Lyn and Alison to kick some drafts around. We're allowed to do that, right Susan?

Dr. Daniels: Yes, you could work on drafts via email and then you probably will want to have another meeting in June to talk about this and so we could either do a teleconference or another in-person meeting, whatever you like. And we can schedule that pretty soon.

Ms. Lewis: So I'm happy to participate in the team effort. I don't want to do it by myself by any stretch of the imagination. And I think what would be really helpful, what I -- just kind of taking it back to the concrete here. I'm hearing that the subcommittees jointly at least, those who are attending here today, are interested in seeing some recommendations related to the promulgation of regulations under the Children's Health Act of 2000 around a statement in support of legislation that's consistent with the principles that you know we might want to reiterate related to seclusion and restraint in the schools and positive behavior supports. Are there other concrete ideas that the group would like to see in such a statement?

Dr. Rice: Well, we talked about the statement that this is bigger than an HHS issue as well, so convening across agencies as well and then maybe indicating that we've heard several issues in terms of culture change, training, supports, enforcement, and maybe thinking some of the topics that could be addressed in a joint, whether it's across agencies, with members of Congress, White House representatives, what we want to say.

Ms. Lewis: So some kind of interagency convening or event to focus on this issue across HHS, Department of Ed and potentially Department of Justice?

Ms. Singer: Can't we do that today with the exception of the Department of Justice?

Ms. Lewis: I'm sorry, we couldn't hear you, Alison.

Ms. Singer: I was saying didn't we do that today with the exception of the Department of Justice? I mean, I think we have to talk about the outcome of this meeting and how we want to move it forward.

Ms. Lewis: Well, I think that what I'm hearing and seeing is you know, I think that those of us who are here are here as representatives of the IACC and part of the question is can we suggest that the Secretary through, you know, one of our various entities, whether it's CMS or SAMHSA or ADD or the Office on Disability bring together you know frankly agency partners and members who have the authority over resources and policy to then address recommendations. And that's why I keep coming back to kind of what, you know, so besides having another conversation, what would we want those agencies to do. Would it be to think about how policy implementation might become more consistent across settings? Given, you know, absent legislation are there other guidance or administrative efforts that multiple agencies could be taking on that would begin to impact the field, and are there resources that might be brought to bear to change that? I mean, one of the things that Larke touched on today and I think is the perspective of SAMHSA is that bringing together and having a very focused call to action process really is part of what shifted the change at SAMHSA and created the initiative that eventually became resources and technical assistance and training, et cetera, for the effort to eliminate and reduce seclusion and restraint at SAMHSA. So you know, I think that we can say we'd like to have more interagency collaboration but to what end? And I just would love the members' thoughts on what we actually want those feds sitting around the table to do.

Dr. Rice: And to follow up with that we had talked about, you know, a White House summit like the bullying summit, how do we integrate that into these recommendations. I'm not sure how we do that but it seems like to have that larger culture change that that would need to be part of the process, not just agencies.

Ms. Blackwell: So is there any opportunity Sharon, do you think, in Section 2402 to look at these issues? Because you mentioned, you know, what is there that we could do.

Ms. Lewis: Well, I think that -- and Rosaly, maybe you want to jump in on this as well -- but I think that when we've been looking at 2402 and for those of you who are not 100 percent sure what we're talking about here, there's a provision in the Affordable Care Act that Ellen mentioned in her presentation that requires the Secretary to promulgate regulations to ensure that home and community-based services as delivered by states outside of Medicaid are respective of the individual, foster independence, and there's a set of statutory requirements. And there is a cross-agency group of us that have been working on the development of that reg. We are really seeing this as we've been calling it a meta reg because it will cut across multiple areas and is not like a spending clause reg where it's, you know, where it's tied specifically to a program. And we've been looking at it in the context of what the statute directs related to person-centered planning, quality, self-direction and I think that everything that's in there is consistent with what we're talking about here. I don't know if there is an opportunity to get into explicit issues like seclusion and restraint because I think it then becomes a slippery slope in terms of how is that applicable. I mean, I think we've talked about basic human rights and civil rights and self-direction and the importance of person-centered planning which I was very happy to see several of the presenters reference the importance of that individualized approach in addressing seclusion and restraint. I don't know if 2402(a) is the best place to get at it. So, I mean I can bring it back to the -- I will make the commitment to bring it back to the 2402(a) group that's been meeting and say this came up at the IACC and there may, you know, and see if there's any opportunity to address it in that context. I don't know if it's the best place.

Ms. Redwood: If we view this as a civil rights violation and it seems like that language would fit in there nicely. And I think the more places we can have it as long as it's consistent --

Ms. Lewis: Right.

Ms. Redwood: -- the higher the likelihood that it will actually be --

Ms. Lewis: Yes. So I think -- I think it's a good point. I think that something else to think about in terms of the framing of recommendations and thinking about the administration's commitment to community living and kind of going back to some of the things that we heard today about at the core of this is -- is somewhat of an attitudinal change around basic human rights and an expectation of access to community. And in order to access community you have to have relationships. And when you are -- when challenging behavior is being managed through these techniques we heard that it's damaging to relationships. So that's kind of the train of thought that I think we might want to take as we're thinking about this and how we might push or recommend that within the concept of community living are there -- is this something that might be addressed under that initiative as well.

Dr. Correa-de-Araujo: Just wanted to make sure that if this is addressed under Section 2402 of course it's an opportunity but violation of civil rights, it's more than that. So we don't want it to be limited to Section 2402. And the other thing that I want to remember -- remind people is that we go back to the same problem. We don't know how we are going to enforce Section 2402 and we don't have any funds attached to Section 2402. So just keeping that in mind.

