U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

MONDAY, SEPTEMBER 13, 2010

The Subcommittee met in Conference Rooms A1 and A2 of the National Institute of Mental Health, located at 6001 Executive Boulevard, Rockville, Maryland, at 1:00 p.m., Ellen W. Blackwell, M.S.W., and Lee Grossman, Co-Chairs, presiding.

PRESENT:

SUSAN DANIELS, Ph.D., Office of Autism Research Coordination, National Institute of Mental Health, and Designated Federal Official

ELLEN W. BLACKWELL, M.S.W., Co-Chair, Centers for Medicare and Medicaid Services

LEE GROSSMAN, Co-Chair, Autism Society

GAIL R. HOULE, Ph.D., U.S. Department of Education

JENNIFER G. JOHNSON, Ed.D., (representing Sharon Lewis), Administration for Children and Families

CHRISTINE M. McKEE, J.D.

ARI NE'EMAN, Autistic Self-Advocacy Network

PRESENT (continued):

DENISE D. RESNIK, Southwest Autism Research and Resource Center

CATHY RICE, Ph.D., Centers for Disease Control and Prevention (For Edwin Trevathan, M.D., M.P.H.)

STEPHEN M.SHORE, Ed.D., Autism Spectrum Consulting

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PROCEEDINGS

1:06 p.m.

Dr. Daniels: Thank you. This is Dr. Susan Daniels, of the Office of Autism Research Coordination at NIH, and I would like to welcome you all to this call, members of the public, as well as members of the Subcommittee.

I'd like to start by doing a public roll call, just so that everyone knows who is on the call, or in person here with us.

Ellen Blackwell? Can you just say here if you are here?

Ms. Blackwell: Here.

Dr. Daniels: Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: Henry Claypool? Not here.

Gail Houle?

Dr. Houle: Here.

Dr. Daniels: Larke Huang is not here.

Jennifer Johnson?

Dr. Johnson: Here.

Dr. Daniels: Christine McKee?

Ms. McKee: Here.

Dr. Daniels: Ari Ne'eman? Not here.

Denise Resnik?

Ms. Resnik: Here.

Dr. Daniels: Cathy Rice?

Dr. Rice: Here.

Dr. Daniels: Stephen Shore?

Dr. Shore: Here.

Dr. Daniels: And, Bonnie Strickland or a substitute? Not here at this time.

So, today we have an agenda which includes a special presentation by our Subcommittee Member, Dr. Stephen Shore, who is going to talk about education, and then the main focus of today's conference call is going to be a discussion of plans for our November 8th Services Workshop. And, our major goal is to finalize the agenda for the workshop, and Lee and Ellen have been working very hard on a draft agenda, which is in your packets, and it's available on the web. So, you may look at that, and that will be the subject of our discussion.

And, after that we are going to look at the Services Subcommittee Roadmap and the IACC Services Subcommittee recommendations that were developed previously, and discuss how that might relate to our plans for the workshop.

And, we'd like to then follow with a round robin, just to see if any of the agencies or private organizations have any news to report to the Subcommittee, and then we will end our call, or our meeting.

So, at this time, I'd like to again welcome you, and then turn the call over to Lee Grossman and Ellen Blackwell.

Mr. Grossman: Hi, this is Lee, and I want to thank everybody on the Services

Subcommittee, as well as listening in, for being here.

We are scheduled to go until 4:00. I doubt that we'll need that much time.

I'm physically here on the NIH campus, and Ellen is calling in, so please bear with us as Co-Chairs, as we can't make eye contact, that we may be struggling a little bit as we try to co-direct, all of us do this agenda.

I'm going to move straight to our first presenter, which is Dr. Stephen Shore.

Dr. Daniels: Actually, this is Susan Daniels.

Ms. Blackwell: No?

Dr. Daniels: Yes, that's correct. I just have one housekeeping announcement that I wanted to make for people who are watching this on the web, on the webinar, that we are going to be switching computers during the course of this meeting once or twice, and if that happens it may kick you out of the webinar.

If that should happen, please just log back into the webinar again, and it should be okay, but there is a web address that you can use if you have other technical difficulties, but, hopefully, that should take care of it. So, don't be alarmed if that happens.

All right.

Ms. Blackwell: This is Ellen Blackwell. Before Stephen starts, I just wanted to say thank you, Stephen for being with us today, and Stephen's presentation is part of a series of presentations that we decided to embark upon in the Services Subcommittee.

We had a wonderful previous presentation from HRSA and our colleagues at the CDC. Cathy Rice is with us today, representing the CDC, and also a very excellent presentation from Sam Odum, who works with our colleague, Gail Houle, at the

Department of Education.

So, if anyone is interested in looking at those presentations, Susan, I believe that you have them available, if an individual drops a line to the box at NIH, is that correct?

Dr. Daniels: Yes, that is correct. In the future, they will be up on the web, but we are just in the process of making those available on the web.

Ms. Blackwell: And, that would include Dr. Shore's presentation today as well.

Dr. Daniels: Yes, you can just email and ask for it.

Ms. Blackwell: Excellent. Well, Stephen, we are so glad to have you with us, and off you go.

Dr. Shore: Great. It's great to be here to be with people who are dedicated to improving the lives of those of us on the autism spectrum.

As I was thinking about what we need to bring forth, in terms of services, and education, and helping people with autism, I was struck by the realization that what we do for children with autism, whether it's a special method, or technique, such as the Miller Method, or Applied Behavior Analysis, TEACCH, Daily Life Therapy, and so on, really what we are looking at are extensions of good teaching practice.

And, the same holds for accommodations that we make in our schools. So, really, the question is, how can we frame what we are doing for children with autism in the school, not as some sort of expensive add-on that you place after the curriculum has been developed, but more, how can we build curriculum so that it speaks more to the attendance of universal design, so that everybody benefits.

And, one example of universal design, for example, curb cuts or ramps that we see to buildings, where people with mobility impairment. If you watch people walking into such a building, often you'll see that many more people will take the ramp rather than climb the stairs, even if they have two perfectly good working legs, and that's because the ramp is easier than stairs.

So, what was originally an expensive retrofit or accommodation ends up being useful to everybody, and that might be an example of universal design.

So, let's let the fun begin. First, a little bit about me. I think you know, I guess everybody here knows who I am, and I've talked about in the past looking very much like an egg at 24 hours of age.

But then at 18 months, what I often call the autism bomb struck, where I lost functional communication, had meltdowns, tantrums, self-stimulatory activity.

However, I don't know if we should be calling it the bomb. Even though it may seem like that a bomb has exploded in the lives of a family whose child has been diagnosed, what may seem like a bomb has gone off for the educator who is told that they are going to have a child with autism included in their classroom. Really, given that we have much greater awareness of autism these days, with an incidence rate of about 1 percent. And, with this awareness comes research, and with research comes intervention.

So, for people with autism, I think that means that leading a fulfilling and productive life can become the rule, rather than the exception.

And, we have the tools to do that right now. Of course, we need to continue our research to improve what we have, but taking what we have now there's a lot we can do to help people on the autism spectrum, and by extension everybody else.

So, I was hit with the autism bomb, you might say, it took my parents a full year to find a place for diagnosis. Fortunately, that no longer is the case. There was so little information known about autism, there was no Autism Society of America, there weren't other organizations in those old days to support people on the autism spectrum.

And, upon being diagnosed the professionals, as was common in those times, recommended institutionalization to my parents.

Fortunately, just like today, my the parents of today, my parents advocated on my behalf and convinced the school to take me in about a year. And, it was during that year that my parents implemented what we would call in today's terms an intensive, home-based early intervention program, emphasizing music, movement, sensory integration, narration, and imitation. It was probably most closely aligned with one of the developmental cognitive or affective approaches that we have today.

There wasn't very much from what we now call Applied Behavior Analysis, however, that doesn't mean ABA is bunk, all it means is that my parents figured out what I needed, and provided for that, and again, at a time when even the concept of early intervention didn't exist.

What did they do? It was mostly my mother. My dad was there, too, but in those days it was the father's job to be like a saber-tooth tiger or a mastodon, and the mother stayed home and did mommy-type things.

First, she tried to get me to imitate her, which didn't work. Then she flipped it around, and when she began to imitate me, I began to become aware of her in my environment. We developed a bond.

Then she was able to move me along to work on challenges of communication, social interaction, and the other challenges that people with autism have.

The key implication is that my

parents developed a bond with me before we were able to move on, and the key educational implication is that a bond has to be developed with the learner, a trusting bond, before any good education can occur.

According to Arnold Miller, the developer of the Miller Method, my parents got inside of what is known as zone of intention, my awareness of the environment around me.

Why don't we fast forward to adulthood, where I found university life to be a utopia. It still is a utopia for me, that's why I'm a Professor of Special Education, I had more friends, if I wanted to ride my bicycle at midnight I could find someone just as strange as I was to also ride at midnight.

With college comes dating, still a source of confusion to me, but I don't need to worry about it now, because I've been married to this wonderful lady for the past 20 plus years.

More of what went on is in my book,

Beyond The Wall, and at this time I now serve as a Professor of Special Education at Adelphi University, researching on matching best practice to the needs of children on the autism spectrum.

You might say that I spend most of my time in a sheltered workshop for people with Asperger's syndrome, where those of us on the spectrum are allowed, and sometimes even encouraged, to perseverate on our favorite interests. We get other people to perseverate on these interests. Sometimes social skills are not the best. Some people call this a university.

So, moving along, looking at children all over the spectrum. The spectrum is wide, it seems it's incredibly diverse, and upon looking at that my research, starting with my dissertation on examining five promising approaches for treating children on the autism spectrum, stems from the fact that during my doctoral program I noticed that there were a number of approaches, and what also would happen is that people would tend to get locked into these approaches, to the exclusion of others, and to the detriment of children on the autism spectrum.

I heard a lot of my approach, and fill in the blank, is the best approach, the others aren't worth looking at, and I saw almost none, no research focused on matching best practice to the needs of children on the autism spectrum.

Every now and then I'd see a study that would compare two approaches, and what would happen is that one approach, it's almost as if the decks of the cards -- the cards were stacked in favor of one approach over the other, so I didn't think that that was a really good way of going about that.

So, I set out to see what people said about comparing approaches. There was nothing there. So, it became important to me to open this line of research of fairly comparing approaches and looking at where their strength may be, towards the idea of matching best practice to the needs of children on the autism spectrum. I chose five approaches. There's many more approaches than the ones that we see here, but my dissertation had to be finished some time in my lifetime.

And, this was just focusing on education, then there's biomedical approaches, and various other techniques, such as sensory integration, picture exchange communication, inclusion, social stories and power cards.

And again, this information, while it is scattered throughout the internet, you can pour through the millions and millions of websites to find it all, I felt that it was important to put this all in one place, and probably the best thing to say about this is that I'm the dummy who wrote *Autism for Dummies*, and that's where it is.

So, what are some findings, recommendations and conclusions of my study?

No, I didn't take matched groups of children and give them different approaches, and then measure what happened in the end. One reason is that given the diversity of the autism spectrum it would be almost impossible to find that number of children who could be matched according to age, where they are on the autism spectrum, previous experiences with other interventions, home life, and so on.

So, I opened the research by talking to key developers of these five approaches that I mentioned earlier, and that meant talking to Ivar Lovaas, who then turned me over to a student, Tristram Smith, and then talking to Arnold Miller of the Miller Method, and then talking to Serena Wieder of Floortime, for example, and seeing how they think about children on the autism spectrum. How would they handle situations involving challenging behaviors, how would they explain challenging behaviors according to their approach, and then handle these challenging situations according to their methodology.

So, here is what I found, and this is just a summary based on the conversation of these five people. I also felt it was an important time to do that, because at that time autism had been around for a while as a diagnosis, maybe 55 or 60 years, and the key developers of most of these approaches were still alive and I could talk to them. And, that meant talking to people who had been working at this for, in some cases, over 40 years.

So, in brief summary, contrasting the approaches, and achieving desired behavior, there's a major contrast between what practitioners of Applied Behavioral Analysis does in order to do this, focusing on achieving normal behavior, with undesirable actions eliminated or redirected, the TEACCH approach, the environment seems to be really key in accentuating the strength of people on the autism spectrum.

As we move on to daily life therapy, there's a focus, a real focus on leading a balanced lifestyle, physical, of the physical, emotional, and intellectual components of a child.

The curious thing about daily life therapy is that it's the only approach that was developed for regular education, but it seems to work really well for children on the spectrum as well.

As we move on to Miller and Floortime, DIR, the focus is now more on development, where is the child developmentally, and what can we do to close the developmental gap, based on our understanding of how the person with autism perceives the work.

Now, which is the best approach? And, I think that's the wrong question to ask. The question is, ‘which approach is best for the child I am supporting at this time?’

And, in looking at these

approaches, it seems that the behavioral approaches, in general, were more prescriptive, whereas, the developmental approaches were more child-centered, and I found that to be very interesting as well.

Moving on, unique aspects and contributions of every one of these approaches, ranging from intensive data collection, the idea of functional behavioral assessment, positive behavioral support, these are some real gifts that the Applied Behavior Analysis people have given to us, looking at autism as a culture, and adaptability to foreign cultures, is what we see in the TEACCH approach, Daily Life Therapy, and the Miller approach as well.

Daily Life Therapy is very group oriented, possibly due to its Far Eastern roots, being developed in Japan.

The Miller Method, again, is developmental, the idea that using varying amounts of order and disorder to help children on the autism spectrum be functional in the world, and to understand their environment. And, this is the only approach, at least based on my research, that really focuses on varying the amounts of disorder to assist people on the autism spectrum.

Floortime is -- seemed to be more emotionally based, developing an emotional connection with the student on the autism spectrum, and also focused on working with the family, which I saw in other approaches as well.

So, what are some recommendations? And, some of these are already being done by the people working on the next version of the DSM, the DSM-5. One is placing autism under its own category, and finding a new home for Rhett syndrome and childhood disintegrative disorder.

What doesn't seem to be happening is subtyping of autism. There are a couple of people, namely, Serena Wieder and Arnold

Miller, who seem to be pretty successful in having developed subtypes of children with autism, and then being able to match that subtype diagnosis to treatment.

A multi-dimensional approach, including the levels of severity, should also be included, and there are hints that that is something that's going to be addressed in the DSM-5. I wish I had more information about that.

