U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE

TUESDAY, MARCH 29, 2011

The Subcommittee convened at 2:00 p.m., at The Neuroscience Center, 6001 Executive Boulevard, Room 8120, Rockville, Maryland, Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

PARTICIPANTS:

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

LEE GROSSMAN, *Co-Chair,* Autism Society

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

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

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

CHRISTINE MCKEE, J.D.

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

PARTICIPANTS (continued)

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.)(attended by phone)

STEPHEN SHORE, Ed.D., Adelphi University and Autism Spectrum Consulting (attended by phone)

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

TABLE OF CONTENTS

PROCEEDINGS

2:05 p.m.

Dr. Daniels: Hi. This is Susan Daniels from the Office of Autism Research Coordination at NIMH, NIH. I am the Executive Secretary of the IACC Services Subcommittee.

I would like to welcome all the IACC members as well as members of the public to this in-person meeting as well as those who might be joining us on the phone.

I would like to go around and do a roll call. So, first, I will go around the room and call on our members to see who is here.

Ellen Blackwell?

Ms. Blackwell: Here.

Dr. Daniels: Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Christine McKee is not here yet.

Bonnie Strickland is not here yet.

Henry Claypool, not available yet.

Gail Houle?

Dr. Houle: Yes, I'm here.

Dr. Daniels: Hi, Gail.

Dr. Houle: Hello.

Dr. Daniels: Larke Huang?

Dr. Huang: Yes, here, on the phone.

Dr. Daniels: Thank you.

Ari Ne'eman? Not here yet.

Mr. Ne'eman: Here, on the phone.

Dr. Daniels: Oh, hi, Ari.

Cathy Rice?

Dr. Rice: Hi. Here on the phone.

Dr. Daniels: Stephen Shore? Not here yet.

Denise Resnik I believe is going to be joining us a little bit late by phone.

Then, today I heard that we don't have anyone from the Administration on Children and Families because the representative is out on leave.

So, I believe that we have the roll

call completed. So, I would like to turn our attention to looking at the minutes of the November 29th, 2010 conference call of the IACC Services Subcommittee.

Do any of the members have any comments or revisions that they would like to see made to these minutes before they are made available to the public?

Ms. Blackwell: This is Ellen.

My only comment is they look really good, Susan. Thank you to your office for consistently doing such a good job with the minutes.

Dr. Daniels: Thank you.

So, if there are no further comments, I would like to take a vote. Would somebody move to accept the minutes?

(Moved and seconded.)

All in favor?

(Chorus of ayes.)

Any opposed?

(No response.)

So, the motion carries, and the minutes have been approved and will be available for the public on the web within the next few days.

And, then, now I would like to turn the meeting over to our Co-Chairs Ellen Blackwell and Lee Grossman to lead us through the rest of the program.

Ms. Blackwell: This is Ellen.

We had planned, and we do plan, to have an update on the state of the budget situation in the various states.

Christine McKee has just joined us as well as some other guests. I do not believe Joy is -- oh, Joy has just joined us. Welcome, Joy.

So, in just a moment, I am going to introduce Joy Johnson-Wilson. In fact, I am introducing Joy.

Joy is the Health Policy Director for the National Conference of State Legislatures, which also has a close

association with the National Governors Association. Joy is based in Washington, D.C.

We asked Joy if she could give us today just sort of a picture of what is happening out in the states, although it seems to be a moving target, Joy, so far as the state budget situation goes.

And, then, following Joy, we will hear from Jeff Sell, who does public policy for our member organization, the Autism Society of America.

And, Joy, I should let you know that, in addition to the people here in the room, there are folks online. They can see the meeting at their computers and hear you as well. So, there is a larger audience than we have with us today.

And we are so glad that you joined us. Thank you.

Ms. Johnson-Wilson: Well, thank you for having me.

It confused me a little bit with

the 6001 and 603, and the "3" came before the "1". I was like oh-oh, I have turned -- you know, I have my own disability, and that is that I am terrible at directions. So, I turned in and I saw "603" and I thought I've done it again; I'm in the wrong spot. But I figured it out.

Thank you for having me.

Okay. I'm also not good at PowerPoint, but we will see how we do here.

Medicaid, in brief, I just thought I would give you a few factoids. The third largest domestic program, it actually has more beneficiaries than Medicare.

More importantly, at the state level it averages 16 percent of a state's own funds, money. That is not counting the federal match. So, in terms of state dollars, it's about 16 percent.

The next biggest slice of states' budgets is elementary and secondary ed. If you throw higher ed in, it's back to about 50

percent of the state budget. So, you can see Medicaid becomes very important when you have an overall budget discussion.

We know for a fact that Medicaid enrollment and spending increases in an economic downturn. So, we're having that.

And there is no statutory provision, there's nothing in the Medicaid statute that protects states when there is an economic downturn or some sort of natural disaster, which leads to states having to go to the Congress and ask for assistance.

We see that twice, first in 2002, 2003. That money was a lot more flexible than the money that we received this time around under the stimulus package, the American Recovery and Reinvestment Act. We are still receiving those funds. We will talk about that.

Managing Medicaid. There is not a lot a state can do in terms of managing their Medicaid budget. That is very important as we

look at what is going on in states right now.

So, it has mandatory and optional benefits. I like to make the point that the optional benefits in Medicaid are not like options you get on a car where you can get the bigger wheels or the smaller wheels, the car would still go, you know, or you could lights or you could get leather seats or you could get cloth.

It's not like that because prescription drugs, for instance, is an optional benefit. And it clearly would not be considered an option now on a comprehensive benefit package.

So, optional does not mean not important or you can really do without it. It is just how it came to be as part of the Medicaid program. It was not part of the core mandatory services when it was enacted in 1965.

It is an entitlement program, which means that, if an individual meets the

requirements, the eligibility requirements, they must receive services.

In terms of budget management options, you can eliminate optional categories of eligibles. So, there are some people who will always be eligible, they are entitled to the service, and there is no question.

States have options of adding other people onto the program. You can eliminate or limit services that are not mandatory services, and you can reduce provider reimbursement or you can impose a provider tax as long as you meet the requirements of the law regarding provider taxes. And you can do some sort of capitated reimbursement, which may or may not save money. It depends.

It is important to note that, as part of the stimulus package, and more recently as part of the Affordable Care Act, they have eliminated one option, in that there are no optional people. Whoever we had on, basically, when the stimulus program, whoever

was entitled, whether they were an optional category or a mandatory, we must continue to cover them through 2014. We will talk about that again.

EPSDT, of course, is very important to you. All the children are covered under EPSDT, which means that, basically, if there is a medically-necessary service that the child needs, Medicaid should cover it. That is pretty much it.

Now there are all kinds of gradations in what is necessary. But the core of it is that for children there is a much broader range of services that are available to children. There are some limits, mostly in the benchmark package wraparound issue.

In some, limits on case management, targeted case management, may affect some of the children that have autism spectrum disorders, depending on what package of services they are receiving. Because they have such a broad range of services, depending

on the child, some of them may be affected by some of the limits on EPSDT.

So, today the enhanced match from the stimulus program will end June 30th, which means that for most state fiscal years that will begin July 1st of this year, this will be the first fiscal year without the extra federal funds to help with the increased enrollment that we are experiencing.

And I will tell you, quite frankly, the states are struggling trying to fill the gap. Why? The revenues are down, and local government revenues are down. We are not expecting -- even if there is a recovery, it is going to be slow. So, we are thinking three to five years, which means we are still going to have some funding issues.

The biggest problem is that most states cannot address the Medicaid gap within the Medicaid program. And so, where are states, then, finding the excess? Mostly in the No. 1 area where states have spending gaps

is education, which is unheard of, but K through 12 is helping to fund Medicaid. And people are hating that. We all hate that because it is a lot of the same kids.

There are some other things they are doing, but anything outside of Medicaid is mostly coming out of education and human services, a little bit on the corrections side, but mostly education and human services.

The maintenance-of-effort requirement, which usually when there is a tough time in Medicaid, in addition to looking at provider reimbursement, states tend to start eliminating optional eligibility groups. They cannot do that this time because of the maintenance-of-effort issue, the MOE, we call it here in D.C. And you will hear a lot about MOE over the next several months because we have MOE until 2014.

So, what are we doing? We are reducing provider reimbursements. That is a problem because some people leave the program

because we are not known as great reimbursers, let me just say. I know this. But we are going to be worse. And so, we are going to lose some people because of that.

Some of our providers are volunteering to have provider taxes imposed because it will help stabilize the program. So, there are states that are either increasing the percent or kind of maxing out on provider taxes by either creating new ones or increasing the amount of existing provider taxes.

If they still have any optional services, they are either eliminating or limiting those services. A lot of states don't have many optional services left. No state is going to eliminate prescription drugs.

Now new limits on existing services definitely is occurring. A lot of that will happen in the prescription drug area, but it also may be about number of visits for

different things.

The biggest new area is taking groups that used to be carved out of managed care and putting them in managed care, particularly seniors and disabled individuals. And they are also closing the Medicaid gap elsewhere in the state budget, which is not much fun.

What do we have coming tomorrow? We have a major expansion of the Medicaid program coming up in 2014. Quite frankly, states are scared to death.

While we receive enhanced match for the new eligibles, these are people who were not eligible for Medicaid under the state plan previous to 2014, but because the base program is underfunded, the enhanced match for the new people doesn't really help us to pay for the people who are already on that we don't have enough money to cover.

We also are very concerned about infrastructure, both in terms of workforce and

facility, and exactly how we are going to provide the services to the new people when we are not reaching the people who we have currently eligible. So, there is a big concern about that.

As the legislators have noted to me, it takes eight years to grow a doctor, and we don't have eight years. So, one of the big issues that will come up will be the scope of practice, to try to extend the use of other health professionals to provide some services.

It is to be noted that in 2014, for those states that are covering people over 133 percent of poverty, they will have the ability to move them into the health insurance exchanges, which is the one-stop-shopping center that the Affordable Care Act authorizes for individuals and for people who are employed by small business.

I thought I would mention state-mandated benefits, and you might wonder why, but I will get there. We have 24 states that

require some kind of autism spectrum disorder coverage, and those are the states. We also have this year Virginia and West Virginia passed legislation that is pending signature by the Governor. Arkansas was the other state that enacted something this year.

The Affordable Care Act requires the Secretary to establish an essential benefit package, which is the core of how the insurance exchanges will work. Because all of the benefit packages, you know, they have the precious metals thing, platinum, gold, bronze, silver, but all of them will have the same essential benefit package. The difference will be co-pays, deductibles, the cost-sharing.

So, the essential benefit package is going to be key in terms of how much the premiums will be, and therefore, how much the subsidies will cost the federal government.

The Institute of Medicine is currently working on the essential benefits

package. In the law, it states that state-mandated benefits are not preempted under the law. However, if you are a state and you have mandated benefits that are not in the essential benefit package, you kind of have to buy them back, that you pay for them.

So, how does this affect you all? If autism spectrum disorders doesn't make it into the essential benefit package, then you have to convince your state legislature to buy it back, to keep it in for that state. So, it is important to see what the IOM is doing in terms of their essential benefit package. It is also important to note where your state is.

I assume that every state is going to have to get some actuarial information on the cost of their mandates and to make some decisions. It is a very tough decision for a state in an election year, but that is what it will be, and that is how it is going to happen.

I thought that would be worth

noting because, while there is a broad difference among the state-mandated benefits on autism spectrum disorder, at least half the states have something in place. I thought that was worth noting.

So, I will stop there and take any questions you might have. I don't know if we are going to wait until the end.

Dr. Daniels: We can go ahead and take some questions right now.

Mr. Grossman: I was just going to ask if there's anybody on the phone who wants to ask a question first.

Dr. Huang: This is Larke.

I have a question about the benchmark planned. Can you say something about that? You mentioned the benchmark.

Ms. Johnson-Wilson: Right. The benchmark plans are based on plans that are offered in the state that meet certain requirements. They are usually based on state employees' health plans or the general

package.

It is some package that is considered reflective of private coverage in the state. So, the benchmark is not the same because it is based on the plans in that state. So, it allows a state to comport their -- and this isn't for children particularly; it is usually for other people. But it allows them some flexibility to make the Medicaid benefits look more like the private coverage that is offered.

Dr. Huang: Thank you.

