U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

TUESDAY, SEPTEMBER 15, 2009

The meeting convened at 1:00 p.m. via teleconference, Ellen Blackwell 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., Center for Medicare and Medicaid Services and Co-Chair, IACC Services Subcommittee

LEE GROSSMAN, Autism Society and Co-Chair, IACC Services Subcommittee

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

DENISE JULIANO-BULT, M.S.W., National Institute of Mental Health

CHRISTINE M. McKEE, J.D.

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

CATHY RICE, Ph.D., Centers for Disease Control and Prevention

DEIDRE WASHINGTON, Health Resources and Services (For Dr. Bonnie Strickland)

ALSO PRESENT:

DIANA DENBOBA, Health Resources and Services Administration

SAM ODOM, Ph.D., Frank Porter Graham Child Development Institute

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PROCEEDINGS

1:04 p.m.

Dr. Daniels: Hello. Do we have anyone on the line from the ICC?

Dr. Shore: I am on the line. Stephen Shore.

Dr. Daniels: Hi, Stephen. This is Susan Daniels.

Dr. Shore: Hi, Susan.

Dr. Daniels: I will turn the meeting over to Ellen as soon as -- is there anyone else from the IACC on the line?

Dr. Rice: Hi, this is Cathy Rice, representing CDC.

Dr. Daniels: Oh, hi Cathy.

Dr. Rice: Hello.

Ms. Washington: Hi, this is Deidre Washington, representing the Maternal and Child Health Bureau at HRSA.

Dr. Daniels: Great. And, anyone else? Okay, so we have three people on the line and I will turn it over to Ellen to do the rest of the introductions and begin the meeting.

Ms. Blackwell: Good afternoon, this is Ellen Blackwell from the Centers for Medicare and Medicaid Services. I am here with my co-chairman, Lee Grossman, who is the president and CEO of the Autism Society of America. We are convening today to have a Services Subcommittee meeting of the Interagency Autism Coordinating Committee.

First, I guess we should go around the table and let folks introduce themselves in the room and then we will get to you folks on the phone.

Ms. Juliano-Bult: Hi, I am Denise Juliano-Bult from National Institute of Mental Health.

Ms. McKee: Christine McKee, I am a public member of the IACC.

Mr. Grossman: Lee Grossman, President and CEO of the Autism Society.

Dr. Daniels: Susan Daniels,

designated federal official for the subcommittee, from NIMH.

Dr. Houle: Gail Houle, Office of Special Education Programs, U.S. Department of Education.

Dr. Odom: Sam Odom, Director of the Frank Porter Graham Child Development Institute at the University of North Carolina and principal investigator for the National Professional Development Center on Autism Spectrum Disorders.

Dr. Daniels: Stephen, would you like to introduce yourself?

Dr. Shore: Sure. Stephen Shore, Assistant Professor of Special Education at Adelphi University and I am my own adult on the autism spectrum.

Dr. Daniels: Cathy?

Dr. Rice: Hi, I'm Cathy Rice with the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention.

Ms. Blackwell: I guess that leaves you, Deidre.

Ms. Washington: Yes, that's me. Hi, I'm Deidre Washington and I am representing Bonnie Strickland who is on this subcommittee and I am the manager or project director for MCHB State Autism Implementation Program.

Ms. Denboba: Hi, can you hear me? Hello?

Ms. Blackwell: Yes.

Ms. Denboba: Hi, this is Diana Denboba. Bonnie asked me to join as well, and I am the branch chief of the integrated services branch in her Division of Services for Children with Special Healthcare Needs.

Ms. Blackwell: Great, thanks Diana. I guess our first order of business today is to say welcome to our guests, who are going to be giving us a presentation about the grant programs being operated at the Department of Education. This is a project that the Services Subcommittee embarked on about three months ago, or three meetings ago I should say and our intent is to have presentations about services and support at every meeting.

Our first order of business today actually is to approve the minutes from the June 16, 2009 meeting. So does everyone accord with the minutes that were distributed by Dr. Daniels?