Ms. Lewis: So co-chairs, is that enough for us to go on I think as a starting point? Does anybody have anything else they'd like to see incorporated into recommendations?

Ms. Redwood: Larke also had a specific suggestion on where the areas they were stuck. And I think it might be nice to ask for some movement in those areas too. She specifically said that that would be -- she would appreciate that support so I'd like to see that included as well.

Ms. Lewis: Yes, that's the -- yes, that's the section.

Ms. Singer: Yes, I jotted that down too. She specifically said that non-medical children's residential facilities.

Ms. Lewis: So I will try to answer the question, probably not as eloquently as Larke would, but I think that part of the issue is what is that, what are we defining there and what are the entities under the Public Health Service Act which is what this amends that receive funds because when you read the statute, the hook is the funding that are non-medical community-based settings. So I -- my understanding is part of the challenge in the reg is defining that.

Ms. Redwood: Just a quick

question for Ellen. You mentioned this morning there was a tiny bit of discussion around monitoring and what's being reported to CMS as deaths. And I'm wondering if that could be expanded to the point where you're actually reporting incidences of when seclusion and restraint was necessary because being able to identify when those can occur and under what circumstances will get us the information we need to be able to target preventative strategies. So I'm just -- I don't know. Ellen, is that feasible to go beyond? Because death is like, we don't want to start with just reporting death.

Ms. Blackwell: I think that at the moment we can't go beyond what's in the interim final regulation. So what Sharon is talking about and what Larke talked about is revisiting the interim final. So I would suggest, you know, go back and look at it and read the condition of participation and that's what we have on the books right now.

Ms. Lewis: And I think what's difficult is -- and Ellen, maybe you can articulate this better than I can, but Medicaid data collection is not particularly granular to the individual at all. It is very broad and systemic data and I think that CMS is working to change some of that with the establishment of a taxonomy that will allow some consistency in definitions. And it is not data that is based on the individual. So it's -- I'm hard -- I'm imagining, thinking of Bonnie's comment about how we might get to that data through a CMS system without extraordinary cost to both CMS and the states.

It might be interesting, however, to see what the policies are in terms of data collection at the state level because some states may have better data than others. And I know that certainly when we looked at this in the education context that was true. Now, what they did with the data was a whole 'nother problem, you know. For example, the state of California can tell you that I think, I forget the number, I used to know this off the top of my head, but I want to say it was around 14,000 students had been secluded or restrained in a given school year, but then that's what they knew, that 14,000 students -- there had been 14,000 incidents. And in terms of follow-up and then what happened with that data it's a whole 'nother question. So it would be -- I mean, what we didn't hear today is what are the states doing in terms of data collection. And I just don't know. I mean, we might be able to also check in with NASDDDS and look at that state map of the policies and see if any of it includes the collection of data. I can tell you that from ADD's perspective that has not been something that we've collected data on when we look at, you know, the state of the states or Charlie Lakin's data or anything like that. We're not looking at individual incidents or events.

Ms. Blackwell: It might actually

pop up in the home and community-based waiver policies, you know, the tracking system. For example, California uses the SEERs. So there might be some data that, you know, at least something that would talk about a system that could be referenced in a state. But as Sharon said, our data right now is really poor as any researcher who's ever worked with Medicaid data will tell you, and our resources are very small. So not to say that that's an excuse, but that is just the way that it is right now. But I was, I have to tell you, I was honestly really pleased when I went to survey and cert and they told me that there were four incidents in the past 10 years. I think that was just amazing. That made me feel like we actually did something that worked and you know, compared to what I remember from 10 or 12 years ago that's really a success story in government. So you know, we have a long way to go obviously but we have come somewhere in the meantime.

And I also wanted to say that I think that one of the duties of the IACC is to put information out for public consumption so I think that we have fulfilled a good part of our mission today in having these wonderful speakers come share with us and talk about this really important issue. So there are a lot of good reference materials on the website and there will be even more up if people missed the presentation today. So I think that's a good day for us. Anything else? Lee? Sharon? Alison? Lyn?

Mr. Grossman: I just want to quickly say that I want to thank everybody's participation. I mean, we were putting our breaks and our lunch aside because the dialogue was so healthy and significant. And I appreciate the commitment everybody was making towards this effort. It's very important. People were putting their attention to it as they should and thank you very much. Thank you, Alison, and whoever's left on the phone as well for hanging in there. I think it was a very good day.

Dr. Daniels: And I'll be following up with both subcommittees about action items and organizing to start working on the letter and with a date. I'll work with the chairs to come up with a date for another meeting.

Ms. Singer: Susan, can we agree now to ask either Gail or someone else from DOE to give us a presentation at the July meeting on the new guidelines?

Dr. Daniels: Yes.

Ms. Singer: Because Alexa did say they would be ready by then.

Dr. Daniels: Yes, I believe we can do that.

Ms. Redwood: Susan, when we sent the last letter to the Secretary you helped us tremendously by starting the first sort of draft and then we worked on it. I hate to volunteer you again but unless, Susan, I heard you specifically say you didn't want to be --

Dr. Daniels: It sounds like Sharon was kind of volunteered to work on it, but I'm happy to provide any assistance to her office --

Ms. Lewis: I mean, I'm happy -- if -- what would be most helpful to me is if we have notes from this last 20 minutes as a starting point that then I'm happy to take that and turn it into, you know, a quick draft that we can share within the chairs and go from there.

Dr. Daniels: Great. Do you have any more comments? Well, thank you very much everyone for being here. It's been a really productive session and we sound like we have many action items to complete in the next couple of months. But I hope that you all have a good evening and thank you for being here.

(Whereupon, at 4:26 p.m., the Subcommittees adjourned.)