Mr. Ne'eman: This is Ari. I have a question.

With respect to the drop, with respect to the expiration of the enhanced FMAP, could you just elaborate a little bit about the potential impact this may have on long-term services and supports in terms of budget cuts and other implications, particularly for DD services?

Ms. Johnson-Wilson: They are

dropping. It is going to be bad. I don't think there is any other way to say it.

What I am seeing is pretty dramatic. It is more dramatic than anything I have seen. I have worked at NCSL for over 30 years, and I have never seen anything like this.

The gap that is created from the stimulus package is huge. The fact that state revenues are not recovering doesn't leave any room for saving things.

So, the fact that they can't do anything on eligibility leaves them with services and reimbursements and looking elsewhere. Raising taxes normally is outside the bound, although there are some states that are raising sin taxes, cigarettes, beer, wine, but those are limited in terms of what you can actually get.

So, this year will be very bad, particularly bad for elderly and disabled because one of the things that they are ending

up cutting is on the human services side, some of the support that helps people that are disabled or elderly.

Mr. Grossman: Joy, this is Lee Grossman. Thank you for your excellent presentation. It is pretty sobering, to say the least.

Ms. Johnson-Wilson: Yes.

Mr. Grossman: You have the full, broad observation of all the states. Are there any states out there that are serving as good models to deal with this crisis that we are going to see with these dramatic cuts? Are there any solutions being brought forward? Are there things that you would like this Committee to perhaps look at doing in terms of our advisory capacity for making recommendations?

Ms. Johnson-Wilson: I think one of the things that happens is every state is now stepping back and saying the program cannot go on as it is currently planned; we will not be

able to support it financially without some changes.

And so, I think they are focusing a lot on the elderly and disabled because that is where the money is; looking at ways of coordinating care, trying to change service delivery and reimbursement based on performance instead of numbers of visits, and that kind of thing.

We are hearing a lot of states talking about global budgets, block grants. They want to figure out a way to limit their exposure.

Now the block grants discussion is based on getting a lot of flexibility from the federal government. We have not been real successful on that with our other block grants. So, I think that there is some nervousness about moving forward with a block grant as we currently look at it. But they are looking at trying to get providers to work off of a global budget, of course. So, there

is a lot of that.

I think the biggest thing that all the various patient groups have to do is start figuring out what is the most important thing for you. If you had to pick from your babies, which baby would you pick?

And to the extent that you have other groups that have the same baby in mind, I would say get together and push for that. Because at this point there is just competition among a lot of very needy individuals and groups. It is who can get the best approach together.

And you need to be able to show that it is going to show some efficiencies and improve the quality of the service, something that will make legislators think they need to do that. I think that is fair. I think that is about where we are.

So, I think that trying to carve out a group that is saying, "We are special, special, special and we need...." isn't going

to work because there is just no money. So, you really have to push for the most important thing and be vigilant, and start working now for next year's budget.

Ms. Blackwell: Joy, this is Ellen Blackwell. I have a question.

I understand, because I work for the Medicaid program, that states are trying to look at those long-term services and supports and figure out what is the balance. But you mentioned earlier the optional and mandatory benefits in the Medicaid program. So, states also have to struggle with the mandatory institutional benefit, which is, of course, very costly, versus the less costly long-term services and supports, and, also, wrestle with their obligations under the Americans with Disabilities Act and the Olmstead decision.

Ms. Johnson-Wilson: Right.

Ms. Blackwell: So, how are they balancing those other responsibilities with

their required service, which is the institutional benefits?

Ms. Johnson-Wilson: Well, they are spending quite a bit of time trying to figure out how to really build an infrastructure for home- and community-based state services. But in a lot of places there just really isn't sufficient infrastructures to put people in the community because you need a broad range of support services, and if you don't have them, then having someone in their home is actually an endangerment and not an improvement for them.

You have to have supports and you have to have oversight. They are struggling with that; particularly in some of the rural areas it is very difficult.

But I think that there is a broad commitment from the states to try to increase the availability of home- and community-based services. There is a great interest and want and there is just not enough supply.

So, we have more nursing home beds than we have available across-the-board support for people in their homes. It is not always less expensive to have someone in their home, depending.

So, I think it is an area that needs a lot of work, but we don't have the workforce right now or the facilities to support home- and community-based care. So, that is something that is going to have to come over time.

Ms. Blackwell: How are the state workforces, the state employees, holding up under the pressures that they face in terms of reform and trying to pursue more amenable options, like long-term services and supports? Because the state staffs in many cases I know have suffered cutbacks.

Ms. Johnson-Wilson: Yes, we are short. We are way short of that.

Ms. Blackwell: You are short, yes.

Ms. Johnson-Wilson: We are so

short on staff that we are leaving money on the table because we don't have staff to do the proposals. That has never happened in my memory.

But the Affordable Care Act had a number of grants. We were wondering why states weren't applying for the grants. In my travels, I found out that it is triage. You know, if it is a grant and it takes 10 pages and you have to have this and that and the other, they go, "Oh, well, that one goes on the back burner because we don't have people to do all of that." If it is send in a one-pager and you can fill in the gaps later, maybe we can do that. And what are the obligations down the road?

And so, they evaluate grants based on whether or not they actually think they have the staff to support it, you know, for either writing a proposal or supporting it after the money comes through. Because if you can't meet the requirements, then you are in

trouble.

So, we have left a fair amount of money on the table. Given everything, it is painful to leave money on the table when you need money.

But one of the ways that states have saved money overall in the budget is by staff reductions, buyouts, and that kind of thing. So, we are low on staff going into health reform that needs staff. It is a very tough time.

Mr. Ne'eman: To what degree -- and this Ari -- to what degree are states really giving thought to the efforts at the federal level to ensure states come into compliance with the Olmstead v. L.C. decision? I mean we know the Department of Justice has been very aggressive. We know that there are mechanisms at HHS OCR and at CMS. Justice has undertook to enforce Olmstead.

Is this something that states are thinking about in terms of, "Well, we had

better not cut this or Justice is going to come after us or OCR is going to come after us."? Or are they just essentially taking things as they go and saying, "Well, if the litigation emerges, then we will deal with it when it comes."?

Ms. Johnson-Wilson: Well, Olmstead isn't the only thing we have to worry about. We have got fraud, waste, and abuse in general. I think we are probably being chased more on fraud, waste, and abuse of various stripes than we are on Olmstead.

But that just falls into a category of things. Also, compliance and inspections on facilities, nursing facilities, and other residential kinds of facilities, those are things that we always have to be concerned about.

I would say at this point in time, given our lack of staff, it is probably a little more challenging now than it might have been in previous years.

Ms. Blackwell: Is there any light at the end of this tunnel, Joy?

Ms. Johnson-Wilson: I hope so. I think for a real light to come on, the economy has to improve. I think that is probably the biggest thing that has to happen because that kind of lets some of the pressure off of the Medicaid program. It brings more revenue into a state, so that they can start doing more things. Right now, it is just very tough.

Dr. Huang: Joy, as states hit this funding cliff, I guess, come the end of June, are there any particular innovative state strategies that you are aware of in general and particularly for the population we are concerned about here, people with autism spectrum disorders? I mean people must be trying to figure this out. Is there any good, innovative thinking around this or strategies?

Ms. Johnson-Wilson: That is the silver bullet question. When I go to a legislature and I am talking to their budget

committee, they go, "So, tell us, what's the silver bullet to figure this out?" There is no silver bullet. There really isn't.

I think in every state, because every state is different, and it matters kind of where you are right now, your snapshot, as to what you can do to mitigate the results of some of those funding reductions. But there is no real great answer.

That is what the legislatures are struggling with. Like I said, very seldom will you find a state cut K through 12, and that is happening. So, I mean, I think that gives you some idea. That is not a popular reduction. It hurts local governments as well, but that is happening. The university systems are all suffering because states are taking their money out of their university systems. It is a really tough time.

So, all I can say is that, when you are working with the legislature, finding those things that are most critical to the

people that you care about is the thing to focus on and to try and save what you can of those services, knowing that everybody else is doing the same thing.

Mr. Grossman: Thank you, Joy.

This is Lee Grossman.

We are going to be moving on because I think we have already gone over our time limit.

I want to truly appreciate your being here and making this presentation. It was, as I said earlier, very sobering, but that is the purpose of why we wanted you to be here, is so that we could start talking about what we know, what we are hearing, what we are seeing is the reality of the service cuts right now.

We are already late. Anyway, the next speaker we have is Jeff Sell, who is the head of public policy for the Autism Society. He is also going to be talking about the crisis that currently exists.

Mr. Sell: Hi. Boy, Joy, you cheered me up with your thoughts.

(Laughter.)

I feel like I just totally had another baby, and that baby is real ugly.

(Laughter.)

Actually, that kind of fits in pretty nicely to my thoughts because I want to talk about the budget crisis as we all know it and have recognized it. It is an ugly baby. It is devastating, especially to those folks who are living, or trying to live, with autism spectrum disorders.

That brings us right back to IACC. I want to give some recommendations to IACC, at least the Services Committee, at the conclusion of my talk. But I want to kind of take this up to a 40,000-foot view to some extent, go through the budget crisis.

Joy, I think you really absolutely laid it out. I wrote down several of your quotes. I mean just the problems with the

FMAT cliffs that we are going to be facing, and it will be jaw-dropping.

That scares the hell out of me in a lot of ways because we think our problems are severe now, and, in fact, they are severe now. It is going to get worse unless advocacy organizations step it up. There is that old saying the squeaky wheel gets the grease. So, I think a lot of us in this room need to do a hell of a lot of squeaking and make our case known.

And the good news is or the upside, and I don't really take issue with you -- I kind of live in my own imaginary world. I have four kids and two with autism. So, I just have to convince myself repeatedly that I'm happy and things are good.

But I see a silver bullet in this. It is the basis for my recommendations to this Subcommittee to make upstream to IACC and, then, send a letter to Secretary Sebelius. The simple solutions is jobs, jobs,

jobs, jobs, and more jobs.

Base those on an employment-first policy, which I have in the handouts. I am not going to get into nauseating details with respect to what those policies are and how they will improve the economy, and why these cuts will actually worsen the recession rather than improving the recession.

I think a very good and strong and powerful argument can be made, even to the most fiscally-conservative Republican, that this is the right way to go, and we can prove it and we can back it up with actuarial data.

If you start from just the basic underlying proposition of jobs, they're good, and then you save taxpayers money. I don't think anybody really disputes either one of those two points. I have heard President Obama say it repeatedly. We have got to start focusing on jobs.

Individuals in the intellectual and developmental disability community, they want

jobs, too. They truly do believe that jobs are good. What we have learned from the data and the study after study after study is our folks can thrive, can work. Even those with the most profound intellectual and developmental disabilities, if we give them a little bit of support, with that little bit of support, let's just say a dollar, we are going to end up savings $7 later on down the road if these people can actually get meaningful employment in an integrated setting with a little bit of support.

And I am not talking about sheltered workshops or things like that. I am talking about jobs and a competitive wage, which we have seen it so many times, model programs around the country that work and where people with severe intellectual and developmental disabilities can thrive.

It is not only just to save money and to reduce the burden on taxpayers. It is also the social benefits. They are profound

for individuals with intellectual and developmental disabilities.

I am going to go over some facts. I know to some extent I am preaching to the choir, but this is coming from the advocacy and grassroots organizational perspective to a large extent.

And we all know the prevalence of autism is just off the charts. A growing number of families are faced with these dramatic cuts. As Joy explained, things are going to be getting even worse.

Actually, I may just skip through some of these slides because I think, Joy, I pretty much just would paraphrase everything you have just said, and my first three or four slides were calling the attention of this Subcommittee to how devastating the crisis is.

One example -- and we are seeing these at the Autism Society almost daily, and anybody who subscribes to any news feeds -- I pulled this out of The Houston Chronicle. I

used to live in Houston.

There was a large rally down there. It was extremely shocking to a lot of folks outside of the developmental disability community to learn that we in Texas, or those folks in Texas, were looking at 40 percent reductions in State funding of community-based care program.

And even more shocking to that, at least to me, was a lot of the folks who have dedicated a lot of their life to accepting Medicaid dollars to provide services, they are being asked to reduce their fees.

I want to use one example. I think Ellen and I both presented, I don't remember, it's last year or the year before, and we were looking at optional and mandatory benefits.