At least at this time, it seems that the concept of the autism spectrum is so broad and diverse that the term has, actually, become useless for planning intervention. So, is there a way that we can tighten up what we've identified, what we've diagnosed, towards setting up an intervention.

There's a lot of research going on globally, and I think the more that we can collaborate, formally and informally, the better off we'll be.

Diagnostics I touched upon a little

bit earlier, the idea of better subtyping, to allow for closer matching of characteristics and needs to intervention.

And also, looking into how intervention helps or exacerbates other commonly, co-occurring conditions, such as ADHD, Tourette's, post traumatic stress disorder, and so on.

And finally, what it seemed to be is that working on helping people on the spectrum seems to be progressing at a more evolutionary, rather than revolutionary, pace. So, the things that I'd like to see going on faster, at a faster pace, but I'm not sure what we can do about that.

The spectrum of autism, as currently conceived, is so wide that it's practically useless, because of such great variation of presentation in people on the autism spectrum. And, maybe we are dealing with multiple conditions that express themselves as what we call autism.

For example, some people who I have talked to in the biomedical arena believe that what they are looking at maybe is not autism, but it seems to look like autism, and it acts like autism, but when biomedical issues are resolved there seems to be some great improvement.

So, that was my best effort to take a snapshot in time on how leading theorists think about autism, and how to help people on the autism spectrum lead fulfilling and productive lives. And, I look forward to more research in this area.

Now, moving on to what we see in our schools. Educating children with autism in grade school, what are some techniques that we can use, and how can these techniques be used to, actually, improve education for all students in grade school. So, that's what makes me think of SWAT, and not special lessons in tactics, but more special ways and techniques for helping people with autism, and in return everybody else.

So, are we talking about special ways just to teach people on the spectrum, or are we looking at extensions of good teaching practice. So, thinking back to where I mentioned before, the importance of developing a good bond with the learner, maybe that's something that all educators should be concerned with, whether they are teaching children with autism, regular education, or anywhere in between.

So, that's what leads me to examining to consider these nine educational domains of accommodation. The work of the people who developed Adapting Curriculum and Instruction in Inclusive Classrooms did really well, I believe, in categorizing accommodations into the nine areas of size, time, level of support, input, difficulty, output, participation, alternate goals and substitute curriculum. And, every accommodation that I've come across seems to fit into one of these categories, sometimes more than one.

So, let's take a look at each of these categories, and see how they might be used to help people on the autism spectrum, number one academically, and then two, for social -- for inclusion, successful inclusion.

So, let's consider one, such as adapting the number of items that a learner is expected to learn or complete, or sometimes this can be categorized as quantity of items.

So, what's an example? Well, let us say I'm teaching a regular education class, and now I have a student with autism in my class. This is a -- let's say this is an English class. So, at the end of every week I have a quiz of ten spelling words. The class average over the past 25 years has been about an 85 or an 87, so I'm pretty satisfied that students are learning what they need to learn.

However, the person on the spectrum in my class now has -- he can only prepare for five questions, or I should say five spelling words. So, I'd say, okay, I'll make an adaptation to the curriculum, he has to only do five, everybody else does ten. It turns out he gets four or five right every time, so it's a good accommodation and everybody is happy.

But, if we think forward to transition to adulthood, is this person going to get away with at half productivity at work or at college? And, the answer is no. So, can we look a little bit more deeply into this idea of size or quantity, and, perhaps, I can try giving him a quiz of five on Tuesday, then another quiz of five on Friday, when everybody else is taking their quiz of ten on Friday.

And often, I'll find that works, because often people need a change in the amount of information or chunking, as opposed to a total amount of information to be learned. So, that works, and that's fine, but the problem is, now I have two testing scenarios in one classroom, and that can take a lot of time.

So, the question is, how can this instruction or modification be engineered to benefit the rest of the class, and what I might consider doing is restructuring the curriculum where everybody gets a test, or a quiz of five questions, twice a week, once on Tuesday and once on Friday. And, in this way, my curriculum has expanded to be inclusive of more people, there isn't any special accommodation in this case, but the person with autism or anybody needing their information in smaller chunks is now appropriately served. So, this is what I mean by taking a look at accommodations and considering them as extensions of good teaching practice.

And, what about time? Often, when we think about time, the default is extra time on a project for an assessment. Maybe what the person on the autism spectrum needs is help with conceptualizing the time line with intermediary deadlines written out on a piece of paper. So, I might spend some extra time during break, or after school, working this time line out with a person on the autism spectrum.

However, might it be that the whole class would benefit from some time spent on the intermediary deadlines, instead of just saying this is a long-term assignment, ten-page assignment, and it's due at the end of the semester. And, in that way, by giving everybody a time line as a handout, or spending some time talking about it at the front of the room, everybody benefits, and the person with autism or anybody who needs a little bit of extra help with executive functioning in this area is also served.

Level of support, how much assistance, personal assistance, is needed by a specific learning. Most teachers would probably agree that there isn't enough time to provide support to all students. So, one possible way might be to engage other students as peer buddies, teaching assistants, peer tutoring, or cross-age tutors. And, in this case students are learning from other students. For the student who has mastered the material quickly, or maybe didn't even need to be taught, they get a deeper understanding as you really have to know and understand a subject before you teach it. And also, there's the social implication of the two people becoming friends, as in this case a regular education student helping somebody on the autism spectrum.

It's also important to consider tutoring in the other direction, there may be areas where the person with autism may have expertise and be able to help someone who maybe has autism or maybe a regular education student.

How is information being presented to the learner? Most education still seems to involve a lot of the teacher doing a lot of blabbering in front of the room, students absorb information, and then they regurgitate it later on on a test, and depending upon how much they regurgitate that determines their grade.

However, I think we'd be better served, students with autism, and everybody would be better served, if we were able to engage as many of the senses as possible, hands-on activities. Some people on the spectrum may learn better by doing, rather than by listening, or, perhaps, by seeing, or, perhaps, by listening rather than seeing.

Everybody has preferred learning modalities, whether they have autism or not. So, for those of us on the autism spectrum, those learning modality preferences seem to be an extreme, to such an extreme, for example, that I have a friend with autism with a verbal IQ of over 200, but -- and those of you who are familiar with scoring IQ tests know they don't go that high, so it's just a guess.

However, she's just unable to get any useful information from a map. She is the most non-visual person I know. So, yet, she has autism, so that's what I mean by extremes of modality. Whereas, most people can learn, at least to some extent, through any one of the senses.

Difficulty? Maybe we have to adapt skill level or problem type, rules on how the learner may approach the work. So, for example, perhaps, somebody with autism is just unable to do math in their head. It's good if people can do math in their head, but some people just may not be able to at a particular time.

So, would it be better to provide an aid, such as a calculator, so that the person on the spectrum can grasp the concepts of math in this case, and then later, if they are ready to do math in their head, it may work.

Now, I know I did something like that for myself, I had difficulty learning the time tables, and I would spend hours in my bedroom just going over multiplication problems, using this slide rule contraption called a multiplier pencil box, and then eventually I learned to reverse engineer it, so that it would help me with long division as well. Now I can do these things in my head.

Output, how can the student respond to instruction? Maybe -- are there other ways than just verbal or written communication to -- for a student to demonstrate that they know the answer.

I had a situation in a college course, teaching electronic music. I gave an assignment where students were expected to list the components in the electronic music lab, and indicate their function. One student came up to me, this was a great case of self-advocacy, he said to me, you know, I have enough ADD to sink a battleship, and plus, my handwriting is so messy you won't be able to understand it, so I'll just fail the test, I might as well not take it.

However, if you let me go into the lab to draw a map of how the components are interconnected and how they work, then I can probably do better and still demonstrate that I understand the material.

So, I let him do that, and he drew a great map, and it seemed to be a good assignment to address the visual aspects of my students, and I ended up using that assignment, draw a map of the electronic music studio, in subsequent semesters. So, there's a lot that can be learned from students as well.

So, let us say we have this situation of a weekly geography quiz, and the challenge is to locate a number of countries, India, South Africa and Germany, by indicating which are the countries they border on, and in what direction. So, Canada might be --

Canada's placement might be expressed as being bordered by the United States in the south and so on.

However, we have Elijah here, who is an elementary school student with high functioning autism, sitting frozen in fear because he just can't put into words where these countries are, and fails at this type of test again.

Now, further looking into Elijah's characteristics, we see that he has difficulty in creative writing and mathematics, but when he receives sufficient support from his aid he performs at above grade level in drafting class and in computer-aided design.

So, what might be causing Elijah to have such difficulty in class? And, it might be that he has difficulty converting graphically-based information into word-based information. For him, language, just like with Temple Grandin and many other people on the autism spectrum who are visually based, verbal communication is, actually, more like a second language. But, as we know from people such as Temple Grandin, when relying on a graphical ability that they are able to make great contributions to society as a result.

So, that may be what's happening to Elijah. Is there a way to employ his strength to allow him to achieve success in class? And, as we look at his characteristics and his strengths, we see that he's pretty good at drafting class and computer-aided design, which pretty much gives us the answer. How can we engage his skills and abilities in computers and in drawing on the computer with drafting, to demonstrate that he understands where these countries are located? Perhaps, there's a map program, where he can drag outlines of maps to where they are supposed to be located on a globe.

And then, getting on to how can this benefit the rest of the class, how might these instructions be modified to help Elijah and possibly other students in class. Might we provide this as an option for other students, in addition to the possibility of writing it down in a word-based manner.

Participation, to what extent can a learner be involved in a task? The child on the spectrum, who maybe is unable to participate at the same level of others, maybe they can hold the globe while pointing out location.

A student with ataxia, for example, in physical education, maybe could serve as a cheerleader from the stands during the game.

Or, maybe even better yet, is there a way in which to engage the student in that game of soccer, or football, or whatever it might be? Might there be a way to bring the student right out onto the field and to push, kick, use his hands or whatever, to push that ball towards the goal.

So, these are things that we need to think of.

What about alternate goals or outcome expectation? Maybe a student, no matter how many accommodations we develop, is unable to participate at the same level in a geography class, and maybe we should expect them to locate states of the United States, and not have to locate states and capitols, as everybody else is assigned to do.

Success in music, and music is an important part of the curriculum, and is often a place where people on the spectrum, and with other differences, often it's the only place where people on the spectrum and other differences may be able to excel.

So, let's consider Valerie, who is in senior chorus, she receives intensive support from an aide. She has a well-planned behavioral program. However, she continually vocalizes or moans at a low pitch, whether her section is singing or not. She's also a pacer, she has to walk around the room, and it's difficult to get her to stop doing that.

As a matter of fact, they found it's impossible.

However, you notice that Valerie is much quieter when she is pacing around the room. So, the music director has come to you, he's deeply concerned about the possible negative effect of this behavior for the year-end concert of international music. So, what does one way to help -- how might we help the music director, while keeping Valerie meaningfully involved in the rehearsals and the performance?

What may be causing Valerie to behave in this manner? Perhaps, her moving around regulates her to such a point, and gives her enough body to environmental awareness, that she doesn't have to vocalize, which may be another attempt on her part to understand where her body is in space.

How can we meaningfully employ these behaviors to include her in remaining rehearsals and performance, and what might this look like during the performance? So, what is an interesting way of looking at educating Valerie in a meaningful way so that both she benefits and the other students. And, one possibility might be, is to -- instead of expecting her to do something that seems impossible for her to do at this time, give her something else that's meaningful. She needs to walk. She needs to pace. And, one possibility might be to give her a flag of the country, that represents the country being sung in the international concert of music, and let her walk around the auditorium with this flag, and make that part of the performance, a meaningful part of the performance.

Substitute curriculum, sometimes, for example, we'll have to provide different instruction and materials, so that a student will be able to meet the goals of the curriculum. Suppose a student has great difficulty with writing, writing class, and maybe we need to take her aside and teach her how to get around on a keyboard, on an AlphaSmart or a computer keyboard, with the goal of returning her to the class so that when I have these 20-minute writing sessions at the end of class she's able to participate just everybody else is.

But, it's also important to make sure this doesn't turn into what I call geographical inclusion, which is where we have a person with autism or other difference sitting in the back of the room, perhaps, with their aide, doing something totally different from what is going on in class, and then people say that's inclusion because they are in the same physical space. But, really, what we are looking for in terms of inclusion is meaningful involvement of the person with autism in school, the community, employment and in their residence. And, just like everything else, inclusion is also a spectrum.

Often the question of fairness

comes up. Is it fair to provide somebody with accommodations that they may not -- accommodations that seems like they are giving them an added advantage. And, I think the problem that people often say is that this myth that everybody has to be treated the same. And, continuing along this belief, it looks like -- I can't tell if Kate is wearing glasses or not, are you wearing glasses? Okay, Kate is wearing glasses. Oh, yes, and you are wearing them, too. All right, the three of us wearing glasses. Lee might be, too, but he's looking straight at me so I can't tell. Yes, all right, so we've got four of us, four out of five people wearing glasses. We need these glasses as an accommodation to see, but are we at an unfair advantage from the others who don't seem to be wearing glasses? And, if that's the case, then, perhaps, we need to take the glasses away from those of us who are wearing glasses, because they are at an unfair advantage.

But really, what we are doing is we are just providing for people's needs, providing Lee, myself, Kate, all of us wearing glasses, with an equal opportunity to be successful, not in a school room in this case, but in engaging in our conversation for this Subcommittee meeting, and I think this is how we need to treat accommodations in school as well.

This all speaks to the idea of universal design. How can we design curriculum in a way that it accesses the greatest number of students possible, those with autism, those with other conditions, and regular education students as well?

The accessibility ramps that we see in buildings, that's one example of universal design. As we look at classrooms, how can we apply universal design, or the elements of universal design, to benefit the greatest number of students, considering, for example, inclusive classroom populations. The question is, how can I deliver my materials, create and deliver my curriculum materials, so that I can access the greatest diversity of learners possible, so that I use the senses of sight, touch, taste, hearing, even smell, kinesthetic sense, so that everybody benefits from using all of their senses, and those people who have particular preferences, even extreme preferences for only one sense, they are still able to learn.

Defining the information, so in other words, being clear, being very clear as to what we are supposed to teach. I remember in grade school, it seemed to me that the job of the student, when I was a student in grade school, it always seemed that my job was to guess what the teacher wanted us to learn. And, it shouldn't be a guessing game, a student should know exactly what needs to be learned.