I see no dissenters Susan so I am going to tell you that the meeting minutes are now approved and with that I would like to go ahead and move into our presentation.

I thought we might just as well let Gail and Sam get started because they have a really exciting presentation and it's in the packets and for those of you participating via the phone you should be able to see it over the Internet. Is that correct Susan?

Dr. Daniels: Yes. The presentations will be visible over a webinar on the Internet, available on NIH videocast.

Ms. Blackwell: Thank you. Gail I am going to turn it over to you.

Dr. Houle: Good afternoon. Thank you very much for the invitation to present to the Services Committee of the IACC. I am Gail Houle. I am an Associate Division Director for Early Childhood and Parent Programs with the U.S. Department of Education.

The mission of the Office of Special Education Programs, in which I am working, is a mission that is dedicated to improving results for infants, toddlers, children and youth with disabilities ages birth through 21 by providing leadership and financial support to assist states and local districts to provide comprehensive IDEA Individuals with Disabilities Education Act services.

These are the services that are provided to children from birth through 21 through the public funding that the federal government provides to the states.

There's another part of the Individuals with Disabilities Education Act that may not be as familiar to people and that is the Part D program. The Part D program is what we are going to focus on today and in particular, Sam Odom will talk about one initiative within the Part D program that reaches out to states and nationally for services enhancement and improvement for children with autism spectrum disorders.

An overview of the Part D program, the national activities, include the funding of personnel development grants, state improvement grants, technical assistance and dissemination centers, technology and media projects and parent training in information centers. The personnel development projects have been of particular interest to many people in the autism community. These projects address the need for highly qualified personnel to work with infants, toddlers or children through age 21 with disabilities. We are funding currently, among our personnel training grants, five awards at the doctoral level that specialize in preparing students to teach and work with children with autism spectrum disorders, 29 Masters degree programs and two certificate degree programs.

Before I finish today I will give you a list of the programs that make that available on the IACC website. The programs are supported by the U.S. Department of Education and when we support a professional development program, it means we provide student support, so there's funding available for students who would like to be trained and go into the field of working specifically with children with autism spectrum disorders.

Sam, who will follow me in this presentation, Sam Odom, Dr. Sam Odom, is with the National Professional Development Center on Autism Spectrum Disorders. The purpose of that center is to increase the capacity of states to implement evidence-based practices for early identification, intervention, education, professional development and technical assistance and he will give you some details about exactly how they implement those strategies to work with states in the Training of the Trainer model, which states are then responsible, with oversight and technical assistance, for implementing the best practices for children identified with disabilities in schools or early intervention programs.

We have technology and media projects and those projects are called our Stepping Stones projects, again a small, kind of research and development, and they have to do with early intervention education and transitional, meaning youth who are transitioning from high school to post-secondary or work settings. Those Stepping Stones awards, we have two that focus on autism and they are technology-based. There will be a link to my email during this presentation so you'll be able to find me and contact me. I am not able to go into the details of all those projects and all the projects right now but I would be more than happy to do that through the web.

Parent Training and Information Centers are another highly-used project program funded by Congress through IDEA Part D. We have at least one Parent Training and Information Center in every state and we have regional technical assistance training centers for parent information. These centers provide training and information to parents of children with disabilities and they can be located at this website, taalliance.org. On that website you will find a map and you will be able to click on your state and find where your Parent Training and Information Center is located.

There are 70 PTIs, 30 Community Parent Resource Centers which are smaller centers but are dedicated to specializing in providing the services that are needed for populations who have culturally or linguistically diverse needs, who need material translated into languages other than English. We also have two national centers, one to serve families of military dependents and one to serve the Native American families throughout the United States.

Now these centers are located, specifically the military center in the State of Washington and the Native American center in the State of Florida, but they work throughout the country.^^We have six regional technical assistance centers as well.

This is my contact information and if you would like to receive more information on any of these centers, if you would like links, if you would like a synopsis or if you would just like to talk to a contact person at the Department of Education, please feel free to call me or email me at this email address and I will be more than happy to talk to you.

My background is as a speech language pathologist and I have a lot of experience and training in working with children and families. I am always happy to talk to you about what's available through the U.S. Department of Education.