Ellen, dental coverage, is that an optional benefit?

Ms. Blackwell: Dental coverage is optional.

Mr. Sell: Yes.

Ms. Blackwell: In fact, most states have now removed dental benefits from their Medicaid programs.

Mr. Sell: Yes.

Ms. Blackwell: Dental services are available to children under EPSDT, but not to adults who have outgrown that program.

Mr. Sell: You know, obviously, I am from Texas, so I am not the smartest guy in the world in a lot of ways. But jobs are good; teeth are good, too.

(Laughter.)

I have never quite understood why that one was an optional benefit.

As Joy was going through that, I went back to my twin sons who have autism. The only dentist that they have ever been able to be treated by is a lady by the name of Maria Green. Maria practices in Spring, Texas. She, as a result of me and a lot of folks spreading the word around the Houston area, went from having four or five patients

with autism to over 300 patients with autism, just because she is a miracle worker. This is great, and she accepts Medicaid. So, people just flock to her.

I got an email from her last night explaining the reduction in fees for an optional program that she was participating in. And she said, you know, "I don't think I'm going to be able to continue. I'm going to have to just start taking private insurance or cash, or something like that. I feel so bad because you've increased my business exponentially, No. 1, and, No. 2, I love your boys. They're really neat and I'm just very attached to them, but I don't know if I can continue to treat them. I've got some recommendations for you."

That hit me like a ton of bricks. I think it really highlights some of these frustrations that those of us in the advocacy community are feeling when we look at some of these cuts.

I want to get right to the recommendations and actually give us back some time to have a discussion on some of the recommendations.

These are not ironclad to any extent, but my main recommendation to the IACC Services Subcommittee would be, and hopefully you guys will make this upstream to the full Committee and a letter to be for Secretary Sebelius, but kind of a very strong letter to Secretary Sebelius addressing the crisis in lifespan services and support, and with respect to that, call attention to, I think, six or seven different things.

The first of them is requesting more aggressive and more home- and community-based options. Those of us in the autism community can back up with actuarial data that home- and community-based supports are cheaper than institutional care. I think we have seen it. We are able to articulate that message both at the federal level and at the state

level, and there is really no question about it anymore.

We also need to strengthen the pre-vocational service definition in technical guidelines and existing regulations to increase the support to integrated employment as a preferred outcome. That starts from the age of transition on through secondary education. We have got to start looking at employment of our kids and our loved ones and our family members as a preferred outcome of almost everything we do.

I am not going to criticize IACC here, but it seems as though the Services Subcommittee has to some extent been almost a stepchild. And we have focused a lot on a very worthy cause, looking into the etiology and the cause of autism and a lot of research related to that.

The Services Subcommittee I think has a duty and an obligation to really make your voice be heard. There are folks out

there living either in situations where they are totally unemployed or they are grossly underemployed. That just cannot be tolerated anymore.

If you look at the recession, and you can actually make the argument that jobs are good and it is going to save taxpayers money, I am hopeful that this is an argument that IACC will take very seriously and will listen to the recommendations from the Services Subcommittee as they are made upstream, so to speak. And this is something that we can move forward on and actually improve people's lives in the very near future and start to help train folks that have intellectual or developmental disabilities, particularly autism, become employable.

The third recommendation is strengthen supported employment. There is a supported employment service definition in the guidelines. Supporting individual integrated employment is the preferred outcome as well.

The fourth recommendation has a service definition for career planning services to support integrated employment as a preferred outcome.

No. 5, states should be required by CMS to ensure a continuous annual rebalancing of funding of employment and day services to focus on the preferred outcome of beneficiaries with disabilities securing and retaining integrated employment and optimal economic self-sufficiency.

No. 6, CMS should develop a strategy to collect integrated employment outcome measures. My thought on this is, once we start placing our people in jobs, we are going to demonstrate those measures very clearly and directly and, then, direct states to report on those outcome measures, CMS's quality improvement standards, in an effort to determine the impact of the recommended change, which I think would be profound.

There's a lot of folks out there

looking to IACC to ramp up the work and the importance of the Services Subcommittee.

That is just a cute, little picture of my two boys. They have grown up now and they are 16. Hopefully, within the next couple of years they will be getting jobs as well. But I fear that, without an increased presence of the Services Subcommittee and IACC taking on the lead role in the responsibility of coordinating these services with respect to integrated employment at a competitive wage, the only alternative we will have is legislation. Then, even if we do get the legislation, we will need to coordinate it. So, I think IACC's presence will need to become even more important in the days ahead.

I don't think sitting idly by is an option in this case. The crisis is, as Joy very aptly described it, jaw-dropping. To those of us who are active in this community, all of this in this room and everybody on the phone, this really is frightening.

I am going to end with I think the solution is as clear as the nose is on my face, and I have a rather big nose. I can see it usually when I talk. But it is jobs. It is focusing on employment in an integrated setting at a competitive wage. I think that is something that we really need to take very seriously and start focusing on.

It is not the end-all by any stretch of the imagination, but it is the sort of thing that is very concrete that makes sense in a recession time. I would request that the Services Subcommittee take to heart my request to send a letter upstream, get the full IACC approval, and, then, send a letter upstream to the full Committee to take on this issue, and do good things.

That is all I have at this time.

Ms. Blackwell: Does anyone have questions for Jeff?

Dr. Huang: This is Larke Huang.

Is there -- and please forgive my

ignorance around this -- is there a guideline or sort of an evidence-supported package around supported integrated employment that either your organization or some others have developed for people on the autism spectrum disorder?

Mr. Sell: Yes, there is. There is a great White Paper that an organization, well, actually, a collaboration of a number of disability organizations, a collaboration for more self-determination has put together. A lot of that is based on research and data that has been collected over the years.

A couple of states have actually implemented employment-first policies and done so very successfully. Washington State and Oregon come to mind. But there is a lot of research behind it.

We have seen the data. We have had a couple of congressional briefings on it. I would be more than happy to share that with the Subcommittee at any point in time.

I actually, for those of you on the phone, I have got a more detailed policy brief with citations in it that I have also presented to the Subcommittee.

Dr. Huang: It would be great if we could get that for those of us on the phone.

I asked the question because at SAMHSA that supported employment is something that we hear from the populations that we serve as being probably more therapeutic than some of our other therapeutic services.

We do have what we call one of our evidence-based toolkits for states and communities. We have a number of these in different areas. One of them, and it has been recently revamped, is our supportive employment toolkit.

I am just wondering if it makes sense, Ellen or Lee, for me to get that to people or to think, is there some convergence of what is in that which is both -- it is a placement-first, a jobs-first piece. But it

talks about the infrastructure development and services.

I am just kind of throwing that out there as a possibility. We are also very much looking at jobs and employment as a key piece of individual service plans.

Mr. Grossman: Larke, that is great. This is Lee.

Yes, please send that on. That was something I wasn't aware of. Maybe others were, but I was not.

That is actually one of the beauties of this Committee, is that we do have these various service-related agencies sitting at the table that do have pieces of this puzzle to help us solve it.

Dr. Huang: And, Lee, I say that because in the block grants that we award to states we do require them, to the degree that we can, to report on certain outcomes, employment being one of those outcomes.

So, we also moved this particular

tool to states to use. They need to report on whether they are using it or not. So, there is a bit of a state infrastructure around it as well.

So, I will get that to you.

Mr. Grossman: Okay. Great.

I know we are trying to get Stephen Shore on the line. He texted me to say that he has a question.

Are there any other questions from people on the phone?

Mr. Ne'eman: Yes. This is Ari Ne'eman.

I guess one of the big questions that I would raise here is, how can we ensure that the jobs agenda that is moving forward is really promoting jobs in integrated settings at or, hopefully, above minimum wage?

I know many of the folks in the disabilities community have been concerned as of late at the overreliance on sheltered workshops for the developmental and

intellectual disability community.

So, I just wanted to flag that issue and see if Jeff wanted -- or I'm sorry, I don't recall the name of our other speaker -- but see if either of our speakers wanted to weigh-in with regard to that.

Mr. Sell: Ari, this is Jeff. Yes, I do.

I think the key to it is a twofold approach. No. 1, we have been looking at 14C certificates and sheltered workshops and more segregated settings for far too long as acceptable. We have recognized, I think from our experience back in the seventies and eighties in shutting down institutions without having appropriate home- and community-based supports in place, that that was a mistake. It was the right thing to do to focus on that and to go down that path, and to get our folks more out there in the community and provide them with the appropriate supports they need to thrive. However, the home- and community-

based supports were not there at the time.

If you equate that to the jobs issue we are looking at now, 14C certificates and other benefits to employers are just not sound policy for a variety of reasons. I think some of the crises that we have seen or horror stories, such as Henry's turkey farm out in Iowa, where individuals were making 14 cents a week and living in squalor conditions, but, yet, they were drawing down large amounts of Medicaid dollars -- at least the employers were; it was not being passed on -- it is a practice that has just come to an end. It has reached its time and it is unacceptable to those of us in the intellectual and developmental disability community.

However, with that said, we have got to start ramping up employment-first policies and focus on customized or integrated employment in a non-segregated setting or in an integrated setting and providing the supports backstream from the transition stage.

It can be done. It is a policy that we have examined. And, Ari, you have been very helpful with the work on the collaboration to promote self-determination.

But I don't think we will be successful if we don't have both pieces of that puzzle, the first piece being the employment-first policies and, then, secondly, phasing out over a period of time in a way that makes sense to all stakeholders the 14C certificates and the sheltered workshop problem that over 400,000, nearly 500,000 people are placed in at the present time.

Mr. Grossman: This is Lee.

I am going to channel Stephen Shore since he still can't get on the line, but he did send me a question.

Dr. Shore: I did get on the line. I don't know if you can hear me.

Mr. Grossman: Oh, okay. Good timing.

Dr. Shore: Can you hear me?

Mr. Grossman: Yes. If you could speak up a little bit louder?

Dr. Shore: Oh, okay. Good.

Anyway, I heard Jeff say something about, I think I heard him say, if I heard it correctly, that if we don't provide assistance now, we are going to pay seven times more later. I was just wondering if anybody has cost it out, what this massive under- and unemployment of people with autism costs society in the United States. I know that there has been some work on lifetime cost of autism. But I think it might be a really powerful number, if anybody had it.

Mr. Sell: Yes, Stephen, this is Jeff.

Spend one now and save seven later, that is Jeff. If you need to cite that, that's me.

I have seen some actuarial data that is all over the place. I have actually taken it apart a little bit from a

cost/benefit side, and it is a little bit more challenging. But the one in seven I think represents the average of four or five pieces that I have looked at and that I can cite. It could be a little bit more; it could be a little bit less.

I would like to see the GAO or some other organizations really take a good, hard look at this and give us some number that we could cite to state legislatures and cite to Congress, rather than some of the studies that, looking at it as if I was going to cross-examine the author back in my old trial lawyer days, I am not real comfortable with some of what I have seen, but I think we are getting there. But I don't think we have a real concrete, definitive number in the context in which I would like to have it just yet.

Dr. Shore: All right. Well, at another time, I would like to talk to you more about this.

Mr. Sell: Okay.

Dr. Shore: Thanks.

Mr. Grossman: Other questions from the Committee?

(No response.)

Let me make a few comments then. This is Lee.

I know from our experience at the Autism Society this crisis is just unimaginable at this point. We are getting calls daily from families that are losing their services. People are being kicked out of their employment programs, out of their housing situation. It has reached a crescendo that is truly remarkable, unbelievable, and tragic.

For me, I believe that in our advisory capacity with the IACC this is something that we need and that we are certainly compelled to do, to make recommendations to the Secretary to begin to address this crisis.

How best to do that? I think that is needed to be done by the full wisdom of the Services Subcommittee, but I would like to make a recommendation or a motion for us to discuss that some of us be given the authority to draft a letter to make recommendations to the Secretary that we would, then, present to the full IACC for their consideration. And if approved, then it would definitely go to the Secretary.

Any comments?

Mr. Ne'eman: I think a letter to the Secretary around this is a great idea and an important step. But my hope would be we could take action on that immediately.

Mr. Grossman: Ari, were you saying take action on doing a letter to send to the full IACC or what was your action?