Accessible and non-biased material, so we are talking about material that isn't biased against people with autism, and against people of other cultures as well. Some of us look at autism as a culture, so avoiding culture bias.

So, the curriculum that doesn't reach everybody is, how amenable is it to accommodations. So, in other words, being mindful of the fact that, perhaps, certain concepts need to be converted into Braille or read out loud, if it's in printed form.

Being simple and clear, make sure the student understands the test. I mean, it's something that seems obvious. Sometimes I don't see enough attention being paid to whether the student understands, number one, what is on the test, and then two, exactly how to take the test. Readability and comprehensibility, again, that speaks to being clear, simple and direct, using a font that's easy to read, a large font, so that everybody can read, and these are just some things that I think of when I think about universal design, so that students, both with autism and other special needs, and regular education students, can be successfully served in education.

So, I get back to that question, as to whether we should be talking about special ways and techniques just for people with autism, or are we looking at ways of expanding how we teach so that curriculum planning and delivery are really just extensions of the teaching practice.

Thank you very much, and I think we have a few minutes for questions.

Ms. Blackwell: Hi, Stephen, and I want to thank you so much.

Dr. Shore: Hi, Ellen.

Ms. Blackwell: I, actually, do have a question.

I get the sense, you know, that you work a lot in inclusive school environments, and as you may recall we had a presentation on inclusion at our last full IACC meeting. So, I kind of wanted to get a sense from you about, you know, I think it's hard for parents, you know, especially parents of younger children, to make decisions about where their child is educated. But, do you have any guidance or sense of, you know, how things work in an inclusive setting versus a segregated setting?

Dr. Shore: I guess I have to ask you to rephrase the question, because I'm kind of stuck on that last phrase, how things work in an inclusive and non-inclusive setting.

Ms. Blackwell: Well, it sounds like most of your work is done in settings where children are included in regular classrooms.

Dr. Shore: Yes.

Ms. Blackwell: Is that correct?

Dr. Shore: Yes, that's correct.

Ms. Blackwell: Okay. So, you know, you feel that that can be done, you know, with accommodations successfully, right?

Dr. Shore: Right.

Ms. Blackwell: And, would you say that inclusion overall is, you know, beneficial to the person with autism, or should be considered first?

Dr. Shore: Well, I think we all need to have a bias to inclusion. The ideal is that we would have 100 percent of inclusion all the time for 100 percent of the people.

But, unfortunately, the reality of availability of resources and materials rears its ugly head. I mean, let us suppose we have somebody with autism who is having severe emotional outbursts, and they are throwing chairs around the room, and they are throwing scissors, and they are just disturbing the class. Should that person be included in the class at that point?

And, the answer is, we need to find a way to deal with those issues, so that, number one, that student isn't a disruption to the class, and two, how can we work it so that we can work in as much inclusion for that student as possible, perhaps, by addressing other issues related to emotions, behavior, perhaps, sensory issues, biomedical issues, so that that student is also more comfortable in that environment.

So, I think the best way to look at it is, having a bias towards inclusion, with the realization that you can't always have inclusion.

Mr. Ne’eman: This is Ari. Actually, I joined the call a little bit late, but just as your presentation was starting, Stephen, I was pleased to have the chance to hear all of it. It was excellent.

I guess I have one question. You mentioned in the beginning that a lot of your work has been around comparing different service provision methodologies, particularly, in regards to early intervention, and various educational methodologies.

You know, as we start to look at

the policy implications of our discussion, you know, obviously, one of the big things that comes up is things like insurance mandates, and reimbursement for certain kinds of services, and, you know, I guess my question to you is, do you see there to be any kinds of risks arising with privileging some methodologies over others, as states and public programs make decisions as to what kinds of educational methodologies to make available, and what kinds not to?

Dr. Shore: I think what we need to do is examine the idea that different approaches work for different people, and that privileging a methodology, or even just a few methodologies, written into legislation as a requirement, I think that could be dangerous. And, what we really need to do is to have the option of selecting from a number of promising methodologies.

For example, for one student an approach derived from Applied Behavioral

Analysis may work just fine. For the next student, perhaps, they'd be better served by the Miller Method, Floortime, Daily Life Therapy, or some other.

So, what I would really like to see, the type of wording I'd like to see in legislation is not, for example, 40 hours of ABA, or 20 hours, or any number, but rather, a certain number of hours, and if we look at educating children with autism that was published, I think it was in 2000, they recommended 25 hours, a minimum of 25 hours, so that's a baseline that we can start with, and again, not legislating particular intervention, a particular intervention, or particular interventions, but being able to select from a pool of promising interventions.

And, of course, our challenge is to define what is a promising intervention.

Ms. Blackwell: This is Ellen, and I would just add that we had an excellent presentation in, I believe, October of 2009, from Tony Charman, C-H-A-R-M-A-N, from London, who, actually, took a lot of information about the evidence base behind various types of Applied Behavioral Analysis base treatments, and it is available I know on the NIH webcast site, and I believe that Dr. Charman's presentation is also available from NIH on request.

I think that's an excellent answer, Stephen, and, you know, I would have to say that after listening to his presentation, obviously, one size does not fit all.

Mr. Ne’eman: I think that seems to be exceedingly good sense. Stephen, thank you very much.

Dr. Shore: You are welcome, Ari.

Ms. Resnik: This is Denise Resnik.

Stephen, thank you again for an excellent presentation. What you said resonated with me on so many levels, and it does make a lot of sense.

I wanted to inquire a bit more

about the Miller Method that you referenced. Is there empirical data on that intervention?

Dr. Shore: Empirical data, there's very little empirical data and evidence-based data on all of these interventions, unfortunately. We really need to find a way to fairly assess and compare interventions, compare between interventions.

There is some research on the Miller Method, if you go to the Miller Method website, millermethod.org, that will lead you to more information about the approach. There's also a book written by Arnold Miller called, surprisingly, *The Miller Method*, published by Jessica Kingsley, which also will provide some additional insights on this approach.

Ms. Resnik: Okay, thank you.

Ms. Blackwell: Denise, this is Ellen.

I don't know if I've mentioned it before, but CMS and NIMH co-sponsored a study that we published in March of this year. Unfortunately, I had some trouble getting it up on our website, but it is available on our contractor's website, I-M-P-A-Q, Impaq International, and it is a study of the evidence base behind various interventions for people with autism.

Ms. Resnik: Excellent, Ellen, thank you.

Ms. Blackwell: That's an excellent reference if you have not had a chance to look at it.

Dr. Shore: I think I know the study you are talking about, that's a very good study. I think it was released just this year, in 2010, maybe February.

Ms. Blackwell: Yes. Yes.

Ms. Resnik: Could we put that website in the follow-up notes?

Ms. Blackwell: Could you do that, Susan, or maybe even a link on our --

Dr. Daniels: We could put it in

the minutes.

Ms. Resnik: That would be great. Thank you.

Mr. Ne’eman: Can I just add to that, the Institute for Education Sciences recently posted some information assessing the evidence base behind, I believe, Applied Behavioral Analysis, and recently posted that on its website, and certainly, came to some, I think, very intriguing and very important conclusions.

So, if we can put that on the website as well, I'd be glad to send the link to OARC.

Dr. Daniels: Yes, Ari, if you can please send me the link and we'll put it in.

Dr. Shore: Thank you, Ari.

Mr. Grossman: This is Lee, and I have -- I'm going to take moderator privilege here and take the last question. We have to move on in our agenda, but I will -- I did want to ask you, Stephen, and this is piggybacking on what Denise's question was about empirical data.

What is your feeling on the need for empirical data to validate any particular type of methodology, intervention, service, support, for people with autism?

And, the reason I ask that is because, it seems as though we have to be more eclectic in nature, and look at what the individual needs are, and not to put words in your mouth, but I kind of wanted to hear what your feeling was on either one of those.

Dr. Shore: Well, I think you are addressing the issue that it's very hard to -- it's very hard to research or develop research studies on these approaches the way -- using traditional means. And, that's because human development is really, really messy, and it's hard to measure with the particular tools that we have.

And, that's why I think it's -- that's why I like to use, consider the term "promising approaches," as opposed to evidence-based research approaches, because if we open the field up to promising approaches, where we've seen that these approaches have done some good, if we have a good amount, we have to define what good amount is, sufficient amount of anecdotal evidence from parents, and from clinically-based studies, then we need to take that into consideration.

Mr. Grossman: Thank you, Stephen. I thought that was superb, and we appreciate very much you sharing this information, and I'm going to move on to our next agenda point.

Dr. Shore: My pleasure. Thanks, Lee.

Ms. Blackwell: Yes, and I echo that, Stephen. Thank you so much for adding to our roster of excellent speakers. We really appreciate your participation, and I know it's hard for you sometimes with your schedule to make the time. So, thank you so much for doing that today.

Dr. Shore: No, my pleasure.

Ms. Blackwell: Okay, so as Lee said, we are not together, it's a little bit hard for us to moderate a discussion when we are in different places, but our next agenda item is to discuss our workshop, which is planned for November 8, 2010 at the Rockville Hilton, and we have a draft agenda, and it is, indeed, a draft.

And, I would have to say that it also relates rather closely to the next agenda item, which is the discussion of the Roadmap and making the recommendations to Secretary Sebelius. So, Lee, feel free to chime in, but I would have to say that in developing this agenda we came up with a theme. We worked very hard with the staff at OARC. Thank you, Susan and Della Hann, who is not with us today, and the theme is "Building a Seamless System of Quality Services and Support Across the Life Span."

And, when Lee and I first started

talking about the workshop, you know, we kind of had several different aims. One was to look at cost effectiveness, because of the strains that today's fiscal systems, particularly, state education systems, and state developmental disability systems, are facing right now. So, we kind of had that as an underlying theme, and then we also wanted to look at systems that are working well that might offer -- not just examples for other jurisdictions, states, school systems, or developmental disability systems, but also speakers and ideas that could be used to develop, perhaps, a set of recommendations that could be given to the Secretary by the end of this year.

So, that's kind of where we started out with the draft agenda. So, Lee, do you have -- what would you like to add?

Mr. Grossman: I think you are on a good roll there.

Ms. Blackwell: Okay, and we had,

as Susan will attest, you know, many discussions, but if you -- again, and sort of taking our agenda items backwards, but we have some new members on the Services Subcommittee, and I know that today you were sent a copy of the 2005 Roadmap, which was developed by the previous Services Subcommittee, and also a document that we developed in February of 2009, which was really more of sort of a shorthand roadmap.

We took what we thought were really the best things from the roadmap, and we tried to integrate some of the feedback that we got from the public, and then we got, we actually got a little mixed up, frankly, because the next step was to start looking at areas that the public and others had identified as problematic, and where we could make recommendations.

So again, that's where we thought we might be able to go with this meeting, certainly, systems reform is always at the top of our list here at CMS.

So, that's kind of where we went with this draft agenda, and I have to say that it was almost, for me, I'm looking at a file almost two feet thick, there were so -- there are so many areas that need to be addressed that I don't think it's possible, in fact, I know it's not possible, for us to address all of the areas where we might make recommendations in one day. So, I think that Lee and I would both agree that this workshop is just a start, and that we can certainly try to highlight some of the problem areas where we might want to make recommendations to the Secretary on November 8th, but it is by no means the end, it is simply the beginning.

Does anyone have any comments?

Dr. Houle: Ellen, I -- this is Gail, I am going to have to leave the meeting for about 45 minutes, I've been called away, and then I'll join again. So, if you don't hear me making any comments on services, it may not be because I don't have any.

Ms. Blackwell: Okay, maybe we could table our discussion of some of the educational items until you get back.

Dr. Houle: Okay, that would be great. Thanks.

Ms. Blackwell: That would be good.

Anyone else have comments about -- you know, so far as, you know, this being one of several meetings?

Ms. Resnik: Ellen, this is Denise, and when you talk about this being one of several meetings, so this workshop being one of several meetings?

Ms. Blackwell: Yes. I think there are so many areas that we can address, Denise, I, actually, myself go, oh, employment is an area where we could have a whole day on employment, and there are just so many things that we could talk about and look at, as far as recommendations, that employment is, actually, not on this agenda.

So, and then there were other programs that I ran into that I just thought were really interesting, that we just don't have time for. So, I sort of stuck those back in my folder and went, well, maybe these are things we could do through a larger -- at one of our regular meetings, or we can ask the IACC if we could have another workshop.

Ms. Resnik: Yes.

Ms. Blackwell: Susan, isn't that something that we have the ability to do?

Dr. Daniels: This is Susan.

Yes, we may want to plan a different workshop for another time, so you don't have to feel like we need to include every single topic in one workshop.

However, I wouldn't be planning to have six workshops in one year, or anything like that.

Ms. Resnik: And, this is Denise speaking again, with that in mind, I think it would be helpful if we could identify what those other topics would be, so that we do manage expectations and the demands as we know from this community, in terms of what, you know, we are all looking for, and, perhaps, talk about a phase 1, phase 2, phase 3 approach even, that if you are wanting -- and I appreciate the aggressiveness of the deadline in terms of looking to get something to the Secretary, in terms of initial public policy recommendations by year end, but then looking at, perhaps, a more expansive strategic effort, in terms of delving a bit deeper into some of those policy recommendations, as well as adding some new topics during 2011.

And, I think it would be great if we had a roadmap that could help, you know, manage some of the, you know, again, expectations and articulate where we as a Services Subcommittee are going with public policy, understanding that this may be an initial set of recommendations, and that more would be forthcoming, based on a process that we are setting up.

Dr. Daniels: I would like to just remind you of that the IACC Sunset on September 30, 2011, and so the urgency to get some recommendations completed before that is real, and so you might want to consider, yes, you may want to do other things in the future, but to try to finish something before that Sunset date hits.

Mr. Ne’eman: This is Ari --

Mr. Grossman: Wait, Denise and Ari, just to remind you, the next agenda item is, actually, going to do that. What we are going to be looking at, what the roadmap is, and I would think that we are going to want to put timelines in there, too, in terms of how the Services Subcommittee will move forward.

This notion of urgency, it's there, it's real, and it needs to be addressed, because we do want to start moving towards getting recommendations to the Secretary as soon as possible.

I'm hoping that this workshop that is in November will just be kind of the launching pad for the Subcommittee really doing some heavy lifting to take the information that's presented there and coming forward with some strong recommendations.