With that I would like to introduce Dr. Sam Odom, who is the Principal Investigator for a center that we have funded for the past several years. It's the center supporting the use of evidence-based practices for learners with autism spectrum disorders. They have strategies and methods for reaching through the states to the local communities for improving evidence-based practices and infusing those practices in children's learning. Thank you.

Dr. Odom: Well thank you very much for the opportunity to talk with you today about the work that we are doing across the country in different states.

I am the Principal Investigator for the National Professional Development Center on Autism Spectrum Disorders. We are a center located at several universities. Our purpose is to promote the use of evidence-based practice in programs for children and adolescents with autism spectrum disorder.

Our home site is at the University of North Carolina at the Frank Porter Graham Child Development Institute.^^Ann Cox is our budget director and our colleagues are at the University of Wisconsin at the Waisman Center. Len Abbeduto and Linda Tuchman-Ginsberg are the investigators at that location and also at the University of California at Davis Medical School at the M.I.N.D. Institute; Sally Rogers and Sally Ozonoff are both investigators at that location. At each of our locations we have a range of individuals that are not mentioned but who contribute very positively to our project.

If you are on this webinar today

or sitting in this room you probably don't need to be convinced about the need for professional development associated or related to autism spectrum disorder. It's pushed by the increasing numbers of children identified as having ASD, the emerging evidence about effective practice and the responsibility of school systems to provide a free and appropriate public education and appropriate I think is a key word here, appropriate meaning an educational program that is based on proven practices, on science, on research.

The increased prevalence of ASD as you all know has been dramatic over the last two decades. It's shown very clearly in the prevalence numbers within schools, which in 1991, when the Department of Education first identified autism as a diagnostic category that there were around 5,000, 5,400 individual children, from six to 22 that were identified, to in 2004, there were later statistics that make this point even more dramatically I think. But for ages six to 22 there are over 166,000 children in this country served and another 25,000 from three to five years of age.

Those numbers push schools, push educational service systems, to provide an appropriate program, and in doing that to prepare professionals to provide that program, such a program. There is growing agreement around what efficacious practices are and that comes from different places. The National Academy of Sciences, back in the early part of this decade, proposed a number of practices and models that have evidence of effectiveness for students with autism and autism spectrum disorders.

The National Standards Project, which is located at the National Autism Center in Massachusetts, has done an exhaustive review of evidence-based practices, and their report is just about ready to come out. It should be out this month, but it's been about at least four years in development.

In the report, they have examined the literature, identified practices from that literature, that have a basis of support in research. They followed a very systematic approach, and I'll come back and talk about those in just a few minutes. There are a range of reviews and syntheses and in the larger field of education there is very much a general movement towards evidence-based practice, partly pushed by No Child Left Behind, but also pushed by a broader emphasis and interest in the field.

So the challenge for school systems is that there's a lack of -- there may not be training available for teachers who are already in school systems. That is, teachers who may have gone through the system and received a general degree or certification in special education, or other professional students, for instance, pathologists, occupational therapists, physical therapists.

Another challenge to the promotion or use of evidence-based practice is that service systems are often resistant to innovation or just by the nature of an organization, there's a process that one has to go through to introduce innovation that may be effective and sustainable and we'll talk some about that.

We propose that, in order to accomplish this goal of promoting the use of evidence-based practice, that it's going to take what we call 21st century thinking. That is the professional development of the 20th century, we feel, may not well be sufficient to meet this challenge of today. And it was a challenge of yesterday, too, but to effectively systems, we feel that requires that we look to this new emerging field of implementation science, to inform our professional development efforts and also to take advantage of what we have called the enlightened professional development practices or approaches and I'll come back to talk about that.

Most people who talk about implementation science, the leaders within implementation science, discuss the importance of following a systems-level view of introducing innovation or change in those systems, one that requires an individual or a person promoting change to not only focus on -- for us, it might be a classroom or a program, a specific program for a student with ASD -- but also to examine the organizational features of the larger service system that makes the system and the factors that may influence those features.