Mr. Ne'eman: Well, you know, my hope would be that we could draft a letter, that we could authorize our Co-Chairs to draft a letter to present to the full IACC.

I think, to my mind, this issue, particularly around the issues of the upcoming budget cuts related to the enhanced FMAP, and other areas relating specifically to Medicaid, and some of the issues around Medicaid and upcoming budget cuts, and just some opportunities for people on the autism spectrum, I see no reason why, given the kind of testimony we have heard today, we couldn't authorize sending a letter to the full IACC with our Co-Chairs drafting it on this.

Ms. Blackwell: This is Ellen.

I was just going to ask that maybe we could table this discussion until I do the next presentation where we talk about some of the opportunities that states do have at their disposal now because of the Affordable Care Act and that could be taken advantage of to help people with autism. Because the Secretary is well aware of most of the things that I am going to touch on in my presentation.

Mr. Ne'eman: And I think we definitely should cover that, but I think the thing that jumps out at me, Ellen, is we are empowered with regard to the IACC to make recommendations to the Secretary. Unfortunately, we are not so much empowered to make recommendations to the states. So, I definitely think we should hear that presentation. I think it is very important. I think it is very relevant.

But there are things that we can be advising the Secretary to do through HHS, OCR, and CMS in anticipation of this upcoming expiration of the enhanced FMAP. I think given what is at stake for people with disabilities, we need to be seriously considering those things.

Dr. Daniels: This is Susan.

I just wanted to take a moment just to check to see if anyone else has joined us on the phone, whether Denise Resnik or Henry Claypool have joined us.

Dr. Strickland: This is Bonnie. I'm here. I have been here since --

Dr. Daniels: Oh, great, Bonnie. Thank you.

Dr. Strickland: I am sorry I couldn't get down there. I got out of a meeting late.

Dr. Daniels: No problem. So, great. I just wanted to have an accurate idea of who from the IACC was on the phone. Thanks.

Ms. Blackwell: This is Ellen.

I am waiting for a little help with my presentation to come up here.

Actually, I put myself on the agenda today. The timing actually seemed good because Joy and Jeff were going to be talking about budget challenges, and I wanted to just take a couple of minutes to talk about the tools in the Affordable Care Act that Joy mentioned earlier.

It is kind of like there are some

really good incentives for states that can help them solve these problems, maybe not solve the problems, but maybe help them address some of the problems.

But I think Joy accurately pointed out that with shortages in state staff, and perhaps long-time experience that has been lost as people retire, that especially with these new options, it is very hard for states to try to figure out, what do we need to do? Where's that deadline?

So, CMS, my agency, is doing a lot of work to try to support states as they try to figure out these problems. We see that every day.

So, this is just a quick slide that gives you an idea of the breadth of the Medicaid program. If you do the math here, it is over $300 billion a year. You can see that the nursing facility spending still outweighs the spending on long-term services and support, even though ever since 1981, when the

home- and community-based services benefit was added, it is still really the scale is not fully tipped into community-based services.

Also, we should note here that state systems are still fragmented and very complex to navigate for families and people with autism.

So, what does the Affordable Care Act do? It really supports integrated settings. It offers a lot of new options in the world of home- and community-based services or it strengthens those options that were already there.

It helps so far as linking services and in some cases it offers enhanced FMAP, which is the state match that Joy referred to, to help states modify their delivery systems.

Most states receive about a 50 percent match from the federal government. States that are poorer states receive a greater percentage of match from the federal government.

So, let's talk about some of the benefits. The first benefit that I wanted to mention is Section 2302. This really memorializes in the state plan a concept that CMS began supporting several years ago. Many parents who have children that have been diagnosed with life-limiting illness were forced to resign their curative care to elect hospice services. A couple of states, California, Florida, Colorado, actually established home- and community-based waivers that permitted parents to get some home- and community-based services while their children were enrolled in hospice.

So, this is a nice option. Again, it is an optional program the states can elect to put in their state plans that provides children with medical care at the same time they are enrolled in hospice care.

Okay. This is a big one, Section 2401, the Community First Choice Option. It will be effective October 1st. It adds a new

section, Section 1915(k), to the Medicaid program.

It is an optional state plan benefit, again, an optional benefit. It has certain benefits embedded in it, attendant care, other support. It has an option for states to elect self-direction in terms of service delivery models.

People have to have a pretty low income, 100 percent of the federal poverty line, or they have to meet the typical institutional-level of care requirements. This is one of those programs where states do get a 6 percent enhanced federal match, which one would think would be attractive, but, again, we don't know exactly how this will all come out.

CMS did publish a Notice of Proposed Rulemaking. I included the regulation number here in case anyone would like to read it because we are accepting comments on this regulation until the end of

April. It is CMS 2337-P. I would urge everybody to take a look at that.

Section 2402, several people that are involved in this Committee, Henry Claypool, Sharon Lewis, people from my agency are involved in this provision of the Affordable Care Act.

It looks at how to remove barriers to home- and community-based services and directs the Secretary to promulgate rules. This is more of a cross-HHS perspective. So, we are on that Work Group at CMS, and we are working on it.

Section 2402, also some changes to the Section 1915(I) benefit that was put into this statute in 2005 as part of the Deficit Reduction Act. This is an option that I think the Congress envisioned would substitute for sort of the workhorse of the fleet benefit, the home- and community-based services waivers, I mean that a lot of folks may be used to hearing about.

The benefit as it was initially put into the statute did not permit states to provide other services, which are a really important piece of home- and community-based services, to just include the statutory services and, also, initially permitted states to target particular geographic areas.

So, now some modifications were made to this benefit through the Affordable Care Act. States are actually required now to provide services statewide. They cannot cap enrollment the way they can in the home- and community-based waivers.

So, I think, as a tool, this is just another different piece that a state would want to look at in providing home- and community-based services. I don't really think it is better or worse than something else. It is just when a state is evaluating how it is providing these services, it does give them an additional option. So, there it is. The Congress put it out there.

Section 2403 relates to our money-follows-the-person demonstration. This is a demonstration that, again, went into place through the Deficit Reduction Act in 2005. But this time the Congress said we are going to keep the money coming. So, we recently awarded an additional $4-some billion to these additional states.

The program is really tailored to helping people who are living in institutions get out of them. So, I see it, it provides some transition services to people, either people who have been living in institutions for a long time -- most of the people have to be living in an institution for at least six months. It provides states just another way to try to get them into community settings. Most of these people end up being enrolled in home- and community-based waivers, but there are some additional supports available for them in that transition process.

The adult health quality measures

piece, Section 2701, I think it is important to mention this because in the past we talked a lot about child health quality measures. So, this is really the first time that the Department has weighed into looking at adult health quality.

So, that is coming. I think there was already a request for comment that was sent out. Those are due in January of 2012.

So, Section 2703, this is a big one, the health home provision. I think in some ways we have states very interested in this provision, as Joy knows.

We have issued a State Medicaid Director letter that talks a lot about this. It was effective in January.

The law itself actually includes specific conditions, but it does leave a little bit of leeway so far as other conditions that a state might want to identify.

It is a very nice benefit that

makes the assumption that people should have a team of people who understand their needs helping them navigate the home- and community-based services and medical services that they need as an individual.

Now CMS is also providing some support to states to sort of design these programs, and states receive a 90 percent federal match for the first eight quarters that they implement the benefit. Then, their match reverts to what it was previously. Again, one of those things where that's how the Congress wrote it.

It does raise questions about how a state would sustain -- I see Joy nodding. You know they get the money upfront, but, then, what happens after the eight quarters? So, I think that if I were a state -- of course, I am not a state -- I would have to be thinking: well, is my investment going to pay off? What do we know about cost savings involved in this sort of program?

But, generally, we are very supportive of these efforts. They certainly go to the more person-centered system that we like to see.

The balancing incentive program, this is Section 10202. It is effective in October, and it offers, as Joy said, puts additional money on the table. We hope states will take it.

But this provision is really helpful to states that are sort of struggling with that big imbalance between their institutional care and their home- and community-based services.

Then, there are certain requirements that states have to implement to get this additional money. So, we are working on getting additional guidance out on this provision, obviously. We are working on it very hard, but I would hope that some of the states that are struggling with getting a more balanced system take advantage of this.

Section 6407, this is a provision that relates to physicians actually having face-to-face encounters with patients before they certify that the individual needs medical equipment and supplies or durable medical equipment.

And, then, care coordination, these two provisions are pretty interesting to me. The first one actually applies to different kinds of Medicaid waivers, Section 2601.

Previously, the Medicaid statute permitted states coming in with new home- and community-based waivers to receive only three-year approvals. This Section 2601 says that it really applies to people who are duly eligible for Medicare and Medicaid. But a state can possibly ask the Secretary under certain circumstances if she would approve a five-year period. Or, for example, in a Section 1915(b) waiver, which is traditionally a two-year approval, would the Secretary consider offering a state a five-year

approval? So, there could be some administrative simplicity and savings in Section 1601 for states if they can meet the criteria listed in the statute.

Section 2602 established our new Federal Coordinated Health Care Office. This office, which is led by Melanie Bella, well-known to many folks in Medicaid, is very interested in looking at this group of people who are dually eligible for Medicare and Medicaid.

As you can see from these numbers, there are costly enrollees in both programs. We are looking at distributing grants to states to try to figure out how to serve these people in a really good, quality way and help states experience cost-savings.

So, Joy mentions what happens in 2014, perhaps 16 million new people come into Medicaid. My observation is that states are, indeed, very interested in trying to figure how they are going to gear up for this new

group of folks in terms of physical infrastructure, service infrastructure. I know that many of our states are really focused on that now. And you can see about 50 of them may be served through the Medicaid program.

So, there's a lot of opportunity. I think as we have heard here today, there are certainly plenty of challenges at the same time.

So, this is what we hope the new, redesigned service system will look like. You can see the person-centered part at the top. I really hope that we can preserve that and keep that at the top because it is really, really important.

People like to have control of their services. We would like to see some of the service systems that are now fractured be much more integrated. And, then, of course, we want to preserve quality, especially as we see states backing off services, reducing

amount and duration, scope. We want to make sure that people are safe and healthy in all of our programs.

I am just going to go through these very quickly. These are the provisions of the Affordable Care Act that support person-centeredness: individual control, quality, and integration.

These are the pieces that offer states that additional money on the table that I hope that they are not walking away from, Joy.

And states, in addition to this new stuff, there's plenty of good old stuff in the Medicaid program. Home health benefits still includes medical supplies and equipment. There are lots of good benefits in Medicaid that are mandatory. But as you have seen before when I carried the mandatory and optional list into a presentation, it is not what people typically expect from their health insurance programs.

So, I looked at our autism programs yesterday when I was writing this slide. I counted 14 Section 19158 waivers that are targeted to people with autism. Only one of those service adults.

And, then, one section 1915(a) contract in Pennsylvania that is aimed at adults. I actually think that this Section 1915(a) is a far underused provision in the Medicaid statute. I really like what Pennsylvania did with it. It could be used very well for demonstration programs, where a state might not be interested in looking at Section 1915(a), maybe where a state has just one provider who is interested in providing services to a particular group of people in one particular geographic area.

I mean we run several 1915(a) contracts. There is a big one in California called SCAN. They just sort of pop up around the country.

We don't normally review them at

CMS. Our regional offices approve the contract between a provider and the state. But I think there is potential there. That is one of the old benefits in Medicaid.

In the home- and community-based waivers, the services are all over the place. There is usually a behavior support service for people with autism. A lot of these waivers are aimed at children. So, they are looking at early intervention services that might not be available under the optional rehabilitative services benefit.

And, then, each state and the District of Columbia maintains a waiver targeted to people with intellectual disabilities. So, we know that there are many people with autism served in those waivers, in addition to these targeted waivers.

And, then, I believe there are probably some people with autism served under the approved Section 1959 coverage. I would really have to go look at each of the states.

We probably have maybe 10 or 12 states that have used Section 1959, but for different populations and different purposes.

But here is our list of states. The ones at the upper right end are the most recent ones: Nebraska, Montana, North Dakota. We actually have a couple of states now that have exhibited interest, even in this economy, in establishing new home- and community-based waivers for people with autism. I think these were probably initiatives that ramped up a while ago that are ripening now.

So, what are we to do in CMS to help in the Medicaid program in particular? We understand the states have serious budget concerns. We see it every day in what they submit to us in their requests.