I think that with the expertise and the energy that we have with the Services Subcommittee, that we should be able to curtail the need for many other types of workshops and conferences. There's enough information here among the people that are here, and the agency that we can call upon, and I think that we should be able to put together some pretty strong recommendations in a fairly short amount of time.

Ms. Blackwell: Yes, I agree, and I would have to, for you new members, I do have to remind everyone that the Services Subcommittee is really a subset of our mother committee, the IACC. So, we have to do this pretty quickly, once we have the meeting we have to develop the recommendations, and then I believe we have to present them to the Full IACC, and as soon as we get buy in we can certainly have something done by the end of the year.

I believe that is aggressive, but also doable, and it certainly doesn't, as I said earlier, prevent us from engaging in other activities, like strategic planning, and making additional recommendations later down the line.

So, you know, I think it's doable, and I think it's definitely needed.

Should we take a few minutes, perhaps, to talk about what we have developed so far, because it is really important today that we make sure that we get all of our speakers in order, and, you know --

Mr. Grossman: Ari wanted to say something.

Ms. Blackwell: Oh, sure.

Mr. Ne’eman: I -- no, I would certainly agree with you, Ellen, that we can expedite recommendations within, I think, at the latest, 90 days after the workshop.

But, before we get into the follow-up, you know, I do want to, actually, feeding into the topic we are just going to start, which is, essentially, giving some feedback on the speakers you proposed, raised what I think is a very significant gap in what is otherwise a very promising start, in terms of our agenda, namely, that there are no self-advocate speakers. You know, I think it's --

Ms. Blackwell: Ari, can we go through them one by one, and then maybe folks can make suggestions where there are holes, because I agree with you, and I think there's a lot of opportunity.

As I said, I'd hope by the end of the day here we've got ourselves a great launching pad to, you know, put the finishing touches on here.

So, if we go by them one by one, I think that would be great.

Mr. Ne’eman: I have no objection to that, but I do want to just make very clear that I think it's very important that regardless of what number of phases that we are considering here, that all of those have some substantial self-advocate involvement in all stages of the process.

Ms. Blackwell: I think especially in the area of peer support, maybe when Gail comes back in a few minutes we could talk with her as well, but that's an area where we could certainly use a self-advocate on that panel.

Mr. Ne’eman: Well, also community living, but I think there are definitely a few different options.

Ms. Blackwell: Well, let's talk about, again -- so let's go through what we developed, you know, sort of step by step.

Dr. Rice: Ellen, before we do that, this is Cathy Rice.

Ms. Blackwell: Hey, Cathy.

Dr. Rice: I just want to, one, thank you and Lee for all the thought you've put in. You really identified a lot of, you know, really touched a lot of areas.

One thing I would like to suggest, as we go through each speaker, could we think of it in terms of the RFI priorities, and say what priority that speaker addresses?

Ms. Blackwell: Yes. Actually, when I thought about this, Cathy, I started to think backwards, because I started thinking, what might the recommendation be.

Dr. Rice: Right.

Ms. Blackwell: And, how might this speaker support the recommendation. So, that -- maybe that's putting the horse -- or the cart before the horse, but I thought, in terms of making the recommendations, it would be very important to have speakers that would support recommendations.

Dr. Rice: Right. I remember you

stating that, so it might be helpful for the rest of us to kind of --

Ms. Blackwell: I, of course, cannot say what the Committee would decide to recommend to the Secretary, but that's kind of how I thought about it when I thought about speakers on some areas.

So, Nancy Thaler, who -- for those of you who don't know Nancy, Lee, I know you know Nancy very well, as I do. In fact, Nancy worked with us at CMS for over a year, helping develop the Home and Community-Based Waiver Application. Nancy is the Director of the group that is all of the state directors of developmental disabilities, so you can just imagine 50 states, 50 DD directors, certainly, in this fiscal environment they are facing a lot of challenges to their programs.

Something Lee and I thought we wanted all of our speakers to talk about, or to address, is what you see at the top of your -- where we are today, and where we hope to be in ten years.

So, I think the world of Nancy. She is extremely articulate. She recently testified in front of the Congress about Olmstead and the Americans With Disabilities Act issues, and I think she is just uniquely poised to talk about the challenges and also the hope facing our DD systems in the United States.

Lee, do you have anything to add about Nancy?

Mr. Grossman: Well, she has a lot of practical knowledge, having run the DD system in Pennsylvania.

Ms. Blackwell: Yes.

Mr. Grossman: She has a great deal of expertise and probably 30 years of advocacy as well. And, she understands autism. We did a conference with her and the state directors of DD division directors, I believe it was last year, in Nashville, where we were training them, it was a two-day conference for the DD directors, specifically, on autism.

Ms. Blackwell: Perhaps, you could talk a little bit about Bill East. You are much more familiar with Bill than I.

Mr. Grossman: Well, when Ellen and I were talking about what -- who impacts our community the greatest from a services standpoint, obviously, education is one of the main providers of services, particularly, from preschool through the transition years to adulthood. And, as a result, we thought it would be great to get somebody that has an influence over what's happening at the state level in education, and we really couldn't think of anybody better than Dr. Bill East. He's the Executive Director of the National Association of State Directors of Special Education.

This is the second NASDSE, their acronym for their organization. Nancy Thaler runs the first NASDDDS acronym.

So, with Bill, his organization is

very familiar with autism. They also have come out with Communities of Practice in Autism, have been, as best they can, training special ed directors on the state level through that Communities of Practice initiative, to understand autism.

Bill has spoken at a number of autism conferences in the past year about leadership and the direction of what he believes special education should be heading, and it just seemed like if we are going to be talking about the future there's a person that has great influence over the state directors of special education, and, certainly, gets it, as far as I'm concerned.

Ms. Blackwell: Thank you.

Charlie Lakin, for those of you who don't know Charlie, he has -- Charlie must have a 20-page resume. He's one of the nicest, smartest people that I've ever known.

Charlie works with the University of Minnesota. He's also been very instrumental in doing certification and training for direct support workers.

He's really a jack of all trades in some ways. In this capacity, Charlie has been working with NASDDDS, and when I say NASDDDS, the two acronyms for both of the organizations sound the same, so I'm talking about the DD folks. Charlie worked on a project called the National Core Indicators Project, and this is sort of the precursor to legislation that is in the Affordable Care Act that deals with adult quality measures.

Charlie, has some very interesting data on how people with autism are doing in the developmental disabilities system.

We, CMS, hired Charlie to do some work on our Home and Community-Based Waiver Program a few years ago, and there was just a little information about autism, but I think it would be very interesting to hear how people with autism are faring, and where they are in the developmental disabilities system, particularly, after they finish with school.

So, Charlie has that data at hand, and it is very interesting. The core indicators deal primarily with quality of life factors, and, you know, quality of life measurement is not terribly different for people with disabilities than it is for people without disabilities.

So, that is something we have not heard about yet, and I think it sort of fits in nicely with Bill and Nancy.

Dr. Rice: Ellen, this is Cathy.

So, if we go through each of these, my being very concrete, as you can tell from my comments most of the time that's how I think, for Nancy Thaler, so would she -- would this -- would her topic be in line with infrastructure, and then Bill East school services, and Charlie Lakin community?

Ms. Blackwell: Well, I think that all three of them are really going to talk about what we know today, and where we want to be in ten years. That's kind of the theme of this introductory session.

Mr. Grossman: I'll fill in the blanks a little bit.

Ms. Blackwell: Okay.

Mr. Grossman: I would envision, because we would, obviously, want to talk to all the speakers and give them some direction, and I would envision Nancy Thaler talking about adults, community and providers, and Bill addressing infrastructure and school services, and then Charlie, which I would imagine he'd be community and infrastructure as well.

So, would you agree on Charlie, Ellen?

Ms. Blackwell: Yes, for sure, and I would also add that the developmental disability systems in this country serve many, many children who are enrolled in the Medicaid program. So, I wouldn't -- I would say that although Nancy might talk about adults, because the DD system is the only support system, generally, in this country for adults, a lot of the DD programs are also supporting children.

Ms. Resnik: This is Denise.

In your discussion with the speakers, will you ask them to be presenting some of their innovative and most promising models?

Ms. Blackwell: Absolutely.

Ms. Resnik: Okay, great.

Ms. Blackwell: That's where we are going, Denise.

Ms. Resnik: Okay, great. Thanks.

Ms. Blackwell: So, we would take a break, and then we would hear from a very interesting gentleman, Mike Head. I don't know if any of you are familiar with Mike. I, actually, have had an opportunity to work with Mike recently, here at CMS, sort of from the sidelines.

Mike has been around for many

years, and he works now as the head of the Long-Term Care Division for the State of Michigan. He runs all of the state's mental health programs, and other support programs.

Mike, in the State of Michigan, and Michigan is unique, every single individual is offered self direction as a service free option.

And also rather coincidentally, actually, Mike and Jim Conroy, who we are suggesting as our next speaker, Ari, I know that you know Jim very well, Mike and Jim worked several years ago on a cost analysis of the cost savings associated with self direction.

So, we thought this might be a really nice team. For one thing, they know each other quite well, and a possible recommendation might be that all states be required to offer self direction in their programs, like the State of Michigan.

So, I think Mike can talk very

vocatively about how self direction works, and Jim can certainly, not just talk about the cost savings, but the satisfaction that comes when a person controls their own budget, is able to hire and fire their own staff. There are just so many doors that open when the individual gains control.

So, Michigan is a state system, I think Mike can do a great job talking about how that works in the state, and Jim can certainly add to that with a little bit about why self direction and how it saves money.

Ari, do you have any thoughts about that?

Mr. Ne’eman: I think it's a great one/two match up, and I guess the only additional thing that really occurs to me is, I think, you know, the combination are particularly well suited, because Jim, I believe, played a very important role. The Pennhurst study, which underlies outcomes from de-institutionalization, and he has a lot of experience, really, assessing quality of life measures, you know, around the individual, which I think, you know, compliments very well the discussion that Charlie Lakin is going to be giving us, around system-wide quality of life, and quality measures.

So, great choices.

Ms. Blackwell: Thank you. I think they will be wonderful. And, the fact that they know each other is just a complete bonus.

So, the next speaker, and we had to be mindful of time when we planned the agenda, so --

Mr. Grossman: Ellen, can you address Cathy's concerns about the -- what issues under self direction would be addressed, her top priorities?

Ms. Blackwell: Yes. I think that a possible recommendation, as I said, that might come out of this, would be that the Secretary recommended every state offer self direction in, for example, it's Medicaid programs.

I mean, we do have -- we have states that offer self direction in our programs, but not every state. For example, not every state offers self direction, and we see a patchwork across the United States, especially, in terms of what's offered, and the amount of control that people have, and it can become extremely complex in managed care delivery systems, which Mike, in some ways, is uniquely qualified to address, because the services that they deliver -- the state delivers through its mental health system are delivered through a risk-based payment methodology.

Mr. Grossman: That sounds like it hits all of the six RFI priorities. It's all community, family support, school services, providers and infrastructure.

Dr. Rice: Yes, I see.

Ms. Blackwell: Cathy, I was still thinking recommendations, but, yes. So anyway, I think those two will be great.

The next proposed speaker, I have -- I heard wonderful things about her, and had a great conversation with her on the phone.

Universal assessment is something that some of you may have heard our colleague, Henry Claypool speak about. Assessment is, you know, most people that have children are probably more familiar with the IEP process, but in the adult world assessing people and trying to develop individual plans, it's really, again, sort of an uneven process.

So, Washington State may actually be unique, in that throughout all of its programs, including programs for elderly adults, the state has adopted something called the "Care Tool," and Linda happens to be with the Division of Developmental Disabilities, and it is fascinating to hear what the state did to level the playing field to assess people with developmental disabilities, not just to make sure that they receive the appropriate services, but also use universal assessment as a way to project expenses for the state legislature.

So, it is really -- I can't say enough about how fascinating it is, and it really did amazing things for turning around the lives of the people who were being assessed. Linda tells me that it sort of forced case managers and families to start thinking in terms of what people could do, and not what they couldn't do.

So, it's really, really interesting to hear about this, and a potential recommendation to the Secretary could certainly be that states adopt standardized assessment practices.

So, Washington is, as far as I know, unique, and I think what Linda has to say is just really, really great.

Cathy, I know you are looking at those topic areas, and I don't know which it would fit under, probably again several.

Dr. Rice: Yes, I was thinking infrastructure to some degree, but I think one of the things we should think about in our next discussion after this is, for the recommendations -- if we organize around the RFI priorities what may be missing from that, and it seems like assessment as a topic is, in itself, maybe one -- a separate -- a separate issue that came up in the earlier 2005 plan, when we talked about early and continuous developmental and medical screening, but thinking of assessment more broadly throughout all stages of life, and in every setting involving the individual to evaluate where they are, what their needs are, whether it's at the primary beginning of identification, what the concerns are, or program planning, or progress, wherever that is, it's kind of a cross-cutting issue we may want to think of as a separate area for recommendations.

Ms. Blackwell: It might even come under providers, and although, you know, again, Linda works for the Developmental Disabilities arm, many, many children are served through these Medicaid programs, and through these state DD programs.

So, again, it isn't just adults that are being assessed, it's children as well, because, you know, children are not only receiving services through the school, but also in many cases through Medicaid programs, and other state-based programs.

So, that's our suggestion for universal assessment, and possibly a recommendation.

And then, we've already made our way to lunch. We talked about a couple of speakers, and we have listed here Michael Strautmanis, who some of you may recall from our meeting with the Secretary in the fall. Another suggestion that I had was -- hold on, I've got to grab my notes here -- that we bring in Tom -- help me out, Ari -- I've got a desk full of papers in front of me --

Department of Justice.

Mr. Ne’eman: Oh, Tom Perez.

Ms. Blackwell: Thank you, Tom Perez, who speaks very -- gives a wonderful talk about Olmstead and Americans With Disabilities Act enforcement.

So, I, actually, kind of wanted to hear what the Committee had to say. You know, Lee says Mike is a great speaker, and he can certainly present the administration support of people with autism.

Mr. Grossman: Yes, I've corresponded with Mike. November 8th is too far out in front of his schedule for him to make a commitment at this point, but it is penciled in, and when they get closer to the date we'll know for sure if he can sweep in on it.