So, in beginning this process, when we applied for our national center, we proposed working with states to assist them, to support them in establishing a professional development system that they could put in place in classrooms, first in individual classrooms that might be demonstration sites, but then more broadly, within their system in the state.

And it follows, this multi-level design that I talked about, the slide that you are seeing right now, I like to call my fish-bowl slide because it looks a little like a goldfish, swimming around back and forth, circling, but it should convey the multiple levels across years that we have worked with, and the multiple steps that we take.

Beginning at the top with a state application: states apply to work with us; we have an application set of deadlines and the application is online. The applications are reviewed by reviewers who are external to our working group, but who are very knowledgeable about our center. And they rate the applications just like there would be an application for a grant to the federal government. We select three states a year to work with.

Those states have to establish a strategic plan in working with us and in that strategic plan they chart out the next two years of work with us, with guidance from what we need for them to tell us and also the resources that they can devote to the professional development activities.

So across the first year, they identify participants who are going to be involved in a summer training and who are located at three or four sites within their state, classrooms that may exist within their state, and they identify the level of classrooms, the age range of kids, for which they think professional development may be needed within their state.

So for example, when we worked with one state, our coverage is from birth to age 22, with the primary focus being on the school-age programs from age three up to age 22, so states may -- we ask states to identify a pre-school demonstration site, a model site, an elementary school site, a middle school site and a high school site that they would involve from their state and states may come back and tell us that their most critical need is for example in middle school, so we may alter our training based on what those states' needs are.

But during the first year, they establish that plan, they commit resources, they identify individuals who will be involved in training and planning and all of those individuals participate in an online course, they participate in a summer intensive training workshop, but importantly, if we stopped at that workshop we think that we would be practicing that sort of 20th century mode of professional development that I alluded to. Now I may be being a little unfair to the 20th century, but we feel like, to take the practices and the content that we think is important from the workshop into classrooms, it requires support, it requires technical assistance, within classroom programs in order to make that leap.

So we work with state technical assistance teams to provide that ongoing assistance within classroom sites for teachers to select, to identify, select and implement evidence-based practice with specific children in their program. Now I will talk more about how we get to that point.

Our teams in the states collect information about children's performances, about the quality of the programs in that first year, and for our evaluation we collect those data at the beginning, at the end of the year, but we use those beginning-of-the-year data to work with teachers around issues of quality and implementation.

As we enter the second year with states, in the first year, with the summer intensive workshop, our personnel take the lead and we collaborate with states on delivering the workshop. With some states, they are ready to go so they jump right into it, state personnel, in organizing and planning and participating as workshop leaders or directors. For other states -- and this is the typical model -- we take the lead in the first year in setting up the workshop because we want to serve as models for professional development for states. In the second year, state personnel takes the lead.

We participate in the summer intensive workshops but we sort of hand off or encourage states to state personnel, state staff to be the more primary people in delivering the summer workshop, and then also taking that next step of providing technical assistance. That continues across the second year.

In the third year we follow up to move out of those states that we've been in, working with for two years, and we follow up to determine whether they continue using the professional development work that we all have worked on together with them.

So that's a brief scroll through

what we, sort of the process. I'm going to talk more about the content in just a minute.^^But at least it's a brief scroll through the schedule.

NIRN is the National Implementation Research Network and Dean Fixsen, Karen Blase, Melissa Van Dyke and colleagues are organizers of that network, but it's made up of a group of individuals who are interested in implementation of human services practices, individuals from across the country.

And it doesn't just focus on special education. Human services within mental health, more broadly within health, are part of this network. It very much is an embodiment of current thinking in implementation science and we -- Melissa Van Dyke, Dean Fixsen, Karen Blase -- have identified sort of a process, a set of stages that new practices or innovation may go through in getting to the point of actually being used as a sustainable and ongoing set of practices within an organization. The stages go from exploration, installment, initial implementation, full implementation, innovation and sustainability.