On February 3rd, the Secretary issued a letter to the Governors. I would urge you to read that letter, if you are interested, where she indicated our willingness to work with states to help them

try to figure out what they need to do. We are actively doing that.

States can come to CMS and say, "We need help. Here are the areas that we want to talk to you about." We immediately establish what we are calling MSTAT teams. We meet with our states as often as they like. We talk about whatever they want to talk about. We stand ready to provide them with immediate technical assistance, and we are already in the process of doing that. I think I was on two or three MSTAT calls this week already, and it's what, Tuesday?

So, you can see that the states are taking advantage of the Secretary's invitation to provide help. We are certainly doing our best, sort of like the ambulance, just send that ambulance right away. Because I always think we are the best.

I mean maybe I am biased in this way, but states can purchase technical assistance from others, but I always think we

are free. States can come to us and ask, "What do you think?" or just say, "Here's what we want to do." Then, we are happy to help try to figure out what that is. Maybe that wasn't always the perception, but that is absolutely the truth.

So, part of this piece that is really important is transforming the long-term services and support system. So, in our effort, we are really trying to help states figure out ways to continue to keep the emphasis on long-term services and support.

We are working on a Section 1115 waiver template. We have a number of states, California, Hawaii, Vermont -- I am trying to think. Arizona was the first state really to use the Section 1115 authority to provide home- and community-based services.

As Joy said, states are using managed care delivery systems as one mechanism to look at how to save money in these long-term services and support programs.

So, the Section 1115 authority has become even more popular in the past year or two. Instead of rewriting the wheel every time a state comes in and wants to put long-term service and supports into its Section 1115 demonstration, we are trying to come up with a streamlined way to do that, so we don't have to rewrite our wheel every time.

But we have learned. We have learned from California. We have learned from Hawaii. I mean every time we do this I think that that was another piece of trying to build what this template will look like in the end. And we are still learning.

So, we are also looking at issuing some guidance on how to use managed care because, again, that is what states are doing. We worked extensively with the State of California, which recently mandated seniors and people with disabilities into its revamped Section 1115 waiver.

That is another place where, if you

are really a policy wonk -- I know at one point we met with the State every day, every day for months, Joy. Okay?

So, there is a section in that waiver on seniors and people with disabilities, and it is posted on the California website. It is also on the CMS website.

But I think there is a lot of good information in there about the types of safeguards that the CMS required the State to integrate into that demonstration that, again, are the building blocks, rather, could be the building blocks for other states.

So, this is the three-part aim that our Administrator, Dr. Berwick, talks about: population health, experience of care, per-capita cost. If you hear about the three-part aim, there it is.

And, then, here are some links that I thought might be helpful. We have also established an Innovation Center. I think

that is a good website. It is sort of keys into the Federal Healthcare Office that is looking at duals.

There's our regular website. You can actually go on the CMS website. If you click the Medicaid link, you can find the home- and community-based waivers in your state. Every one of them is up there. Every amendment is up there.

I always tell people, you know, the best thing to do, if you want to understand a waiver, is to read a waiver. It might not be the "funnest" thing in the world to sit down with a couple hundred pages, but if you really want to understand the services that are available to individuals who enrolled in these waivers, you need to look at Appendix C, which was to services, and Appendix J, which talks about the state budget forecast associated with those services.

And, then, again, you can get updates on what we are doing at CMS signing up

at this little link here.

Then, tomorrow there's this sort of little-known Work Group called the Multiple Chronic Conditions Work Group. I am on this Work Group right now representing CMS, but I haven't really seen autism come up as a focus of the Work Group.

It has done some very good work in terms of people with chronic conditions. Many people with autism have concurrent chronic conditions, as we all know, for example, seizures disorder.

So, this is a Work Group that crosses HHS. I would urge you to take a look at that website. We issued a strategic framework for people with multiple chronic conditions. I just think it is part of the autism equation, too.

So, that is my happy news. There is stuff out there. How states use it -- because, again, Medicaid is really a state-based program -- it is really up to the

states. And as Joy represented here today, I guess it is a bad pun, but they are kind of all over the map in terms of how they are approaching what they are doing with their Medicaid program.

So, we are watching this play out on the federal end. I am sure everybody in the states is watching it play out in the state end. It is a very difficult time for everyone, for state employees, for federal employees, for people that are enrolled in our programs. I mean we all have to work together to try to solve some of these challenges.

Okay. So, I will turn it back over to you for a minute, Lee.

Oh, does anyone have questions?

Dr. Rice: Ellen, this is Cathy Rice. I just have a quick question.

Can you guys hear me?

Ms. Blackwell: Yes.

Dr. Rice: These presentations have been really helpful. Will these be posted on

the website, so folks can access them with all the great links and resources that are available?

Dr. Daniels: Yes, we will post them on the website, Cathy.

This is Susan.

Dr. Rice: Right. Thank you.

Ms. Blackwell: Go ahead, Joy. Joy had a comment.

Ms. Johnson-Wilson: I would just say, with respect to some of the new opportunities in the Affordable Care Act, to the extent that the state was moving in that direction, they are more likely to take advantage of some of those opportunities.

Some of them require that you have something going on or that you are going to increase something. This isn't the right time for that.

But if you were already trying to increase your home- and community-based services, and you had something in motion and

maybe weren't able to fund it, then that is when some of these new opportunities are most helpful.

But if they require new investment, or if they have a large enhanced match that drops off, been there, done that, and they are not so anxious to pick up an enhanced match that doesn't fill out.

So, I throw that out there as something. They will ask, "And what happens after that?" So, if you want that, then you have to help identify how you sustain it over time. So, I just make that recommendation.

Ms. Blackwell: Other questions?

Ms. McKee: I just have a general comment about the discussion that was following with staff. I guess I want to be, as we head forward into the next section talking about possible topics for a services workshop and possibly getting together with the Safety Subcommittee, what we are really talking about is what Joy brought up. That is

picking our babies.

To give you a little story, when she mentioned that Medicaid is coming after education, I have a personal story to share here. Where I live, the thing that might be on the chopping block is the program that supplies support for augmented communications technology/visual support for our kids.

If you go down the list of what we know from our research that was published last year about our evidence-based practices, that is what is on the chopping block, all of this research we have done on how to teach our kids in K through 12, at the core of it.

So, we need to see doing some real communication with our providers. I think that this group needs to get together. I am not sure about workshops and townhalls. I would love to see the advocacy organizations, people who have been out there working, come together and to have more of a focused group discussion about how is it that we as a

community create the loudest voice and prioritize these babies, so we are not all pointing at each other, so Medicaid doesn't get the money over our K through 12, where we have this huge investment now. And now we might not realize its benefits.

So, I would really like to see that kind of activity as we move forward, and to really take Joy's advice to try to pick our babies and what we are really going to move forward with and focus on with Secretary Sebelius.

Mr. Grossman: Are there any questions from anybody on the phone?

(No response.)

This is Lee, and let me respond to that, Christine.

I would think that in the recommendation that I was making for the Services Subcommittee to move forward to make recommendations to the Secretary, that is really the only thing that we can do in our

capacity here, based on our FACA rules.

I would hope that whatever recommendations would come out would be broad-based enough that it would cover not only the adults, but it would cover education, everything.

Because these budget cuts, this crisis that is occurring is impacting early diagnosis, early intervention, transition services throughout the lifespan, adult services, education. It is taking away people's augmentative devices.

To me, that is something that everybody here at this table should be supportive of, that somehow we have to bring to attention that what you are taking away is not somebody's job, for example. You are taking away everything that they are able to, primarily most of what they are able to subsist on and to have some sort of quality of life.

That is the impact of these cuts.

It is not that you are maybe getting by with a little bit less. You are getting by with nothing. These cuts are that dramatic and they are that harmful to the individuals impacted and the families that are trying to help them.

We get calls every hour about this. I got a call from a friend of mine who has been very active in the autism community for decades, who is a real leader. He lives in Illinois. He is 75 years old. He basically retired two years ago. His son is severely impaired. He is in his late forties. And he got a letter just two weeks ago from the State of Illinois saying that his services are gone.

This guy called me up. He is a friend of mine. We cried together on the phone because I had no solutions for him. He doesn't know what to do now. He has no clue what steps he is going to take. He doesn't know where to put his son. He cannot care for his son.

And probably what is going to happen is that his son will end up on the street and become either incarcerated or institutionalized, which is something that this gentleman has worked most of his life to avoid.

And these are the types of cuts that we are facing now. I think that, at a minimum, this Committee and the IACC as a whole should be raising this to its highest priority, to ask the federal government to do something about this, to step in.

I think that we can come up with some logical plans and some recommendations that we can put forward. You know, some of the things that Ellen described are very meaningful. I think that there are some other suggestions that we could put on the table. But just sitting here and not saying anything, to me, right now is not an option.

Ms. Blackwell: I think that a lot of the frustration with Medicaid goes back to

the way that the program is all structured. Joy mentioned that at the beginning. I mean this program was designed in 1965, and the benefits that people really want and say that they need are optional benefits.

That is where states are really, really struggling, these home- and community-based waivers, home- and community-based services -- I'm trying to think -- dental, mental health services. I mean these are things that people don't generally consider to be optional services.

I mean as long as an individual is zero to 21 and they are eligible for Medicaid, they are covered by the Early Periodic Screening, Diagnostic, and Treatment Program. But I think that where we are really starting to see the pain is in the adult services world. I mean we already could see that there was a big drop-off there, but now it is huge. It is a chasm.

So, for that population, in

particular, I mean states are required under the statute to provide EPSDT to children. And they are facing these new obligations in 2014, but so far as the over-21 crowd, that is where you are really starting to feel the pain.

And again, we don't have the answers. So, I think that we need to think about, if we make recommendations, what would these recommendations be? What could the Secretary do in her role as Secretary?

Because I have to say that I think the Secretary is aware of all the things we discussed today. So, what could the Secretary do to change? You know, I think that is what we need to focus on and really talk about doing.

Others?

Mr. Grossman: Are people still there?

(Laughter.)

Ms. Blackwell: Well, I guess our next order of business --

Mr. Grossman: Well, I mean I just don't want to drop this because I put it out on the table that we should make some sort of, somehow put something together to make a recommendation to the full IACC on addressing this crisis.

I mean saying that she is aware of it, I would hope and would appreciate that and understand that. I think the Committee coming forward and stating the problem and, again, making some level of recommendations would be much more impactful, and to move it up to the highest priority.

I feel that, going on what Joy had mentioned, that we have to get loud. We have to be out there. We have to be making statements.

I can't think of anything that is more important right now for us to be advocating for the needs of our community than by bringing --

Mr. Ne'eman: Hello.

Mr. Grossman: Yes?

Mr. Ne'eman: I apologize. I was on listen-only for a moment. I was trying to weigh-in when you were soliciting feedback.

Mr. Grossman: Yes, I was surprised you were quiet, Ari.

(Laughter.)

That's a positive statement.

Well, do you want to say something? I will be quiet maybe.

Mr. Ne'eman: Well, I just wanted to weigh-in very briefly that I agree very strongly with what you and Ellen are saying around we need to move our attention now to what can the Secretary be doing about these things.

To me, I think there is actually substantial leverage for action. I mean we cannot fundamentally change the nature of the Medicaid program, but we do have HHS OCC, Health and Human Services, Office of Civil Rights. So, we can encourage them to really

explore and investigate systemic Olmstead complaints. We have CMS, and CMS has some enforcement powers.

I think it would just be very positive if they got a strong message from the IACC which says, when you are looking at states that are applying to amend their state plan, really take into account the impact this is going to have on people with disabilities.

And, then, finally, I think it would be really valuable if we really communicate to the Secretary that we support the work that Tom Perez is doing in the Department of Justice to stop a lot of these budget cuts where it would threaten the right of people with disabilities to live in the community, and we really hope HHS provides all possible support and coordination to the work that Justice is doing.

Dr. Houle: Hi. This is Gail.

I wanted to ask, do you have available -- I know it would be, it is

available in the public domain -- a copy of the HHS Administration requested budget for this fiscal year and next fiscal year?

Dr. Daniels: It's on the web.

Dr. Houle: It's on the web? Okay.

Dr. Daniels: Yes. Yes, if you need a copy of that, we can hunt it down and try to provide it.