Mr. Ne’eman: I think Mike would be a great speaker. It just -- it does occur to me that Tom Perez, Justice is just doing some really incredible things, in regards to both the Olmstead enforcement and a stronger line around ADA enforcement in general, and that does seem to be an area we haven't given sufficient focus, in terms of some of the legal requirements there.

I could see advantages from having either speaker, but I do encourage us to seriously consider the merits of Tom Perez.

Ms. Resnik: This is Denise.

Would Tom Perez be an alternate to maybe some of the other speakers that we have lined up, or, perhaps, as we've talked about, you know, a subsequent workshop, the opportunity to involve him, because he does sound -- obviously, this is very timely, and I think Mike Strautmanis, if we could get him, would also be excellent. But, I'm feeling like, you know, there will likely be others, like, perhaps, Tom, that we are not going to want to miss, and maybe that's where we start our -- our parking lot.

Mr. Ne’eman: I think the one

challenge that does occur to me, and it's a challenge with both Mike and Tom, is that they are both big names. I mean, you know, Mike is the senior official at the White House, Tom is Assistant Attorney General for Civil Rights, so, I mean, neither of them are people we can sort of just give a break out. They are both people that wherever we -- wherever we put them, we need to give some level of centrality on the agenda.

Ms. Resnik: Okay. Good point, Ari. So, maybe we do this, and, Ellen and Lee, would it be possible if we had Mike kind of kicking off the day, at that very high level, and then have Tom as the lunch speaker?

Ms. Blackwell: I'm a little bit worried about time, Denise.

Ms. Resnik: Yes.

Ms. Blackwell: But, what I, actually, had suggested to Della is that, you know -- I mean, we may not be able to get either one of these folks, but we could -- you know, we could, certainly, try to get Mike, and then have Tom as a back up, and then I suggested that we get Tom to come talk to us at a full IACC meeting.

Ms. Resnik: Okay.

Ms. Blackwell: I had already suggested that to Della, because I think the entire Committee would really enjoy hearing from Tom about -- about the efforts that are being made to enforce ADA and Olmstead.

Dr. Rice: Ellen, several of us in the room together are nodding about that recommendation, to have Tom come to a full IACC meeting.

Ms. Blackwell: Yes, okay.

Mr. Ne'eman: Sounds like a great idea.

Ms. Blackwell: Susan, is that doable?

Dr. Daniels: This is Susan.

We can add him to the list of possible invitees to the IACC.

Ms. Blackwell: Okay. So, it sounds like we have a plan, which is good.

The next panel, and we do need to talk about this a little bit, because Lee and I had several discussions, and I had a long conversation with John Martin, who is, actually, on our agenda at the end of the day. He's just a wonderful man.

He is the Developmental Disabilities Director of the State of Ohio, and I talked to John initially, because I know that the state has adopted policies that are -- and John doesn't like to say it as restraint free, but more positive strategies in their DD programs.

And so, John and I talked a lot about, you know, adopting policies that were not aversive, and then Lee and I had a subsequent conversation, because there is a bill, there are a couple bills floating around the Congress right now that are aimed to address restraint and seclusion in educational settings.

And, Lee suggested our colleague on the IACC, Sharon Lewis, who, apparently, used to work for George Miller, the Congressman from California who has been very active and engaged in this piece of proposed legislation.

So, we have not spoken with Sharon about being on our agenda, but, Lee, you said you believe she's uniquely positioned to talk about restraint, and if we wanted to have a panel, rather than single speaker, since John is going to be there anyway, we could also have him on the panel.

One of the problems I ran into is that I was having some difficulty finding states that have engaged in the sort of positive support versus aversive support.

So, I would suggest that we speak to Sharon about it, and maybe solicit her ideas, but that's kind of where we ended up on this community safety piece.

Another place that I -- and I,

actually, suggested this group for one of our full meetings, because I think that it's just too much in 45 minutes, but the City of Taunton, Massachusetts, is doing some remarkable stuff with cooperative program between the States Attorney's Office, the police department, the social supports network, there's a whole group of people there who have put together informally a great program that diverts people from the criminal justice system, especially, a lot of people who have autism spectrum disorder.

So, initially, I guess I was sort of viewing them as possible presenters, but I kind of like this idea of having Sharon, and then possibly John, and maybe even another state, talk about restraint and seclusion.

Anyone have any thoughts on that?

Mr. Grossman: And, the other reason we are having the recommendation for Sharon was that this goes beyond just restraint and seclusion, she can address safety on a much larger issue, and, certainly, is very well versed on how it impacts the entire disability community.

Ms. Blackwell: Does that sound good to the Subcommittee? I mean, it's a very important topic.

Dr. Rice: I think that's -- this is Cathy -- very important under community and support services, so yes.

Ms. Blackwell: And, these are issues that, obviously, affect, not just children in schools, I mean, anyone who has read the GAO report that came out, what, about 18 months ago, but also adults living in the community, and also people living in institutions.

So, this whole idea of safety is -- this is an area, Denise, where we could certainly go in another meeting, dig much deeper.

Dr. Rice: And, Ellen, this is Cathy, again, just add too -- also, in terms of the home, issues that families are facing, in terms of safety.

Ms. Blackwell: Yes. Yes.

So, that was our thought about community and safety.

And then, you know, this whole idea of training the direct service workforce is -- it's really important, and there are some very interesting things happening at the Department of Labor.

But, one of the -- and Carrie Blakeway is a consultant that we work with here at CMS, she's with the Lewin Group, and I think that Carrie would do a fantastic job talking about -- I think, not only can she talk a little bit about the Department of Justice program, or the Department of Labor program for certification, and, again, that's another potential speaker for another Services Subcommittee meeting, or maybe one of our full meetings, but Carrie can kind of set the stage for what happens when support workers are, actually, trained appropriately.

And again, this is an area where Dr. Lakin is also very well prepared, and since he's going to be with us this day, I thought we might want to add him to the panel. We probably should talk with him about that, but it was difficult, but I did find a state that, actually, Indiana, that had some grant money, and put a program into place. Carrie worked with them, and Randy Krieble, who ran this program, just has wonderful things to say about it.

Of course, what happens when you train providers, and they get some grounding in their jobs, they tend to stay longer, recruitment and retention are huge problems in the direct service workforce across the board, in terms of education system and the adult system. And, I think Randy has a very interesting story about what happened when they did get the money to support this program.

So, I thought that he would be great to talk about what, actually, what, actually, occurred when they did train and there were very large cost savings associated with the retention.

Ms. Resnik: This is Denise.

Does he also speak to compensation, certification, and, you know, making this a career for folks?

Ms. Blackwell: Yes, I think Charlie would, actually -- I'm thinking that we should probably put Charlie on this little panel, too, because of Charlie's expertise in the direct support world.

The certification for direct support workers out of the University of Minnesota, there is, actually, a module on autism, Denise. So, Charlie can talk a little bit about that.

And then, the Department of Labor program, I hope that Carrie will tell us a little bit about that, because it's complicated, but the provider ends up having to pay for the additional training, and a lot of providers are reluctant to do that up front, because it's hard to see the benefit down the line, but once they do, they really experience cost savings and much greater worker satisfaction.

So, this is, certainly, you know, a very important topic, and, potentially, a recommendation to the Secretary to be that some government programs pay for training of direct support service workers.

So, that's, I guess, how I'm seeing what the recommendation could be.

Currently, Medicaid, for example, does not pay to train direct support workers.

Ms. Resnik: It sounds like a good recommendation.

Ms. Blackwell: So, that would be nice to hear more about that, and then the next one, Denise, I know I don't have to say anything to you, I can imagine, I mean we all know this is probably the toughest problem to deal with, as far as adults with disabilities, and elderly people as well. Medicaid does not pay for room and board, and the housing support vouchers are few and far between, although our colleague, Henry Claypool, was instrumental in having a number of vouchers released through HUD this year that were assigned to non-elderly disabled people, including people with autism.

So, you know, tough to make a recommendation about housing, but I think it's possible that we could develop a recommendation that government programs, for example, you know, perhaps, explore ways to pay for room and board, and to support that recommendation. I mean, we know at CMS that amazing things happen when people with disabilities live in their own home, and Maine is one of two states that has developed a rental assistance program. These are sometimes called bridge programs, and what they do is, they, literally, bridge the gap between the time the person with the disability is able to access a housing choice/Section 8 voucher, and the time that they need to get into their own home.

So, I thought -- the guy that runs the program, and I just jotted his name down earlier, and I, again, apologize, Randy -- bear with me for a minute here -- he is fantastic, and this Maine program, again, is a bit unique. It is, primarily, aimed at people with mental illness, but -- I'm sorry, his name is Sheldon Wheeler, and Sheldon has been around for many years. He hails from New York, and he can just -- you know, he is here to attest at what happens when people live in their own home. So, that, I thought, would be a nice pairing with Patti Scott, who, Patti is a consultant, she's with a group called Neighbors, Incorporated, in New Jersey.

Unfortunately, Patti is not going to be in the country that day, but she has suggested one of her colleagues, perhaps, could sub for her.

But, Patti and her colleague are also positioned to talk about what happens when a person gets in their own home, and I think this also is a nice tip of the hat to self direction, because when a person controls their own home it starts to help control everything in their life.

So, a potential recommendation, again, could be that government programs find ways to finance housing for people with disabilities.

Ms. Resnik: Ellen --

Mr. Ne’eman: Ellen --

Ms. Resnik: Go ahead, Ari.

Mr. Ne’eman: Ellen, sorry, Denise -- Ellen, this is Ari. I think those are both great. I just -- I wanted to raise an additional possibility here.

ADD, Administration on Developmental Disabilities, is currently financing -- is currently funding SABE, ASAN, and NYLN, the National Youth Leadership Network, which is a youth-oriented, self advocacy group, to hold a one-day summit around housing issues in the community, to more carefully define that which should and that which should not constitute community living arrangements, you know, with the idea that this could conceivably inform regulations around what the home and community-based services waiver will and will not fund.

You know, I see that as another area that would make a lot of sense to bring up here, would also bring to the table some self advocate speakers, and speak to a very important area of systems change, which could very easily lead to recommendations.

If we think about, you know, what recently happened in Missouri, that the state is trying to build group homes on the grounds of an old institution, and call that community living. Unfortunately, CMS struck that down, but it's something that's happening increasingly commonly nowadays.

That seems to me to be an area of policy that really calls out for us to undertake some leadership around.

Ms. Blackwell: Can we -- I agree with you wholeheartedly, of course, Ari -- can we add that to -- like I've got a list here, Denise, like our parking lot list, so can we add that to our parking lot list, because I'm not -- I don't think in this housing options recommendation there's anything -- I mean, I don't know that we would dispute that, you know, a person having their own apartment is not home and community based, but I understand what you are talking about completely, and I think that that might make a good topic for another meeting, or even maybe at our regular meeting, because we do have -- we are developing a regulation now. I mean, the timing for CMS might not be great, and I'm not sure it would quite fit in with the two speakers for this panel, but I can --

Mr. Ne’eman: Well, it sounds to me like one of the speakers is withdrawing, so I mean, I think --

Ms. Blackwell: The guy -- the fellow that I'm suggesting comes in is one of the originators of the Home of Your Own Project, his name is Joe Wykowski. He runs --

Mr. Ne’eman: Oh, Joe is great.

Ms. Blackwell: Yes.

Mr. Ne’eman: You know, I like him.

Ms. Blackwell: Yes, I thought Joe would be a nice -- a nice speaker with Sheldon. I mean, he does a lot of housing project work. He's from Oregon. He runs a self-directed organization there.

So, because Patti can't be with us, I'm suggesting that Joe be our other speaker.

Mr. Ne’eman: I mean, in principle I think that sounds fine. I guess my concern is, particularly, because I know CMS is undertaking work around this, I think it is important that we try and find some way to fit in this issue in the services workshop. And, potentially, it's under the self direction heading, or it's under a different heading, but, you know, I really do see it as important and timely, to be looking at defining what is, and, more importantly, what is not community living.

Ms. Blackwell: Would that be something the Subcommittee would be interested in hearing CMS talk about at a future meeting?

Mr. Ne’eman: Well, I think, you know, we want CMS to talk about this, I just -- the issue is, my understanding is CMS doesn't yet have a position on it, and ADD is funding a gathering of self advocates from across the country to come up with a position on it. And, my hope would be that we can utilize this as an opportunity to inform recommendations that may assist CMS in coming to its policy conclusions around this.

Ms. Blackwell: That would be

great. As you know, we are always interested in soliciting the views of advocates and others who, you know, who want to express them. So, we would look forward to getting those recommendations, and it sounds like Joe might be a nice adjunct to Sheldon.

Would the Subcommittee -- I mean, I think they make a great team, and if we could end up with some kind of recommendation about, you know, making arrangements to help pay for housing, I think that would be terrific.

Mr. Ne’eman: I guess my point is that if we are going to put this in the parking lot, my hope would be that given the time sensitive nature of this that we prioritize it.

Dr. Rice: Ari, this is Cathy.

Is the meeting of the self advocacy you were talking about, is that coming up soon, and is that something that members of the Subcommittee could listen in on?

Mr. Ne’eman: It's going to be on

September 22nd in Kansas City. I don't believe there's going to be a call-in line, but, you know, if anybody is in the area people should certainly feel free. But, there's going to be a report coming out of it that we can certainly distribute, or if, you know, we have time at the October IACC meeting we can present it to the Full Committee.

Ms. Resnik: This is Denise.

And, Ari, to your point, in terms of that information coming back to the Full Committee and helping to inform public policy recommendations, just like the work that has been done by Advancing Futures for Adults With Autism, which has been significant, the focus on that has been how do we also get the private sector engaged in developing more choices.

So here, Ellen, the focus is on the benefits of the, you know, home, and I think we are all aware of -- you know, many of us certainly are aware of what that means in the stability. As we look to this informing our public policy recommendations, I just want to make sure that we have the right component that will help us in terms of those public policy recommendations.

So, what we are talking about here are the benefits of owning -- or of living in a home, away from your parent, and again, we are talking about adult housing here, or are you expanding this also to include families who are not able to care for their child with autism?

Ms. Blackwell: No, I think we are looking at adults in this sense, Denise.

Ms. Resnik: Okay. And then, would that be home of your own, you know, and understanding that there could also be other options and ways for us to expand opportunities for adult housing.