So we looked at how we were going about doing professional development in states and compared it to the NIRN model of stages of implementation, and it found -- coincidentally, I wish I could say we planned this from the first -- but we found that our process really does map onto their model very well, and you can see that from this slide with the elements within our model application, online course, first year implementation and so forth, very much reflecting the set of stages that NIRN has identified as being important.

I want to talk a little bit about the content that we have worked on developing in the first two years of our project. One of the initial parts of our training is through an online course that introduces basic concepts about autism spectrum disorders. It is designed to provide basic information for individuals who may not have basic information, or, for individuals who do, a common vocabulary, a common way of talking about concepts and features.

So when we begin working with the state, and they have identified individuals who are going to be demonstration sites for their state for the first year, all of those individuals who eventually are going to become involved in our training have to take the online course. It consists of sessions with pre- and post-test for each session, so knowledgeable people can go through it really quickly by doing the pre- and post-tests and demonstrating their knowledge already.

If I was in BlackBoard format, when we work with states, we monitor the course, we manage it for them and when we leave, we leave the course with them to use however they would like. We have had requests from other states who have not been involved with us to use the course and we are working out a strategy -- the real issue is determining how to manage the course, having someone in place to do the technical assistance that's necessary.

The set of guiding principles that you see right there, which are guiding principles for our course, but also they are guiding principles for our model of what we think is important for working with individuals, with learners who have a, I guess, basic understanding. Family-centered practices, we think, are critical, use of evidence-based practice and interdisciplinary training, data driven decision making, we think is also critical, inclusion, providing access to experiences within the school and community, transition planning, systems change, all of those are the basis upon which we built this course, and I won't go through the actual sections of the course, which you can see on this slide, but they reflect the sort of introductory, the basic information that we think is important.

Conceptually we felt like evidence-based practices are critical and important for teachers to use, but they also, and they also operate within a larger context, a context of program quality, so part of the work that we have done in this first year is to develop an assessment, a system for capturing, for assessing program quality within a program for individuals with ASD.

Those differ a little bit from evidence-based practices in that program quality reflects the contextual features of a program and evidence-based practices reflects specific, I think of it as specific tools for promoting specific skills.

So we --

Ms. Blackwell: Okay, can folks on the line make sure that your lines are muted.

Thanks.

Dr. Odom: So, if we think of program quality, the metaphor we use is that of a home, an individual's home, you might think of quality being the house in which practices occur and evidence-based practices being the furniture or appliances.

So for example, a home is made up of space, is made up of light, air quality, temperature, the sort of basic ecological features that contribute to the quality of your life in the home. And we proposed that -- and this floor plan may be an example of that -- so the quality of your life in your home is influenced by those things, the way the space may be arranged, the temperature, texture of the rug for example.

Evidence-based practices are more focused in their function and applied in very specific skills. So in using this home analogy, you might think of a computer station in your home as sort of an analogy to evidence-based practice, in that you have a specific thing that you accomplish at that computer station, or this La-Z-Boy Chair. There's a specific thing that you may accomplish in that La-Z-Boy Chair that doesn't happen in other places but it's designed to result in that outcome for you.

So when we think about programs, we think about more generally program quality that's happening and more specifically, the evidence-based practice that relates to individual learners and the outcomes that we want for those learners, so both, we think, are important.

I want to talk, just right now about program quality. We have attempted, and we are still working on this, to develop assessments that will reliably allow us to measure or to assess the features of quality in programs. We see quality as being made up of all of these features that are on the left side of your screen. We think they promote to a general quality that happens in programs which are associated with learner outcomes.

We developed an assessment called the APERS, the Autism Program Environment Rating Scale. It's an environmental assessment, where an outside observer comes into a classroom, spends a couple of days observing, interviewing, collecting information about the qualitative features of the classroom, and then using our rating scale, identifies or creates scores, generates scores for each of the qualitative measures. I'll talk about that in just a second.

The APERS versions are preschool/elementary and middle school/high school. There are slight differences between the two. They are based, as I mentioned before, on observations and also interviews because in the two-day period, it's impossible to see everything that we need to see, but we feel like we can gather that information by talking to multiple people.