Dr. Houle: I can get it. I can get it on the website or THOMAS. I was just wondering if there were specifics within there that you felt needed to be addressed.

Mr. Grossman: I guess I will sort of back up the Committee. This is Lee.

I mean I would like us to make a decision here if we are going to put something together as a recommendation to the Secretary for the full IACC to consider. I would like us to make a decision on that either way. Then, if we are to do that, to assign people to actually put the letter together in a reasonable timeframe.

Any thoughts?

Ms. Johnson-Wilson: I just have one thought. You are not going to stop the budget cuts.

Mr. Grossman: Right. Right.

Ms. Johnson-Wilson: So, that is not an option.

Mr. Grossman: Right.

Ms. Johnson-Wilson: You know, the states have to balance their budgets and they will balance them. So, that has to happen. They are going to take care of the mandatory populations first and, then, everything else is on the table.

Mr. Grossman: And, Joy, you are absolutely right.

Ms. Johnson-Wilson: So, I think that is important.

Mr. Grossman: Right. No, you are absolutely correct; we are not going to be able to stop the budget cuts. They have to happen. They will occur.

But in our capacity here, we should be able to offer some solutions to them in terms of how our community wants to make them aware of the impact that it has and, then, to make recommendations on what can be done to lessen that.

Ms. Johnson-Wilson: Yes.

Mr. Grossman: And I think that that is in the spirit of how we would make these recommendations. Otherwise, they probably won't be looked at seriously.

Ms. Johnson-Wilson: I would urge you to take a look at the Administration's budget.

I am just saying they have to make some cuts, too, yes, which makes our life a little harder at the state level because a lot of that is going to come out of state and local government.

Mr. Grossman: I am proposing a motion. A second to the motion?

Ms. McKee: I guess I am unsure,

have we decided what the issues are that are going to be in the letter? Or just kind of a summary of what we have been presented?

Mr. Grossman: No. What my motion is, that we put together or we have some people that will work on this letter that will I guess at this point have to be brought back to the Services Subcommittee before it is addressed at the full IACC.

The only other option would be for the Committee to authorize somebody to draw it up and, then, submit it to the full IACC by the next meeting. I would imagine that perhaps the Services Subcommittee would like to look at it at some degree.

I guess the two options that I am proposing is that (a) people to get together and start to draft the letter and then it be brought back to the Services Subcommittee as soon as possible or (b) to have somebody who is authorized to do the letter, complete it, and, then, bring it to the full IACC.

Does that clarify?

Ms. McKee: Yes.

Dr. Strickland: Lee, this is Bonnie.

In terms of what the letter is, I mean I understand what it is not, that it is not you can't cut these programs anyway. But is it more of a letter just to let the Secretary know what the concerns are and to be very specific about that? Or when you said recommendations, that is where I am sort of struggling. Like what would the recommendations look like?

Then, I had a question for Susan, too. I know previous letters have gone to the Secretary, but I was not in the sign-off loop. So, I don't know whether that just happens at the IACC letter or whether that goes through the member agencies.

Ms. Blackwell: Bonnie, this is a FACA Committee. So, the word of a FACA Committee is a non-government document. So,

agency clearance is not required for the word of a FACA Committee.

Dr. Strickland: Okay.

Ms. Blackwell: What would have to happen is for the letter to be drafted and for it to be approved by a majority vote of the full Committee. If the full Committee approves it by a majority vote, then it could go forward.

Dr. Strickland: I see.

Ms. Blackwell: It can be drafted at the Subcommittee level or by some subgroup of the full Committee, depending on what you would want to do, if that is the kind of action you would like to take.

Dr. Strickland: Okay. Thank you. That is very helpful.

So, then, back to the recommendations, are we thinking that they are recommendations specifically related to funding? I am just not sure that the IACC can make specific funding recommendations, I mean

around agency budgets.

Mr. Grossman: I don't think that they would be funding-related. They are more of bringing attention/awareness to the critical nature of what is happening. And I think that we can make policy recommendations. But we would not get into funding.

Dr. Strickland: I see. Okay. Thank you.

Dr. Rice: Hi. This is Cathy Rice.

And this may be an ignorant question, but would it be the Office of Civil Rights or where would an individual go if they lose essential services? So, like in the situation Lee talked about with your friend who is now in the position of not being able to care for a family member, and that family member being at risk for homelessness or other tragic consequences, is there some sort of federal board or place that is under the auspices of the federal government or, particularly, HHS that we could be referring

to in this particular situation of asking that that entity be heightened in terms of their awareness of this issue or have some process to hear these appeals? Is there anything like that?

Ms. Blackwell: Cathy, this is Ellen.

And I don't know the specifics of the situation that was referred to before. But if the individual is a Medicaid participant, there are structures in place -- it depends on the services the person is receiving -- for that individual to file for a hearing, an appeal, go through the regular Medicaid hearing and appeal process, that the state under some circumstances must continue to provide the services until the matter has been adjudicated.

So, the Medicaid program does have a formal hearing and appeals process. Now I don't know where this individual was getting his services from, but there are safeguards in

place to assure that people have appeal right.

Dr. Rice: Yes, I was just curious in terms of the focus of what we are requesting. If, in reality, we know these massive budget cuts are coming, they are going to hurt in a lot of places, can we focus recommendations on making sure that the systems are in place to help those individuals that are really going to be at significant, significant need, not that everybody who is losing services is at significant need, but those that are extremely serious situations, and that we are asking for some coordination or intense effort in terms of making sure those appeals processes are in place and are not cut as well?

Mr. Grossman: First of all, I think Jeff wanted to say something. But, for those of you on the phone that are on listen-only that are part of the speakers, we are trying to correct that. If you could hit *0, that might solve your problem. Because I am

getting texts from people that are trying to talk.

Ms. Blackwell: Is there somebody that did not use the leader code and used the public code to try to get on? You need the leader code that was in my email that went out to the Subcommittee. You can either use that or press *0 and mention that you are a member of the IACC who needs to be on a speaking line.

Mr. Sell: Yes. And, Cathy, this is Jeff Sell.

There are numerous administrative ways which can take a long time and can be somewhat burdensome, but they must be exhausted. There is the Office of Civil Rights within the Department of Justice. There is consumer advisory and more action-oriented councils, city/state.

But, quite frankly, there is some limited immunity, and some of the more barbaric things that I have seen happen

recently have got trial lawyers talking about examining that limited immunity. And I was going to go back to a trial by 12 of my favorite people, jurors.

I don't know if we are going to get to that point, but I know there are a lot of lawyers that are looking at some of these cuts and a variety of abuses that they have perceived. So, I think that is what we would all like to avoid, and I am an ex-trial lawyer. I would like to avoid them, too, but the choice is ours.

I mean we can make recommendations. We can start making substantive change. Or I have a feeling it will end up in the trial lawyers' court.

Mr. Ne'eman: Well, we have seen a few budget cuts actually stopped or mitigated through litigation and intervention from the protection advocacy system and the Department of Justice filing amicus briefs.

I am thinking particularly of some

of the more Draconian cuts that were proposed, pushed forward to California's in-home services and supports program. Some of that, at least for a time a hold was placed on that by the courts.

So, I mean I do think what Ellen raises around Medicaid's infrastructure, that is one area. I think HHS OCR is certainly another area.

But, really, the biggest, I think the real leaders on this in terms of going after states that are making cuts that violate Olmstead is Tom Perez's Civil Rights Division in the Department of Justice.

So, I mean, even if we are just flagging that that is going on in Justice and telling the HHS Secretary, "We hope you are complementing those efforts to the maximum degree possible," I still think that is significant.

Ms. Blackwell: Yes, Ari, this is Ellen.

I have been thinking about this letter, which is still a little ill-defined in my mind. But because this Committee is really focused on individuals with autism, it seems to me that if we sent a letter, we could, indeed, say, you know, we are here to raise your awareness about how the budget and what is happening in the states is perhaps disproportionately affecting people with autism. I don't know if it is disproportionate or not, but we could definitely say that is the purpose of the letter.

Then, I would say definitely encourage the support of Tom and the OCR efforts to follow Olmstead and the ADA.

Another piece I got was from Jeff's presentation, perhaps issues of CMS or urge CMS to issue further guidance on job support programs.

I mean what we could ask for is we could ask the Secretary to look at the impact

of states' cuts on people with autism, but I kind of like your idea of focusing on OCR. I mean I think once you start putting too many things in a letter, it just starts to get cluttered.

So, right now, with these cuts, you are right, the biggest thing that is going to interfere is going to be OCR's efforts to make sure that ADA and Olmstead are preserved. So, it seems to me like that is what is at the bottom of all this discussion. And that would be a very good letter to show the Committee's support that I think that everyone could get onboard with.

Mr. Ne'eman: Well, let me just add one additional component here. I think it is what we can tell the Secretary we want her to do, but it is also just as much what we can tell the Secretary we do not want her to do.

I mean the fact of the matter is that there are very robust conversations going on right now, not just on Capitol Hill, but

also in the Administration and within HHS, on providing states more flexibility in their Medicaid program. And you know, there are some ways maybe that more flexibility could be a good thing if it freed up some of those dollars that are locked up in institutional spending. But it is far more likely at a practical level that, if HHS puts forward plans to allow states to have more flexibility in how they spend Medicaid dollars, some of the things that are going to get cut are optional benefits like home- and community-based services.

So, I think we want to push forward on that OCR; we want you to use OCR to prevent or mitigate some of these cuts. But I also think a secondary benefit of this is that it sends out almost a warning, so to speak, that essentially says, as you consider your various other plans, make sure you do not forget about our community.

Mr. Grossman: Okay. This is Lee.

In the effort to really move this forward, because we have other business to go, I would like to propose that Ellen and I draft a letter and bring it back to the Services Subcommittee, and that we do it as soon as possible.

I am not really sure -- Susan, you might be able to help us -- on how something like that could be moved forward to the full Committee, if we have to come back together in a Committee meeting or if we can do a vote by email, how to best facilitate that?

Dr. Daniels: If your intention is to bring a draft letter forward at the April 11th meeting, which is only a couple of weeks away right now, you would have to have the letter written right away and, then, have it voted on by your Subcommittee, and you need a majority vote of your Subcommittee to support even bringing it to the IACC. And, then, it could be presented during your Subcommittee update at the IACC. If you can't get

agreement on it right now, you would need to schedule another meeting after the IACC meeting and, then, talk about it further until you could get to some agreement.

Mr. Grossman: Well, if we can get agreement from the Committee to move forward, I would like to give it the old college try to get it done as soon as possible, so we can have something to present on April 11th.

I just got a text from Stephen. He can't speak.

Sorry, Stephen.

But he supports the position. I know he can't vote because we've got to hear his voice.

But the motion would be, then, that Ellen and Lee draft a letter that the Services Subcommittee would, then, by I guess electronic vote, approve for us to bring forward to the full IACC. And we will make attempts to be able to present that at the April 11th meeting. Short of that, then we

will just have to bring it to the full IACC at its July meeting, I guess.

Dr. Daniels: So, do we have a second for that motion?

Ms. McKee: Second.

Mr. Ne'eman: Second.

Dr. Daniels: Christine seconds it.

Unfortunately, because we are on the phone, I am going to need to ask people for their vote.

So, Ellen is in favor.

Lee is in favor.

Christine, in favor.

Bonnie?

Dr. Strickland: Oh, we are voting on what, okay to draft a letter?

Dr. Daniels: Okay for Lee and Ellen to draft a letter.

Dr. Strickland: Okay.

Dr. Daniels: And the options are you can be for it, against it, or abstain.

So, you're for it?

Dr. Strickland: I'm for drafting a letter, but for drafting a letter doesn't mean submitting it to the IACC, right, until we have had a chance to review it?

Dr. Daniels: That is correct.

Dr. Strickland: Okay.

Dr. Daniels: So, the Subcommittee would have a chance to vote on whether to move that letter forward to the IACC.

Okay. Henry Claypool I think is absent.

Gail Houle?

Dr. Houle: Yes, I am in the same position as Bonnie. I mean I am voting on a letter that hasn't any content at this point. I am voting on the idea of a letter.

Dr. Daniels: Okay.

Dr. Houle: So, I mean I would vote yes on the idea of a letter, but I would certainly have to see what the content of the letter was --

Dr. Daniels: Right.