And, that's where also the letter to the IACC, which I know you've received, it was attached to that correspondence, just wanting to make sure that we do, you know, allow ourselves the benefit of taking the good work that's been done by, you know, many organizations, including AFAA, to inform our public policy recommendations, understanding that this one workshop isn't going to address it all, that you've done a lot of scoping, you've got a lot of good information, there's more underway, there's a lot of good traction, we'll have a future workshop, but I want to make sure that in public policy recommendations we are doing some things that will, hopefully, engage other private and public sector interests.

So, you know, as you know, this is a big -- a big topic for me personally, and I just want to make sure that as we are selecting speakers that we've got, you know, those that are going to help us maximize the opportunities that are out there.

And maybe, I don't know Joe, but maybe Joe is that person, and, you know, if not, you know, I would like to, perhaps, offer some others.

Ms. Blackwell: Maybe when we rate the recommendations, Denise, we can make sure that we talk about including, you know, making sure that the private sector is included, because, remember, when we make recommendations to the Secretary, the Secretary can only control the programs that she controls. Does that make sense?

Ms. Resnik: Right, but there would be certain things -- yes, that she would control, that would be of interest, that would help engage private sector involvement, and having the public/private collaboration. That's what I was looking for.

Ms. Blackwell: Right.

Mr. Ne’eman: I guess the concern that I would raise, Denise, and I think it's very important that when we do this that we ensure that our speakers are coming in to speak to systemic issues, rather than, you know, parochial interests.

And so, I really would encourage us that we really prioritize people who can talk to systems recommendations, rather than just how particular policies might impact the operating structure or the opportunities of their particular organizations, or their particular service provision programs.

Ms. Resnik: I'm in agreement, Ari, that we need systemic changes.

Ms. Blackwell: For our next topic --

Dr. Johnson: I'm sorry.

Ms. Blackwell: No, go ahead.

Dr. Johnson: Ellen, this is Jennifer Johnson.

Ms. Blackwell: Hey, Jennifer.

Dr. Johnson: A couple more things on the housing.

Ms. Blackwell: Yes.

Dr. Johnson: Just one thought, in terms of another -- and I'm not sure if you would be touching upon this in what you have talked about so far, but I think the issue of housing relates closely to the topic that would come before, in terms of community safety. In order to live in a home of your own, there needs to be the necessary community supports, to ensure safety and well-being for people to live on their own.

So, I don't know if we think about those two topics in similar ways, or to address the whole idea of supporting community living, living on your own.

Ms. Blackwell: I guess in my mind, Jennifer, and now I'm thinking like a Medicaid person here, if I think about a lot of the people that are supported by our programs, I mean, to participate in a Medicaid home community-based waiver, the state has to assure CMS that the person will be safe in the community, in fact, health and welfare is one of our key quality assurances.

So, I guess if I'm imagining a

person participating in an HCBS waiver program, the missing piece is the housing piece. The services have to there, otherwise the person can't participate in the waiver. They would be in an institution.

So, housing is just the biggest challenge that we have, and to give you -- you know, I guess the biggest example is that, imagine an adult with autism participating in a home and community-based waiver, who may or may not have a choice of agency-based providers. And, I mean, the person is supposed to have choice, but the agency decides where the person is going to live, rather than the person deciding where the person is going to live, 99.9 percent of the time.

So, if the person isn't happy, for example, with the services that he or she is receiving from that agency, they may have to move to another place to get services from another provider who has got a house in a different place.

So, the really interesting thing about having a home of your own, whether it's a home that's purchased or rented, is that the person with the disability brings the services into their home. So, it really does change the playing field.

Dr. Johnson: No, and I understand all of that. I guess what I'm trying to address is, what are the -- what are some models of supports that are out there.

Ms. Blackwell: Oh, I think the -- yes.

Dr. Johnson: And, just touching upon that, in terms of the housing piece.

So, for example, what kind of modifications are made in the home to allow a person with autism to live in a home, other types of services. Some of our university centers provide community-based services to support that community living, for example, they have a hot line. So, if there's some kind of an emergency they have direct access to a support person, who can respond to any type of an emergency.

So, those are the kinds of supports that I'm talking about.

Ms. Blackwell: Okay, like environmental modifications.

Dr. Johnson: Right, exactly.

Ms. Blackwell: Sure, maybe personal emergency response systems.

Dr. Johnson: Right.

Ms. Blackwell: Right.

Dr. Johnson: And, I don't know if that's with the housing, perhaps, government programs, and, perhaps, other aspects may be safe, but I just wanted to put that out there.

Ms. Blackwell: No, I think that's a really good piece that I'm hoping that Joe could address.

I know that there's one benefit that is probably one of the most under used benefits in the Medicaid program, the live-in caregiver benefit. And, some states have elected to use it, but when a person lives in their own home, under some conditions Medicaid can pay for the room and the board of the live-in caregiver.

So, a lot of states that have checked that benefit, when a person owns their own home, it just creates these wonderful relationships and, really, adds to the stability of staff.

Dr. Rice: This is Cathy.

I'd like to add to what Jennifer was saying. I think when we are thinking of our recommendations that we broaden the concept of housing to supportive residences throughout the life span, because along those lines of home support it could happen for a child as well, and this is an issue that comes up quite a lot in the state where I'm from, is that many families don't have the ability or the resources to adapt the environment, and many children end up in foster homes, or outside of their home environment, or need specialized residential care, and there's no facilities to assist.

So, I think you can't address that all in the workshop, but when we are thinking of our recommendations that we think more broadly in terms of supportive residences.

Dr. Johnson: Okay, and then just to add to the housing discussion and potential speakers, because I know you have several listed here, I just wanted to let you know that some of our university centers are doing work in this area, and they won't be addressing, specifically, autism, they'll be more broadly addressing developmental disabilities.

Our university center in Mississippi does a lot of work with HUD, and finding and accessing housing for people with disabilities, and making modifications, and those kinds of things. So, they could be a potential resource for this topic.

And then, our university center in

New Hampshire does a lot of research on the topic, and in some ways looking at the economics of housing, they've done that type of research in the past.

So again, two other potential resources for speakers on this topic.

Ms. Blackwell: Could you send us an email, Jennifer?

Dr. Johnson: Sure.

Ms. Blackwell: And then, I was also going to suggest --

Mr. Ne’eman: That would be the UMASS Institute on Disability?

Dr. Johnson: Yes, it is.

Mr. Ne’eman: They, actually, have a number of different autism-related projects and programs, and I just -- I raised the issue because it strikes me that they might be, particularly, well suited to speak about their work, which, you know, I would imagine is being done in a broader DD context, as you said. But, to present it in a context that will be relevant to the unique needs of autistic adults.

So, I'm glad you brought them up.

Ms. Blackwell: It seems like housing is one of these issues, like employment, that, you know, we could take a whole day, a week, you know, to talk about.

So, I think we can keep it on our list of other things, possibly, for a future meeting, or a Services Subcommittee meeting, or even our fall meeting, because it's a huge issue.

Ari, you had some suggestions, I know, on the next topic, the peer support discussion.

Mr. Ne’eman: Yes. Well, mainly I think this is a good opportunity for us to communicate some of the systemic projects and programs that are occurring within the self-advocate community.

In particular, I think Jim Sinclair, of Autism Network International, which is the first autistic self-advocacy organization, and a group that we respect greatly, and work closely with, would be a great speaker to talk about some of the things that are going on on the list, autistic-run peer support, and autistic-led programs in various locations.

But, in particular, the conference Autreat, which is the largest gathering of autistic adults, and has gathered a considerable amount of information as to the benefits, in terms of improve mental health, and improve quality of life, opportunities for interaction and social opportunities, with other people of similar life experiences, in regards to autistic adults and autistic youth.

So, I think that could be a very intriguing and promising way to bring in self-advocate voices to the workshop, while still focusing on our broader mission of ensuring we are looking at systemic issues.

Ms. Blackwell: And, you could

provide Susan with the information regarding Jim, Ari?

Mr. Ne’eman: Gladly.

Ms. Blackwell: Does that sound reasonable, Susan?

Dr. Daniels: Ellen, this is for future IACC meetings or for this workshop?

Ms. Blackwell: That is for this workshop.

Dr. Daniels: For this workshop, okay.

Ms. Blackwell: And, we had sort of a hole here. We, actually, did get a recommendation, and we should talk about this for a few minutes.

Sam Odum -- Gail, are you back on the line?

Mr. Grossman: This is Lee.

Before we move on to Sam, there's a couple other names on peer support that we could put on there.

I mean, Jerry Newport started, as

far as I'm concerned, as far as I know, the first peer support group that I'm aware of, and he did that in L.A., and he's written extensively about that.

Dena Gassner is also somebody that -- she's a national, she runs peer support groups as well in that area.

So, I mean, you could probably start adding some good names to that list.

Mr. Ne’eman: I think Jerry and Dena are also great choices.

The reason that Jim, in particular, comes to mind is that, Autreat has, I think, the last 15 years continuously been the largest gathering of autistic adults run by autistic adults in the world. So, I think it has something of a benefit of both history and continuity.

But, you know, you know me, I certainly support adding self-advocate speakers on other parts of the agenda, beyond peer support as well.

So, you know, if we wanted to add that discussion, I think it would make a lot of sense to come up with more names.

Ms. Blackwell: Well, because this is a system, I mean, we are sort of trying to focus on the systems here, if we could look at through that lens, maybe that would help focus a bit.

I was going to say that Sam Odum has -- there is a school district in Wisconsin that has instituted, with the help of the Waisman Center at the University of Wisconsin, a program throughout the school system, elementary school, middle school and high school, for peer support.

It was, actually, talk defined in a school system that had done this sort of work. So, and then Lee and I also talked about Brenda Miles, who some of you may know, Brenda has done some work with the previous Services Subcommittee, and Lee has done a lot of work with Brenda. I've worked with Brenda on one of my contracts.

I'm kind of in favor of listening to the school system folks talk about, you know, how they integrated these practices into their system.

Hello?

Mr. Ne’eman: Did anybody else hear that?

Ms. Blackwell: It wasn't me.

But, and I also tentatively put the Towson University Center for Adults on here, because this is an established center. It's, actually, fairly new, that put together programs for adults with autism.

But, you know, maybe we could discuss for a few minutes what the recommendation might be. I know in the Medicaid program we, actually, added peer support as a Medicaid service under the Rehabilitative Services Option several years ago, essentially, aimed at people with mental disorders.

No state has asked, in particular, to use this benefit to serve people, children or adults, with autism, so I can't say if Medicaid would say no or yes, but peer supports are a Medicaid service already. So, I was a little bit unsure about what the recommendation to the Secretary would, actually, be. So again, this is my backwards thinking, when we put together this panel I think that we do need to think about what we would be recommending to the Secretary.

Mr. Ne’eman: Well, I wonder if in the context of looking at the education runs here, we might think about somebody like Eric Carter, who looks at how peer supports in the school system can be utilized to support inclusion, and connect that to some of the discussions around the technical assistance that's being provided to states and districts, in regards to including students on the spectrum.

Ms. Blackwell: Well, let's say we

broaden the school district that has, actually, done this, to show that it can be done successfully in a system.

I guess my thought is that the recommendation might be that maybe our Secretary, Secretary Sebelius, recommend to Secretary Duncan that, you know, peer support be required, or, you know, or that CMS and HHS support -- and I hate to be -- I'm not trying to make a pun here, support peer support in HHS programs and education programs.

I mean, I don't -- I don't know how to be more specific about it, because in Medicaid we can't force states to add benefits, but we can urge them to consider things.

Mr. Ne’eman: I think that might make most sense.

Ms. McKee: Ellen, this is Christine.

Wasn't there some recent research, and I'm recalling something that came from

Alison Singer, through email, talking about the importance of peer support, especially, for children who are in self-contained classrooms. And, it had to do with modeling, and that children, we are talking very middle of the road to lower functioning, actually, model their peers better than they model adults, and that we need to be more for our children who are in self-contained classrooms, to provide them with access to peer modeling.

Ms. Blackwell: Yes, I think, Christine, that that's a study that hasn't come out yet, that's coming.

Ms. McKee: Okay.

Ms. Blackwell: That I think we would want to hear about. I was thinking that would be great to hear about at a big meeting.

Ms. McKee: Okay.

Ms. Blackwell: So, I don't know, personally I'm kind of in favor of Sam Odum's suggestion to look at this Wisconsin group, the special ed director who championed this project, and work with the Waisman Center.

I don't know, I think it sort of goes along with the rest of these ideas, where we are going to hear from folks that have, actually, instituted these practices.

Ms. McKee: Do you know if Sam has instituted them with the more middle of the spectrum to lower end of the spectrum for the peer supports, or is it more across the spectrum?

Ms. Blackwell: It sounds like they did this at model sites, and started at elementary schools, and then worked their way up to middle schools and high schools.

Ms. McKee: But, we don't know if they concentrated on a particular area of the spectrum, the more higher-functioning children or across the spectrum?

Ms. Blackwell: I don't know yet. I, actually, have been gone this week, but I can find out more.

You know, I would hope that they

didn't just, you know, solicit only high-functioning or low-functioning children.

Dr. Rice: This is Cathy.

Even if -- I'm not sure about that particular model, but I know Sam Odum has been involved in this type of research for many, many years, and that there's multiple studies across the levels of functioning that he would be able to probably speak to.

Ms. Blackwell: Yes, Sam, actually, suggested this particular school district, Cathy.

Dr. Rice: Okay. Yes, so I imagine, you know, it's certainly important to check, but even if that particular school district didn't address it, we can, certainly, ask him to speak to it across the spectrum, I would think.

Ms. McKee: I think that would be great, because I know that parents of children who are in the self-contained classrooms really struggle to find more appropriate peer interaction time.

Ms. Blackwell: Yes, that is certainly true.

You know, that leads -- that's another area. I have this -- I'm getting a very long parking lot list, Denise.

Ms. Resnik: I know, I'm collecting to, too, and, you know, and as I'm listening, the other list that I'm making speaks to some of the criteria that we are using for selecting speakers, and one of the things that I've heard repeatedly is systemic changes. Another thing is spectrum-wide, to make sure that we are looking at, you know, all points of the spectrum. Another is best practices examples, as well as public policy expertise. Another is also leveraging work already, you know, done or underway, speaks to the conference that Ari was speaking to, my reference to AFAA, I know AFAA has done quite a bit.