So for the preschool/elementary APERS, the dimensions of quality, which are our subscales, are classroom environments, class structure and schedule, positive classroom climate, assessment, curriculum and instruction, communication, staff or peer relationships, that is social relationships that are supported in the classroom, or in the program, personal independence and competence, functional behavior, that is practices within the program that address challenging behavior and promote adaptive behavior, family involvement, teaming.

On this slide is just an example of how the APERS is laid out, which is a five-point rating scale with individual anchors for points one, three and five. Points two and four are made up of, are scored when all of the elements in five are not met but one may be and all of the elements of three have been met so they are intermediary scores, and we are continuing to develop this instrument through other grants that we have proposed.

So when we work with classrooms, when we work with programs, we use the APERS early on to assess program quality and to talk with practitioners, service providers, about what is happening in their program and what they may want to happen over the next year. So it serves as an external, for us it serves as a part of our evaluation plan but for programs it can be used in a more formative way, where program providers, service providers, may identify those features that they want to change across the next year of the program.

Evidence-based practices, as I mentioned a minute ago, are seated within that overall program quality. Most, many of you have heard about the range of, or heard this term anyway, of evidence-based practice a lot. There's I think increasing agreement around criteria that are established for, that may be used to establish evidence-based practices.

When we began our project, actually when we wrote the grant, the proposal for this center about three years ago, two-and-a-half years ago, we had planned to, we colleagues had been working with the National Standards Project and with their review and had planned to use their review as a basis for identifying evidence-based practices but at the time it wasn't ready, so we had to go ahead and develop our own system for identifying practices in which we had established criteria for the selection, the amount of evidence that was needed, we conducted a thorough literature review and selected practices that had sufficient evidence.

Our criteria, we think, reflect, again, an emerging consensus in the field about how much evidence is needed and what kind so in order for us for a practice to be identified as evidence-based, it needed to have at least two high-quality, experimental or quasi-experimental studies, that is group studies, at least five single-subject design studies conducted by different researchers in the field or a combination of those two criteria.

We depended upon criteria that were established by Horner and group, Nathan and Gorman, CEC, the Council for Exceptional Children, established quality indicators, and Sally Rogers and our Laurie Vismara had also established criteria.

So we used those, that review process, that is a literature review that went back only over the previous 10 years so I think we only went back to 1996 in our review. The National Standards Project has gone back to some time in BC, I think. No, they've gone back a long way to the very beginnings of the literature to be comprehensive in their coverage.

We started by looking at outcomes for individuals, noting that we think there are important outcomes for learners with Autism Spectrum Disorder: communication, social, challenging behaviors or repetitive -- we can call it challenging behaviors -- academic outcomes, independence or adaptive behavior depending on the age, and then when we identified studies, research studies, that involved interventions, that had those as outcomes, we sorted the interventions into practices that appeared to be very similar. Some of them followed the same names, some of them were -- they had different names, but they actually employed the same practices.

And that allowed us to sort the practices, or identify the association of practices, to specific types of outcomes, which allows us to work with teachers a little more effectively, we think.

So in this tiny little print that you should see on this slide are the list of practices. We actually have them in bigger font on other slides so I apologize for the small font.

But on my screen I am able to actually read the practices. The practices are listed on the left-hand side of this table. We found a number of practices that were just basic behavioral strategies, like reinforcement and prompting, task analysis and time delay, the sort of tried and true practices that many of us think about as the bases for our programs and are actually components of some of the other practices that I'm going to mention in just a minute.

If you go down this table to about 40 percent of the way down there's a group of practices called positive behavioral support strategies. When we looked at the literature we did not find enough literature of a positive behavioral support model used with individuals with autism to support PBS as a model practice.

What we did find is all of the elements that you typically see in positive behavior support, so that would, could include functional behavioral assessments, stimulus control/environmental modification, that is those setting events that you change to prevent a behavior from occurring, response interruption and redirection, functional communication training, extinction, differential reinforcement of alternative, others, all the DR strategies.

And one can arrange those along a tiered system as does appear in conceptual models of positive behavioral support. So our opinion is that there is good support for positive behavior support in the literature, positive behavior interventions in the literature, although we haven't found it in cohesive models.