Dr. Houle: -- before I make another judgment.

Dr. Daniels: The letter would need to be finished in about a week and, then, would have to go back out to the Subcommittee.

Larke Huang is in non-voting status at this time.

Ari Ne'eman, your vote?

Mr. Ne'eman: I support the idea. I vote yes.

Dr. Daniels: Okay. Cathy Rice?

Dr. Rice: Yes, to support to draft a letter.

Dr. Daniels: And Stephen Shore is in non-voting status.

Denise Resnik, are you on the line?

(No response.)

So, then, of the one, two, three, four, five, six, seven members that are able to vote, it is unanimous to have Ellen and Lee go ahead and draft a letter. And the goal would be to get this letter back out to the

Subcommittee via email next week. Then, we would probably have to do an email vote about whether that letter can go forward to the full Committee.

And if there is a lot more work to be done on the letter, unfortunately, with the timing, we won't be able to get it to the IACC by the 11th. Then, we would have to have another Subcommittee meeting to discuss it further.

Thanks very much.

Ms. Blackwell: Okay. This is Ellen.

So, our next order of business is to describe that, Lee, you are probably better able to discuss this than I, since you serve on both of these Subcommittees. I believe the discussion surrounded a joint Services and Safety Subcommittee meeting to discuss seclusion and restraint in somewhat more depth than we talked about at our meeting in November.

I don't know. Do we have a tentative date for this meeting yet, Susan?

Dr. Daniels: I don't have a tentative date yet, but it is sometime between May 2nd and May 6th. We are going to try to solidify that and get a date out to the Subcommittee.

Mr. Grossman: Yes. This was a recommendation that came out of the Safety Subcommittee, that we have a joint Committee meeting, again, around those dates. We would have speakers come in that would be discussing seclusion/restraint.

There has been a considerable amount of work that has been done on this. There has been GAO reports written, hearings in Congress. There has been legislation proposed around these issues, White Papers published, and even media attention given to it.

So, there has been a considerable amount of information that is already out

there. We were hoping that, when we do meet, that we would bring some of those experts that have been working on this for a while together and, then, come up with some conclusions as to some immediate action that we can take, again, in our advisory capacity, to move forward to the Secretary.

Chairman Lewis -- no, Chairman Miller; I always say "Chairman Lewis." Chairman Miller in the House of Representatives was the lead on this. During that time, Sharon Lewis, who is Co-Chair of the Safety Committee, one of the Co-Chairs of the Safety Committee, worked very closely with him as the lead staff person on drawing up the legislation.

I think, again, this is one of those issues that the IACC can address, and can address well and easily and quickly. There is certainly enough information out there that we can move forward on this issue. The experts would be easy to bring together.

And it is just a matter of doing that and then coming forward with some strong recommendations.

So, what we need is approval from the Committee, the Services Subcommittee, to agree to meet on one of those days in May to discuss this. So, that is the motion on the floor.

Dr. Houle: Could I clarify, would that be the meeting where we would hear from the experts?

Mr. Grossman: Yes. Yes. We were talking about a half-day or a full-day meeting. Those details need to be worked out. I think we concluded that it would be a three-hour meeting?

Dr. Daniels: I think about a four-hour meeting, from what I understand. It might be starting at about 10:00 a.m., having, I don't know, maybe three presentations or so before probably needing to break for lunch, so people don't keel over from starvation. Then,

moving on with the afternoon, having some discussion time for both Subcommittees jointly, and, then, deciding on their products and action items and next steps before whatever product they want to get ready for the July 19th meeting.

Ms. Blackwell: This is Ellen.

I hear what you are saying, Lee, about the fact that there is a lot of material out there, but I think we need to be mindful of the fact that there are people serving on the Committee who this is not their area of expertise. A lot of the NIH representatives are physicians. So, whatever product this group, this joint group, offers to them, I think that we need to make sure that we are giving them the information that they need to be able to take any action that they would take in the future.

So, we may be familiar with, for example, legislation that George Miller has floated around the Congress. Or, you know, we

had Kevin Ann Huckshorn give a presentation on seclusion and restraint at our meeting. But our job is to get some sort of information and, then, present it to our larger group.

So, I think that we have to bear in mind that not everybody is at the same place in knowledge about, for example, how states deal with seclusion/restraint issues, how local education agencies deal with seclusion and restraint issues. And this issue is not limited to -- other legislation that I have seen, you know, it is mostly targeted at children. It is certainly not an issue that impacts only children.

So, I would just urge a little bit of caution. I am a little concerned in saying that we are going to meet for three hours and then send something to the full Committee. I mean, is someone going to be reviewing all this documentation on seclusion and restraint and then presenting it at the joint meeting? I mean, did you guys talk about that in your

meeting at all?

Mr. Grossman: No, they were just looking for approval from the Committee just to join with them. Well, it wasn't even to join with them. It was just proposed that we work together on this issue and have a meeting to do that. I think all sides would be open to suggestions in terms of the timing on it and how we would do it.

Ms. Blackwell: Well, maybe that is actually part of the meeting, to talk about what we would be looking at and how we would introduce these issues in a way that everyone on the Committee could understand. Because I think that is really important. To me, this would be just the first meeting.

I don't know. I am just throwing it out there because I think we need to give it some -- I am not saying it is not important. I am just think we need to give it some thought. What is the end product? And let's make sure that we treat everyone on the

Committee in a way that makes us all equal when we make a decision.

Dr. Daniels: This is Susan.

One possible suggestion would be, if you are going to have a number of speakers at this May meeting, that when you are giving your joint Subcommittee report on this meeting, that someone could kind of summarize the main points of the talks that you heard. Of course, we would provide all the slides, et cetera, to the Committee, if they would like to review those, but make sure they have that background when you present whatever your product is to them for their final approval.

Mr. Grossman: I guess I think that the way that they can be structured, because of the work that has been done on this, is that by the end of the day we should be able to come up with some pretty strong statements, recommendations, and proposals.

Most of this, quite frankly, is going to be geared around secondary education.

That is what the GAO Report was about. That is what the legislation was about. Because in the adult service sector, even though we know that these things are happening, there are federal laws in place right now that address those. Whether they are being followed, implemented, or enforced is another topic, and we can probably quickly address that.

But what is happening in the secondary school system, which is really the issue that the Safety Committee brought up, is, one, that there is a significant body of work that has already been done on that. It is just a matter of --

Dr. Houle: Lee, this is Gail. Let me ask you, can you make available like a reference to that body? Is it a synthesis or something that the whole Committee could read up on?

Mr. Grossman: Yes, sure. I mean, yes, there is much out there.

Dr. Houle: In the form of a meta-

analysis or documents, any kind of written documentation that comprises the body of literature?

Dr. Daniels: This is Susan.

It sounds to me like there are a number of different reports. If Committee members could provide those reports to our office, we could provide the full listing of reports and copies of these reports for the Committee to review prior to the meeting. But we will need the Committee to help us identify the appropriate reports.

Mr. Grossman: The best resource for that would be Sharon Lewis, who has volumes of information. And, yes, that is a great point, Gail. The Committee should be receiving that and know exactly what the information is out there.

Dr. Houle: Yes. Yes, I agree, because we have a process that we have been following all along with the IACC per se when we make decisions and we vote on what goes

into the strategic plan and what the recommendations are. It includes a review of the body of literature as well as actual presentations by researchers who are involved in that body of literature.

So, there is a way for members to, if you will, get up-to-speed. So that, as Ellen said, we are all starting at the same -- well, we are catching up to the place where other people might be.

Ms. Blackwell: I mean, if you flip the equation from services to the medical side, I think it makes it more clear. We have to treat our partners on this Committee with the same respect, not respect, but give them the same information we would want if we would have to deal with one of their issues that is not our normal area of expertise.

And I would also ask, in addition to submitting materials to Susan, that individuals on this Subcommittee start submitting ideas for speakers for this meeting

because that is going to be very important, especially if it is a three- to four-hour meeting. I mean that is a pretty short period of time, I mean for the Committees to meet, debate, and hear presentations, and then write recommendations. It just seems very ambitious to me.

Mr. Ne'eman: Well, that raises an interesting question to me, which is on the issue of restraint and seclusion. I mean, isn't this a topic that those of us on the Services Subcommittee have heard testimony on at the workshop? And I think most of the members of both Subcommittees have some level of knowledge base around it.

You know, do we want to just allocate that time to discussing and determining appropriate policy recommendations? Because, to me, you know, I think most of the folks on the Services and the Safety Subcommittee, maybe not on the Planning Subcommittee, but on the Services and

the Safety Subcommittee have some background in this already.

Dr. Daniels: This is Susan.

That is correct, Ari. However, any product that you put out will have to be voted on by the full Committee. If the full Committee doesn't have a clear understanding of where you came up with the recommendations, it might be more challenging to get it through the full Committee. That is the only caveat to going forward with just knowledge that you all have in your head.

Mr. Ne'eman: Well, I understand that, but I thought we were talking about a meeting at this juncture between the Services and the Safety Subcommittee, not a full Committee meeting.

Dr. Daniels: That is correct. It would be a meeting with the Services and Safety Subcommittees. However, any presentations that would be made at that meeting would be available to full Committee

members to be able to review, et cetera, because this is not something that we can take up the time at the full IACC, to have a whole day devoted to this. In essence, it is a little bit like sort of a workshop plus a working meeting combined.

Mr. Ne'eman: And I understand that. But, for example, we had presentations that are made available to the full IACC on restraint and seclusion at the Services workshop last year. And certainly, we can each make available written documentation or written information.

But I have to wonder, given the members of the full Committee are not going to be present at this Safety/Services Subcommittee meeting, and the members of the Services and Safety Subcommittees don't need the presenters, you know, I don't necessarily know how it benefits us to have these presentations during time that we could be using to deliberate on the actual policy

recommendations we want to move forward on.

Ms. Blackwell: Ari, I understand your sense of urgency, but a couple of things. One is that I would never preclude bringing in anyone from the outside who may have updates or the latest information.

And second, part of our goal here is to educate the public. So, I think it is really important, and, also, there is a perspective here that is missing. That is the local perspective, the state perspective. This Committee only has, really, the federal perspective and then our public members to inform us.

So, I am a big believer in bringing outside folks in to sort of give us ideas. I would always urge us to continue in that path. I think that is one of the most important things that this Committee does.

Mr. Ne'eman: In principle, I agree with you, Ellen. But I have to point out we already have brought in outside people to

share their ideas.

One of our intents out of doing that workshop was that, after that, we would have follow-up or we would have policy recommendations. My concern here is I think we need to allocate this time to that follow-up.

And I would just add here, I think when we look at the breadth of the public members at the table, we do have not just a federal perspective. We also have a state and a local perspective.

So, to my mind here, it does not necessarily make sense to devote substantial periods of time at a Services/Safety Subcommittee hearing to speakers when we have already had speakers, and the people who haven't had access to those speakers or who are not already familiar with the topic won't even be at the meeting.

Ms. Blackwell: Well, I am not convinced that one speaker is speakers. I

mean we had one speaker talk about what was happening in seclusion/restraint, a very informed individual. I don't know what exposure Committee members have had to her one presentation. I do not recall at the moment that it was particularly focused on the group that Lee says he wants this to be focused on, which is secondary education.

So, I just have to say that I think -- I mean I would like to hear from some other Committee members that are on the phone what your views are.

Dr. Houle: This is Gail.

I think that if we are going to put forth any recommendations with any gravitas, they have to have a strong research or evidence base that is documentable behind them. If we can't present that, or we are unwilling to present that, we are putting ourselves at a disadvantage. We are putting ourselves more in the realm of opinion.

Dr. Strickland: This is Bonnie.

I agree with that. I wasn't at the workshop last year, but, nonetheless, I am certainly familiar with the issues around seclusion and restraint.

I do think, though, that the evidence is going to be important. I think leveraging the legislation that has been introduced would be important here, too.

What I am thinking mostly right now, though, is that three hours probably isn't enough time to actually do this subject justice. Maybe we sort of think about how these recommendations get developed over a couple of meetings.

Ms. Blackwell: Bonnie, this is Ellen.

That is kind of what I said after I heard the recommendation for a half-a-day meeting, that I thought it would be much more appropriate to devote a day to this very important topic and try to get a number of perspectives, the state perspective, maybe get

someone from Senator Miller's staff to come in.