So, I'm thinking that that could be

very helpful in our presentation to IACC, and presenting this agenda in the future for helping others understand how we arrived here, and then the staged approach, as you, you know, as we identify what's to come in terms of, you know, future gatherings.

Ms. Blackwell: Thanks, Denise.

The last speaker, I just -- I have so many good things to say about --

Dr. Daniels: Say, Ellen, this is Susan.

Ms. Blackwell: Hey.

Dr. Daniels: Can we, with peer supports, did we come to a decision about who we want? I didn't get a clear idea.

Ms. Blackwell: Let's go back to peer support. I mean, again, I mean I myself would vote for hearing from the school district that did this, and I think the Towson program is an example of, you know, a good -- a decent formal program that's put some supports together in the community for adults, you know, may or may not be the best example, but it is an example. It happens to be local.

And then, I did not get a decision on a group of peers that might be, you know, Lee, you had mentioned Jerry and Dena. I know I've heard from Dena before, she's very good.

I don't know Jim Sinclair, but does anyone have a preference for a self advocate to talk about maybe how to -- you know, that we support organizing a group, and, you know, how it could be, a model could, say, be proliferated into other communities.

Mr. Ne’eman: I'd strongly, strongly support Jim. I think he's been doing this for a considerable period of time, and more importantly I think his is the name that's going to carry the most weight amongst other self advocates.

I think bringing Jim on board is going to ensure that this is going to be a discussion that will be viewed as somewhat more inclusive than would be the case without him.

Ms. Blackwell: Okay, so he could address how the group was formed, Ari, and, you know, how, perhaps, that model could be replicated in other places?

Mr. Ne’eman: Well, yes, and I think one of the other advantages is, you know, Jim is, and I think other people have raised this in the context of other things, you know, Jim does not have an Asperger's diagnosis, he has an autism diagnosis. He comes from a somewhat different background than, perhaps, for example, I do, and I think his experience with autistic culture and autistic-run groups speaks to that diverse background, which I know, perhaps, are some of the concerns that Denise has brought up, and that a few other people have brought up. I think Christine brought it up, which I certainly agree with.

Ms. Blackwell: Yes.

Mr. Grossman: Ari, could you

comment on Eric Carter? I don't know him, but his name keeps being put in front of me, as somebody that's very good to talk about peer supports, and bridging the gap between school and employment. Are you aware of his work?

Mr. Ne’eman: I am. I am. I've seen his name come up in the context of discussions around the inclusive education, and I've seen him present on peer support, and I found him to be very good.

I believe he's university-based. I have to tell you, off the top of my head I don't know which university, but I think the last time I saw him present was at a Maryland Coalition for Inclusive Ed conference, the group Carol, who is our inclusive ed speaker, ran.

So, you know, his is a name that certainly is well respected in the professional community.

Ms. Blackwell: What's Jim's last name?

Mr. Ne’eman: Carter.

Ms. Blackwell: I still didn't hear that, I'm sorry.

Mr. Ne’eman: The name of the peer support person was Eric Carter.

Mr. Grossman: I just Googled him, and he's -- if it's this gentleman, he's at the Waisman Center.

Mr. Ne’eman: Oh, yes, that was it, Wisconsin.

Ms. Blackwell: He's probably then involved with these other folks, that's my guess, the school district model site. I wouldn't be surprised at all.

Mr. Ne’eman: It would make a lot of sense.

Ms. Blackwell: Well, okay, there you go, one more -- one more push for Wisconsin.

The special ed director's name is Julie Laberge, B-E-R-G-E, Susan.

Dr. Daniels: And, that's for the

list for the full IACC?

Ms. Blackwell: No, that's the Wisconsin school district for the peer supports panel.

Dr. Daniels: Oh, okay.

So, how many total people are on this panel right now?

Ms. Blackwell: It sounds like three.

Dr. Daniels: So, it's Julie Leberge, Sam Odum, and who is the third person?

Ms. Blackwell: No, no, no, Julie Leberge, it sounds like you want Jim Sinclair, Ari?

Mr. Ne’eman: Yes.

Ms. Blackwell: And then, someone from the Towson University center. Right now we have Lisa on here.

Dr. Daniels: Sounds good.

Ms. Blackwell: And then, the final speaker, I almost wanted to put him on every panel, because I think he's so wonderful, Brenda Miles knows him very well, John Martin, who is presently the Ohio DD Director, and he has not been in Ohio a terribly long time, but as I said earlier, he's done an incredible amount of work on developing an emphasis on a positive culture. The state has, actually, outlawed prone restraint, and he's such an interesting guy, and has just great ideas about how do we start at the earliest stage for inclusion, and how do we look at every person as an individual? What is the systematic approach? How do we change these legacy programs, like Medicaid? How do we get the school system, and the DD folks, and the county folks, and the early intervention folks together? And, he just has some really radical ideas about thinking systemically about services throughout the life span, and lifetime-integrated approaches, and how to stop people from dropping from system into system, and start streaming the systems together.

So, I thought John would be an excellent end to our day, and really fit in well with our theme of, you know, quality services and supports for everyone across the life span.

He's certainly a great example of somebody who is trying to make a difference in some really tough systems that are dug in.

Does that sound like a plan? I mean, I've just heard wonderful things about him from other people, and then when I spoke with him I was just incredibly impressed. I think we could learn a lot from John.

Dr. Daniels: Sounds good.

Ms. Blackwell: Okay. So, here's my list of parking lot issues. Here's what I got, and I hope other people will chime in.

Here are the ones that I felt like we lost, we lost person-centered policies and planning, employment and vocational opportunities. Vermont is running a very interesting program on person-centered assessment, options, counseling, and peer services ranking, that are very interesting.

We don't have any discussion on here about using managed care delivery systems to serve people with ASD, criminal justice diversion is missing. I know that Gail and I have talked several times, we'd like to hear a lot more about the programs being run by the Department of Defense, the Department of Labor program about direct service worker certification, I would like to hear more about them.

I'd like to hear more about recreational activities in communities for people with autism.

Ari mentioned characteristics related to home and community-based services settings.

We talked a little bit about supportive residences, and other issues related to housing.

Those are the ones that I got as the missing, it seems like a pretty long list of many things, actually.

Do other folks have other items that are also missing?

Mr. Ne’eman: I guess the one thing that does occur to me is that it may make sense for us to get some presentations on the kinds of service provisions that is being funded from state funds, and, in particular, the three things that I have in mind are, the Florida card system, which seems very intriguing in terms of what's being done down there with adult service provision, by no means comprehensive, but very intriguing.

The Pennsylvania Bureau of Autism Services, and the Connecticut Autism Pilot Program, all those things are areas that are looking at ways to serve people who may not qualify for Medicaid-eligible funds, and that seems to be very -- for Medicaid reimbursable services, and that seems to be the area that represents one of the most significant gaps in service provision, currently, in the autism world.

Ms. Blackwell: So, state funded -- Ari, we, actually, did have a presentation from Cathy Reddington a couple years ago on the program for high-functioning adults with autism and employment. It was great. Susan has a copy of that, if anyone is interested in seeing.

And also, I have a copy of the report, the summary report on that program, which I can send to you, Susan, if anyone is interested in looking at it, because it is very interesting.

And, I would also like to add to my list ADA and Olmstead issues.

Mr. Ne’eman: That makes a lot of sense.

I think the state funds issue is a topic worth revisiting, but I'd certainly be interested in reading Kathy Reddington's report, if you'd send me a copy.

Ms. Blackwell: Sure.

Mr. Grossman: And, we've had -- Ellen and I have talked quite a bit about if we should have Nina Wall-Cote from Pennsylvania's part on this also, as one of the suggestions you brought up, Ari, because they've done quite a bit on what they are doing on a statewide level, Medicaid waivers and that's a very, very important step.

Ms. Blackwell: Yes, when I mentioned managed care delivery systems, I, actually, had Pennsylvania in mind, because the state is running two parallel programs. One is a Medicaid home and community-based waiver for 200 adults with autism, targeted to 200 adults. Obviously, these are people that have to meet the criteria for participation in a home and community-based waiver.

The other program is a -- it's a Section 1915(a) contract, and it is also for 200 adults with autism, living in the

Harrisburg area. It's administered by Keystone Services. This is not unique, it is unique in that it serves 200 people with autism, but it's a little bit unique in that the state has entered into a contract with a particular provider, and families can, or individuals, can voluntarily elect to participate in this program. It is funded through a risk-based payment methodology. In other words, unlike the home and community-based waiver, which is fee for service, this Harrisburg project, the provider receives a monthly per member, per month rate for participants, and is expected to provide a full array of services to the people participating in that program.

So, it started enrolling people in July, I believe, of this year, so it may be a little bit early to hear from Nina, but I am very interested to hear the data that this state is going to start getting on what it looks like in the managed care world, and what it looks like in the fee for service world, because we in Medicaid know that many, many more states, Vermont, Hawaii, California, Arizona, the first state and Committee One are starting to manage their Medicaid programs through risk-based payment methodologies.

So, this is an area where I think we could certainly hear a lot more in the Pennsylvania project, because it is targeted at people with autism. It's an excellent example of that.

Dr. Johnson: Ellen, this is Jennifer.

In the past we've talked about issues related to early childhood being included in the discussion, and that would include the regular or general early childhood system and early care system, as well as infants and toddlers, and young children with disabilities.

So, I'd just like to make sure that that gets on the parking list, because I think the agenda as proposed doesn't really cover, really, the early childhood systems, and what kind of recommendations we need to be looking at in terms of early childhood.

Ms. Blackwell: No, I agree, Jennifer, that's going into the list.

Is there anything in particular that's happening in, you know, the zero to five world that, you know, is a systems practice that would be something that we could look at, maybe in our next meeting, that could be built into the recommendation to the Secretary?

Dr. Johnson: I'd like to think about that a little bit more, because there is so much going on, and I think that, again, the question is, do you look specifically at autism, and what's going on to address issues related to children with some autism spectrum disorders, or do you look more generally at the system, and how they are addressing children with disabilities, and including them in some -- and also, I think it gets into an issue of identification, and, certainly, that relates, it can relate, specifically, to children with ASD.

So, I guess it's just a matter of what approach, what topic, the Committee would want to take when we look at early childhood.

Ms. Blackwell: I mean, I think when we start making recommendations about systems, I don't think they are necessarily particular to autism.

Dr. Johnson: So again, this is a tremendous amount of work, and I don't know where we would want to begin to tackle early childhood, because you could tackle it in many different ways.

Ms. Blackwell: Okay.

Dr. Johnson: We can certainly maybe talk a little bit more about how to slice it, and what areas to look at, and where you would want to break it down.

Again, we could look at it from the

services being provided, in terms of inclusion. We could look at it in terms of access to services in general, access to assessment of young children.

So, again, I think there's a lot of different ways for us to look at the issue.

Ms. Blackwell: It sounds like we could spend a whole day on that.

Dr. Johnson: Yes.

Ms. Blackwell: I know, I think we could.

Dr. Johnson: And, there's also family support within that.

Ms. Blackwell: Well, maybe that's a thought, you know, maybe that should be a meeting.

Dr. Johnson: Right.

Dr. Rice: Well, and to follow up on that, this is Cathy, back in august, I don't know if anybody attended, there was an early childhood conference, basically, focused from zero to eight, that was jointly sponsored by HHS and Education, and Joan Lombardi was very involved from HHS. And, the whole idea was to look at systems of care from zero to eight across education, health, you know, everything from WIC services, to Head Start, to traditional education, and may be part of what we should think about in the future as to how to make sure disabilities and autism are a part of that conversation.

Ms. Blackwell: We were a part of a planning process, and we tried to make sure that in collaboration with the Office of Special Programs, disability was addressed, and we did make sure that there was a session on autism included at that conference.

So, I think, yes, as an example of the work that is ongoing in early childhood, and how many systems are involved in the early childhood services, and it might be helpful to look at the work that was done related to that conference. There's going to be some follow-up work done related to that conference, so maybe some connection to what they are doing might be helpful in what we talk about.

Dr. Rice: Yes, in particular, but I think there's seven different committees that are continuing on.

Ms. Blackwell: Right.

Dr. Johnson: The only other thing I wanted to mention, in terms of a topic, and I think this is something, or a topic that can be addressed by all the topics that we are talking about, and that's diversity issues and cultural competence.

I think it's important that any discussion that we have also addresses diversity issues, and implications for people who come from different backgrounds, and are from different cultures, how autism services and everything related to autism, basically, is impacted by somebody's culture.

Ms. Blackwell: So, that could be a recommendation, too. So, that's another one we probably need to tackle. j

Dr. Johnson: Okay.

Ms. Blackwell: We just have these big ones, Jennifer, that's probably another whole day on that, you know, I mean that's huge.

Dr. Johnson: Well, possibly within the topic itself, or it could possibly be a separate issue.

Dr. Rice: Well, Ellen and Lee, this may be sort of a segue to the next topic, but some of these parking lot topics seem to be more kind of cross-cutting themes.

One of the things that I was wondering is, should we think of paralleling the IACC research plan that came up with the core values, and then to sort of cross-cutting themes that are really meant to be integrated into each of the topic areas. And so, some of the things that we've talked about were things like self direction, and maximizing quality of life, spectrum wide respect for diversity, quality, those types of things, that really, no matter what topic we are talking about, should be sort of integrated in that perspective, and maybe that's something as we go forward to the policy recommendations as a group we can think of, you know, what are the core values of this Service committee and plan, and what are the cross-cutting themes that should cut across everything.

Dr. Johnson: That's really good, Cathy.

Mr. Ne’eman: Ellen, what -- you know, it's probably in our interest to time limit to some degree when we will come up with our first initial set of policy recommendations. What did you have in mind?

Ms. Blackwell: I was looking maybe we could hand them in to the Secretary whenever the -- at the beginning of the year.

Mr. Ne’eman: So, we are talking about, you know, by January 1 we have, at the very least, an initial set of policy recommendations, and then, you know, hopefully, we can have a more -- we can spend 2011, and God willing we get reauthorized, coming up with a more comprehensive document?

Ms. Blackwell: Yes, that sounds good.

Susan, when do we -- do we owe the Secretary another strategic plan in 2011?

Dr. Daniels: Yes, we'll be turning in one in January.

Ms. Blackwell: So, we could -- we could, potentially, turn in these Services recommendations to her at the same time?

Dr. Daniels: If you are want to work on them at the same time as you are working on the strategic plan. There's not that much to do on the strategic plan.