I mean I just think that it is too important to spend a few hours discussing and then write something. So, I, myself, would much prefer to have really sort of an in-depth exploration, bringing in folks from the outside to talk with us, and, then, leaving us some time to talk about what we heard.

Dr. Strickland: Is there, to your knowledge, a good evidence review available anywhere?

Ms. Blackwell: Lee just said that there is.

Dr. Strickland: Oh, I didn't hear that. Oh, that is great. I mean, if it has already been done, and it probably was to some extent preceding the legislation, it would be nice for people to have that to review. So that, when we put these recommendations to paper, we sort of say that here is the basis for it.

It wasn't just all of us sitting together after the workshop and putting our thoughts on paper, but that there was a systematic process of reviewing the evidence that has been collected and synthesized, the deliberation of the work group, making sure that it is in sync with the purpose of the IACC, and, then, what we would see as what those recommendations might be based on a specific process.

And I think that takes more than three hours. But I would like to see the evidence review that is already out there, just to bring myself up-to-speed. Otherwise, as I said, I am familiar with the topic, but I am not extremely knowledgeable of the topic. I just would feel uncomfortable sitting down and writing recommendations without getting more up-to-speed.

I am just a representative, and not a member. I would have to be advising Dr. Van Dyke. So, I would have to be pretty sure that

I am up-to-speed on it.

Dr. Rice: Right. This is Cathy Rice.

I agree with what Bonnie has just related. It would be very helpful, if there is a review out there, that maybe part of the presentation would be reviewing the review, so we are all on the same page. Although some folks here certainly have in-depth knowledge of that, I think the point about that, for us to bring these recommendations to the full Committee to really understand, we are going to have to have some sort of synched review of the issue and the perspective.

So, I do agree that a little bit more time would be necessary and helpful for --

Mr. Grossman: Okay. In the interest of time, we have to move on. But just to close this, I would recommend that Ellen and I get together with the Co-Chairs for the Safety Committee and we kind of hash

this out in terms of the planning for the day, and we just get the date set, and do it.

And in the meantime, whatever materials are there, GAO reports, legislative action, reports and findings supporting the legislative activity, we will start compiling that and getting it to the Committee.

Dr. Daniels: So, this is Susan.

I just want to summarize that what I have been hearing through this discussion is potentially the interest in having a more in-depth meeting, providing read-ahead materials to everyone to get everyone on the same page, and having some presentations. Then, perhaps this would be longer than a three- to four-hour meeting. We can make it a full-day meeting. On the OARC side, we have no constraints on that.

So, it is really up to the Chairs to put it together. So, the Co-Chairs of both Subcommittees will help finalize the agenda.

Ms. Blackwell: Can I make a

request? This perhaps is going backwards a little bit. But if Lee and I are going to be working on a letter regarding Olmstead, I would propose that we try to make arrangements for Tom Perez to come to an IACC meeting and talk to the full Committee about some of the issues that the Office of Civil Rights is facing in its enforcement. I think that would be really helpful to the other members, especially prior to sending a letter to the Secretary.

So, how does the Subcommittee feel about that?

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

Dr. Shore: Yes, I believe so, too.

Dr. Daniels: This is Susan.

We have only one more full Committee meeting left after April 11th before the Committee either sunsets or is reauthorized. So, just a reminder, if we are going to have Mr. Perez come, that it would be

an invitation for July 19th. Otherwise, we do have a workshop as well, and he could be invited to that workshop. It didn't work out for the fall workshop, but it may work out for the coming fall workshop.

Ms. Blackwell: It would actually be my preference to have Tom Perez or Sam Bagenstos come to one of the full IACC meetings. I think that that would be a good thing for the full Committee to hear.

Dr. Daniels: All right. So, in this agenda we are past the 4:30 time period. So, the schedule is subject to change. We can continue if the Subcommittee members want to continue.

I would really like to get some guidance on the town hall meeting from the Subcommittee. That would be my priority.

And if you would like -- obviously, a full discussion of the fall Services workshop hasn't occurred at all, and we probably will need another meeting to talk

about that, and the discussion of whatever plans that you wanted to make regarding the previous workshop I think also would have to be deferred for another meeting.

So, it is okay to proceed with a little discussion about the town hall?

Mr. Grossman: Yes.

Dr. Daniels: Okay.

Mr. Grossman: And just for everybody, thinking about sunsetting, I have a timeframe on that. So, if we can all be succinct and short on this?

On the town hall meeting, we have been told by the IACC staff that there is money available to do another town hall meeting, and it was approved by the full IACC to do that on services.

There is a proposal out that we again have the town hall meeting in conjunction with the Autism Society's annual conference, which will be in Orlando, Florida, at the Gaylord Palms Hotel. And the dates

proposed for that would be either Thursday or Friday of the week of the conference, which correct me if I'm wrong, but I believe that is the 8th and 9th of July.

Dr. Daniels: It might be the 7th and 8th. I'm not sure.

Mr. Grossman: Yes. Thursday and Friday for sure. The dates, somebody, if they have a calendar there, they can correct and give the proper dates.

Dr. Strickland: The 7th and 8th.

Mr. Grossman: The 7th and 8th. Okay. Thank you. I should know that.

So, there is a proposal there that we do this, and it is to be a similar format to what was done at the second run conference in 2009. It is open right now for the consideration of the Committee. We can't move forward until we have agreement that we will do that.

The idea of having it at that conference is that is a very broad group of

professionals, family members, individuals on the spectrum. At the conference there will be 1,600 to 1,800 people there. That doesn't meant that the town hall meeting will draw that much. The one in second run drew a very diverse crowd of 200 people to start with. As you would expect at any town hall meeting, after people said their piece, the numbers dwindled.

For those of you that were there, remember the room was quite cold. It was like being in a meat locker. So, I give credit to the people that hung out there. That won't happen this time.

So, that was the background. We thought that the town hall in `09 went very well and that the attendance at the meeting was very good. I would expect it to be at least that, if not more, at this coming town hall meeting.

Ms. Blackwell: Lee, I have a couple of questions.

Mr. Grossman: Yes, ma'am.

Ms. Blackwell: Would the town hall meeting be during the midst of the ASA meeting activities?

Mr. Grossman: Yes.

Ms. Blackwell: So, families would be there? I mean it would just be an option for them, in addition to other options?

Mr. Grossman: Right. Right.

Ms. Blackwell: In other words, the meeting wouldn't be placed before or after the main festivities?

Mr. Grossman: I mean it could, but I think that that would probably limit the attendance.

Ms. Blackwell: Yes.

Mr. Grossman: The intent is Thursday/Friday are the busiest days of the conference. There will still be other breakouts going on during that period, but I think for most town hall meetings after the first 25-30 minutes, when the Committee

members and the agencies say their peace, people line up to make a comment, and after that they move on to other activities as part of the conference.

So, I don't think that our attendance -- it will be during the busiest time of the conference, which I think would provide the greatest attendance at the town hall meeting.

Ms. Blackwell: And one of the challenges facing us, government employees, is that we can't pay registration fees. So, would your organization be willing to help us with that as far as supporting? I know that we can pay for other things, but we face this challenge in all HHS fees right now. We can pay for travel and other expenses, but we can't pay for fees. So, that has been a real challenge as far as our travel with CMS, and ongoing for the past few years.

Mr. Grossman: I would have to defer that, an answer on that. That would be

something that I have to ask the people that are really doing the organizing.

Ms. Blackwell: Because some government folks may not be able to come if they have to pay their fee or their agency has to pay a registration fee.

Dr. Daniels: This is Susan.

I think I will probably need to get a sense from the group in terms of, if there isn't any waiver or discount on registration, whether that would impact ability to attend. OARC can pay for your travel, accommodations, ground transport, and per diem, but we can't pay for the meeting registration.

And the other issue, just as a minor consideration, is in case that it appears that the hotel may be already booked up, our folks might need to stay at a different location and come in on a taxi.

Mr. Grossman: What I can say about the registration is I will do what I can. I will see what I can do. I just can't right at

this moment say.

Dr. Daniels: So, our other option is to have the meeting here in D.C., which, obviously, wouldn't require travel for the federal people who already live in D.C. It would require the normal travel for any public members.

But, given these two options, could I get a sense from the members that are on the phone and in the room as to whether you would prefer Florida or Washington?

So, Lee, Florida, I assume?

Mr. Grossman: Yes.

Dr. Daniels: Ellen?

Ms. Blackwell: I'll abstain.

Dr. Daniels: Okay. Abstain.

Christine?

Ms. McKee: Florida.

Dr. Daniels: Florida? Okay.

Bonnie? Is Bonnie still on?

Dr. Strickland: Yes. I'm sorry, I had to step away for a moment.

Dr. Daniels: Oh, that's okay. Would you prefer to go to Florida or Washington?

(Laughter.)

Dr. Strickland: I would rather go to Florida.

Dr. Daniels: Okay. Let's see. Gail?

Dr. Strickland: No, seriously, it doesn't matter to me.

Dr. Daniels: Okay. Gail, what is your thought?

(No response.)

Are you there, Gail?

(No response.)

No.

Mark, I don't know if you're still on?

(No response.)

It's not a formal vote. I'm just trying to get a sense.

Ari?

Mr. Ne'eman: Yes, this is Ari.

My preference is Florida, if we are paying for the registrations, and probably Washington if we're not.

Dr. Daniels: Okay. And Cathy?

Dr. Rice: Either one is fine.

Dr. Daniels: Cathy, either way.

Stephen Shore?

Dr. Shore: I would prefer Florida. I don't know if you can hear me, but Florida.

Dr. Daniels: Yes, I can hear you great.

Dr. Shore: I can go either way.

Dr. Daniels: Florida. It sounds like Florida is a lot more popular here.

Denise I don't think is on the phone, although she may have joined.

And Office on Disability and ACF are not on the phone.

So, it sounds like people are mostly in favor of Florida. So, we will continue to try to work on that and see if we

can get that organized.

Ms. Blackwell: And maybe, Susan, you could send around a note just sort of updating people on it. The people who weren't on the phone should have a chance to express their preference. We could just try to make it all -- so, thank you for doing that, Lee and Susan.

So, I think, actually, that brings us to our conclusion today. We will have another meeting to continue some of these other things.

I have one last comment, which is to remind everyone that Saturday, April 2nd, is World Autism Awareness Day, and April is Autism Awareness Month. So, as the Services Subcommittee, we would just like to bring that forward. We in the Department are very interested in people with autism, and we celebrate autism awareness in April.

Dr. Daniels: Yes, and this is Susan.

For anyone who might be listening, on April 11th, at our full IACC meeting, we will be having a number of special presentations regarding HHS Autism Awareness Month. So, I would encourage you to attend or watch by webcast, if you have an opportunity.

Ms. Blackwell: That will be in the Reagan Building, right?

Dr. Daniels: Yes, it will be held at the Reagan Building, downtown Washington, D.C.

Ms. Blackwell: Yes, and this is Ellen.

One of the activities will actually be an update from our CMS contractor on the nine-state report that we commissioned on autism services a couple of years ago. One of our contractors will be there to talk about that report, which we expect to be up on the CMS website, hopefully, this week, in celebration of Autism Awareness Day and Month.

It includes some interesting

information, some of it not surprising, but it does highlight some promising practices in some states. So, I look forward to hearing more about that on April 11th.

Ms. Resnik: This is Denise.

I just wanted to let you know I have been a part of this call, part of it, but I haven't been able to talk. So, I'll go wherever you guys want to go.

Dr. Houle: Lee, this is Gail.

I wanted to ask you a question. Do you have a one-day registration fee? So, if we just came for the town hall meeting?

Mr. Grossman: That is a very good question and, yes, we do.

Dr. Strickland: This is Bonnie.

We have to pay the registration?

Mr. Grossman: No, we are working on it. We are going to work on that. I am about to get wrestled to the ground.

(Laughter.)

Ms. Blackwell: Okay. Well, that I

believe concludes today's meeting. We thank everyone for participating.

Susan, do you have anything else?

Dr. Daniels: No. Thank you so much for listening to the call and participating with us here in the room. We look forward to our next meeting and, hopefully, seeing many of you on April 11th.

Thank you.

(Whereupon, at 4:42 p.m., the Subcommittee adjourned.)