Ms. Blackwell: Yes, that's what I was thinking, that they could go together. That would be nice.

Mr. Ne’eman: Well, and I guess to my mind, and I'd like to recommend this and, hopefully, we can pass it along to the full

IACC, I think it makes sense for us to come up with a strategic plan type process for 2011, to come up with more in-depth policy recommendations.

I mean, as you said here, you know, this is one day, and it's very preliminary, and we only have, really, a month and a half if we count the holidays to deliver policy recommendations. We are going to want to go a lot further, and there are a lot of issues we won't cover.

Now, if we can bring together some of these experts on panels, similar to what we do for the research strategic plan, and, you know, essentially, tell them, dig down deep into these areas of policy, and come out -- come up with specific changes in regulation, or what have you, that you made in order to move the ball forward, I think we might get a much more comprehensive document in our hands by the time the IACC is in a position, to potentially expire in September of 2011.

Ms. Blackwell: I like that idea, Ari, of delving deeper, and taking some of the pressure off a one-day workshop, knowing that these and other topics would be more fully vetted and explored.

Mr. Ne’eman: Excellent.

Dr. Rice: This is Cathy.

One suggestion, what do people think about, as members of this Subcommittee, that as each of these speakers are talking, that we each go through and start to think in terms of sort of the opportunities that are available, the challenges, and what policy recommendations we each might see from each of these topics, and then come back together to see where we have, you know, agreement on some of those areas.

So, it at least gives us a structure to move forward with.

Ms. Resnik: Cathy, this is Denise.

I like that idea, and what I was going to sketch out was, you know, some kind of a matrix that maybe we could look at, that aligned our RFI priorities with the speakers, the recommendations, it sounded like the process that Ellen and Lee have gone through to get us to this point.

And then, I think we've added to it, but it could be a good vetting process to determine what our final line-up is going to look like.

Dr. Rice: Right, and that could be a great structure again, if we start with these sort of, what are the core values, cross-cutting themes, and then the opportunities, challenges, and recommendations that this Committee sees as a group we can best use the experts, you know, at the next stage, to help tweak, modify, add, fill in holes, rather than start from scratch.

Ms. McKee: This is Christine.

Along with that tweak and modify, I know we keep putting up the road map that we talked about in the past, it's actually the draft of the road map that has all the appendices attached to it, and the Appendix B, the constraint on achieving successful ASC services, that is -- it's a very long -- we have about ten pages of constraints.

And, if you read through them, some of them are, thankfully, no longer true, but a lot of them are. And, I think that's a really good starting point to start, to look at what are our hurdles, where were we then and where are we now.

I don't know if that's something that the Committee can have access to. I don't know why the appendices don't get into the final document versus the draft. I wasn't a part of the IACC at that point, but it might be something for everyone to look at as a starting point.

Dr. Daniels: This is Susan.

I also was not here in 2005. I have seen that draft document, but the document that we have on the web is what I understood was the final, but I can do some research to find out what transpired during that time.

Ms. Blackwell: Yes, I think, Christine, this is Ellen, that the document on the web is the one that the Committee officially adopted.

Ms. McKee: Is there a reason that we can't circulate the draft, just for the Committee members to review what that panel really saw as the constraints, the benefits, in 2005? I mean, it's quite in-depth. It's a really nice starting point, in my opinion.

Dr. Daniels: Christine, this is Susan.

We can circulate that to you for your research purposes.

Ms. Blackwell: Thanks, Susan.

Mr. Grossman: And, this is Lee.

Somewhere in my archives, and it won't be hard to find, I have the full report, which had, I don't know, 100 plus recommendations, and I think that at various points we've provided that to the Services Subcommittee, but I can find it and present it again as well.

Ms. Blackwell: I think if we could make, you know, four or five recommendations to the Secretary, as a result of this meeting in November by January, that would be a really remarkable achievement. And then, if we could move forward with, as Cathy said, you know, trying to parallel the strategic plan as we go into 2011, not knowing our future fate, okay? That would be great, and we probably want to start thinking about some meeting dates, Susan. Maybe you could help us with that over the next few weeks, so that we can get them onto the calendar.

Dr. Daniels: For the Services Subcommittee or other kinds of meetings?

Ms. Blackwell: No, for the Services Subcommittee.

Dr. Daniels: Just regular Services

Subcommittee meetings, not convened workshops.

Ms. Blackwell: Yes, correct, because I think we are going to want to meet after our meeting.

Dr. Daniels: Yes, we can look for other dates.

Ms. Blackwell: I mean, would that be the group's preference, you know, we are going to need to talk after we meet in November, because we are going to have to do some quick work.

Dr. Daniels: So, you'd like -- when would you like your next meeting to be?

Ms. Blackwell: I think we need to meet right after we have this meeting. What do the rest of you guys think? I mean, you know, maybe give it a week or two in between, but we have to start writing recommendations fairly quickly.

Dr. Daniels: So, some time between November 8th and Thanksgiving?

Ms. Blackwell: Yes. Lee, what do

you think?

Mr. Grossman: Yes, you didn't see it, I was -- I kind of whispered how about November 9th, but -- no, obviously, we need to have this before -- as soon as possible, so some time between the 8th and Thanksgiving should work.

Ms. Blackwell: And then, I think we need to meet again, to -- I mean, even if we just have phone meetings, and start looking at documents.

Dr. Daniels: So, for the November -- the meeting between November 8th and Thanksgiving, though, could we do that as a phone meeting?

Ms. Blackwell: Yes, of course, certainly.

Dr. Daniels: So, that could be a phone meeting, and then other phone meetings?

Ms. Blackwell: Yes.

Dr. Daniels: Keeping in mind that there will be full IACC meetings during that time likely as well.

Ms. Blackwell: Do we know what the dates of those are yet, so we can sort of --

Dr. Daniels: We have some tentative dates if we need them. I don't have them with me.

Ms. Blackwell: Because I would think that we would have to sync our recommendations, if they go to the Secretary at the same time, we've got to get buy in from the Full Committee. So, at some point we'd have to be able to present to the Committee.

Dr. Daniels: So, you could present them -- well, in January is when you would be finalizing the plan, and so you could present them at that same time, and then any revisions could be made after that, and they could be submitted at the same time, if you want them to.

Ms. Blackwell: Okay.

Dr. Daniels: And, there's no -- you don't have to submit them at the same time, if you don't feel like you can.

Ms. Blackwell: No, it just seems to me like that would be optimal, if possible.

I mean, does the group agree? I mean, sending them together seems to give it a little bit more oomph, in my mind.

No thoughts on that?

Dr. Rice: This is Cathy.

I have mixed feelings, because I don't want it to be seen as that's going to be our product, and say, well, if we are only coming up with a small number of recommendations initially, giving the impression that that's really going to cover it.

So, I'm weighing back and forth, is it better to wait until we have a more solid product that really parallels the strategic plan. I'm just talking out loud, in terms of, my silence is undecision, or indecision, because of that issue.

Ms. Blackwell: I think -- Cathy,

honestly, I think if we come out of this meeting with some recommendations that are good, we should just go with them, and say, here is what we've got now. More is coming, because there is more.

The idea of waiting, I mean, I don't know, I don't like the idea of waiting. I'd like to give her something.

Mr. Ne’eman: I agree with Ellen on this. I think -- it's been some time since we delivered a product, in regards to the Secretary on policy recommendations, and in a way I think it's possible that our forthcoming, more comprehensive document, will be taken more seriously in light of the fact that we will then have a history of some results.

Dr. Daniels: This is Susan.

So, do you have in mind having another workshop within a certain period of time, say, were you planning to do a spring or summer workshop, to follow up with your parking lot ideas?

Mr. Ne’eman: I guess what I had in mind in respect to that, is less workshop and more a series of panels, like we did for the strategic plan, and we may, in fact, wish to bring in some of the same outside experts. But, instead of just having them sit there and talk to us, let's put them in a room, and, you know, give them a day or two to really come up with specific recommendations to present to either the Subcommittee or the Full IACC.

But, you know, the work should go beyond simply the IACC members in that model.

Ms. Blackwell: I, actually, would vote for having another workshop to try to cover some of these issues that we didn't get to with workshop number one.

I mean, we could do that pretty expeditiously.

Ms. Resnik: And, I'd like to submit that when we do submit recommendations, and also promote this workshop, and then I'd like to make sure that we identify what's next. Again, I think it's important, demand checks for patients our own expectations and those of the community, too, so that we are, you know, recognizing that we are doing our best, not leaving anything out, but need to stage how we are making these recommendations and moving forward.

Ms. Blackwell: And, I think all of us should be thinking about other issues that we may have missed here. I mean, maybe go back and look at our RFI, and, you know, Lee and I did some segregating of issues, but you new members might want to take a look at the actual comments themselves. Maybe you'll read something into them that we did not. I mean, because we had to make decisions about, you know, what to call priorities, and where comments fell, and, you know, to some degree interpretation of comments is subjective.

So, it might be worth going back and looking at that RFI, the Services RFI, and also the comments from the meeting of the Autism Society last June, to make sure that we are not missing issues, that could turn into recommendations.

Dr. Daniels: This is Susan.

If you think that you would want to have another workshop, and you would want to develop a second set of recommendations prior to, potentially, reauthorization of the Committee, or the sunset of the Committee, you might be wanting to think about having a workshop in the spring, because that would give you enough time, hopefully, to put something else together, if you want to have another set go out before the September 30th date.

Ms. Blackwell: Maybe April or May, Susan?

Dr. Daniels: May is IMPAQ, and so that's --

Ms. Blackwell: Oh, April?

Dr. Daniels: -- so maybe, I don't

know, if April -- April being Autism Awareness Month, a lot of people have pretty packed schedules.

So, March?

Ms. Blackwell: Oh, you guys. Okay.

Dr. Daniels: Maybe we could look for dates in March and April, and run them by the Subcommittee and see if any of those dates sound workable.

Ms. Blackwell: And, people should look to make sure that they don't conflict with other events. April is always a busy month for me with conventions.

Okay, so, Susan, you will send us around a copy of the document that Christine mentioned also, for just thoughtful review?

Dr. Daniels: I have one copy of one document. I'm not exactly sure if it's the document that Christine is looking for, but the one that I have appears to be a photocopy.

Ms. Blackwell: Christine, if you have it, could you send it to Susan?

Ms. McKee: I have a photocopy, it was handed out --

Ms. Blackwell: Oh.

Ms. McKee: -- as a handout.

Ms. Blackwell: I don't know that I have it.

Ms. McKee: Okay.

Ms. Blackwell: Okay, maybe someone could PDF it.

Dr. Daniels: It sounds like some people have it, so someone is going to send it to me, and I'll compare it to what I have in our archives.

Ms. Blackwell: Okay. Well, I think we made a lot of progress today. How does the group feel?

Ms. Resnik: Definitely made a lot of progress.

Ms. Blackwell: I really feel like we'll be able to make some recommendations, and then, you know, get some lift.

And, if the group would like to have a speaker at our -- well, I guess we are going to be meeting by phone next time, if -- would the group like to have a speaker, like the way we had Stephen talk with us today?

I mean, I think that's kind of a nice thing, to have a guest speaker at every one of our meetings, but we, certainly, don't have to do that.

Mr. Grossman: This is Lee.

Just a very brief update. I just got an email from Michael Strautmanis, he's not going to be able to make it on November 8th.

Ms. Blackwell: Okay.

Dr. Daniels: So then, we could move to the other speaker that you also suggested.

Ms. Blackwell: That would be Thomas E. Perez, who is the Assistant Attorney General, Department of Justice.

And, if we can't get Tom, there is another guy, Jeff -- help me out, Ari.

Mr. Ne’eman: Crowley.

Ms. Blackwell: Yes, maybe Jeff Crowley.

Mr. Ne’eman: But, the other thing that occurs to me is Sam Bagenstos, who works under Tom at Justice, and could also speak to the Olmstead issues, but Jeff also has a lot of knowledge around those areas, and, particularly, around long-term services and supports.

Ms. Blackwell: And, what is Sam's last name?

Mr. Ne’eman: Bagenstos, B-A-G-E-N-S-T-O-S.

Ms. Blackwell: Okay. So, we have some alternates.

Thank you, Lee.

I mean, I guess, although I'm sorry to hear that.

Mr. Ne’eman: Mike will be missed.

Ms. Blackwell: And, any thoughts about a guest speaker at our next meeting?

Mr. Ne’eman: When is the next meeting?

Ms. Blackwell: Right after the meeting.

Dr. Daniels: We don't have a date yet, but we'll look on the calendar for dates.

Mr. Ne’eman: I mean, you know, others are somewhat self interested, but I would really like to see this as an opportunity to communicate the findings from the SABE/NYLN summit on defining community.

So, if people are asking, I think that would be a good opportunity to communicate that.

Dr. Daniels: Who is the speaker?

Mr. Ne’eman: Either myself or Chester Finn, the President of SABE. So, you know, whoever we decide would be most appropriate.

Are there any other suggestions?

Mr. Grossman: I think it's the intensity of the last three hours, people are starting to get a little --

Mr. Ne’eman: Dozing off.

Mr. Grossman: -- not dozing off, I think just that coming up with ideas at this moment is maybe a little bit more challenging.

Mr. Ne’eman: Why don't we leave the final decision around the speaker to you and Ellen, you know, and I know you will come up with a good choice.

Mr. Grossman: Thank you, Ari, for having such faith in us.

Mr. Ne’eman: I always do.

Ms. Blackwell: Well, we made it past 4:00, guys, so thanks to all of you for participating.

Are we adjourned? Are we done at 4:00, Susan?

Dr. Daniels: We are done at 4:00, if you say we are done at 4:00.

Ms. Blackwell: Are we done at

4:00, Lee?

Mr. Grossman: Yes.

Ms. Blackwell: Okay.

Mr. Grossman: But, Susan said it's up to you.

Ms. Blackwell: I have nothing else.

Dr. Daniels: The schedule is subject to change.

Ms. Blackwell: I have nothing else. I have a large pile of paper in front of me, and I thank all of you again, and I think we'll have a great meeting, and we made a lot of progress today, and we have some wonderful people that will come and talk to us and help us develop a really great set of recommendations to Secretary Sebelius.

So, thanks very much, everyone.

(Whereupon, the above-entitled matter was concluded at 4:02 p.m.)