I don't know if that makes -- when we work with teachers, we often, around issues of challenging behavior, we often pull together those evidence-based practices to address those behaviors in a PBS format.

So other strategies we found that had support in the literature: naturalistic interventions, discrete trial training, parent-implemented interventions, peer-mediated, PECS, pivotal response training, all of those fit as focused intervention practices that had evidence of success, as well as self-management, social narrative, social skills training, structured work systems, video modeling, visual supports, so a couple of those coming out of the teach model, VOCA.

Although these are elements of other, more comprehensive treatment models, they all stand on their own as having evidence for at least meeting our criteria for evidence-based practices.

What did not come out on this next slide is the support that we've found within different content areas. So if this slide had come out, it would show for which content area we found support for those individual practices and then also at what age, early childhood/elementary, middle/high school.

So for example, for differential, if you go to the first line let's say computer-assisted instruction, you should be able to see, on the slide that I have on my handout, there's sort of a blue coloration for academic and cognition, the three cells under early childhood/elementary, middle/high, EC, EL, and MH, and computer-assisted instruction.

That indicates that for that strategy, that's where we found the evidence, so we sort of go another step further and looking at the outcomes that are typically generated by these practices.

We have been working in collaboration with OCALI, which is the Ohio Center for Autism and Low Incidence Disorders, it's in Columbus, Ohio. We became acquainted with them and then partners with them shortly after our institute got off the ground, our center got off the ground.

They manage the website through

which we have been posting modules that describe the content, the procedural content, for evidence, the evidence-based practices that we have, and I'm going to talk about the modules in just a moment.

If you are interested in looking at some of the modules that we develop, we are still getting them up and onto the OCALI site, with the great help from individuals at OCALI.

But this is the website address. It's free to anyone who chooses to go to the site. You can go to the, I believe they call it AIM modules, A-I-M modules, which was the program that actually Brenda Smith Myles developed originally.

The site will require you to register, which is no more than just putting in your name and giving some information like your email address and it doesn't cost anything.

So the web-based modules also include a pre-test and a post-test, contextual information, specific procedural steps for how you employ the practice in classrooms, case examples, video examples which is kind of slow to stand on that, in getting the modules up and going.

But once that -- features of the modules that are really important: implementation checklists that allow teachers to identify what the steps are in a practice and whether or not they have completed them, or other individuals who come in and observe; a summary of the evidence base, where we identify the specific articles that support the practice; and resources, procedural guides, curriculum, books that a developer, a person who has done research on the practice may have published.

We have developed an evidence-based practice inventory, which is a self-report checklist that all the individuals follow. I mentioned implementation checklists.

So all of those tools focus on the evidence-based practices. We also needed a way of assessing children and using that assessment to link children's goals back to those practices that we had identified.

We decided to use a goal-attainment scale, which actually has quite a long history in special education, as well as other areas of human service. It is a process of measuring attainment of IFSP or IEP goals.

One of the things that we do in our summer training is to work with service providers in learning how to use the goal-attainment scale. We teach the process for identifying goals, for elaborating them into a range of possible outcomes and we measure attainment of goals on a pre/post basis.

So the basis of the goal-attainment scale, and I'll just be quick about this, is to establish a five-point continuum on progress that may be made toward a goal with the midpoint being the expected outcome, the beginning, the lowest point, much less than expected, being the beginning outcome, so in the fall, when one establishes a goal, it would begin there.

In the spring, or whenever it's expected that the goal might be accomplished, if it is accomplished, it would receive that sort of middle rating, and at the end, if there is more progress than was expected, the scale allows that to be documented.

I think that's about it for this segment. On this slide, on the slide show presentation, there are examples of the range of goals, or an example of one goal, that's elaborated across the five-point continuum, three goals that may be typical of individuals with ASD.

The goal-attainment scale is not hard to learn. Pinning down the goal to begin with is probably the hardest part, and it serves as a good communication tool, we feel, between the technical assistance personnel, the teachers and potentially a good communication tool between the service provider, teachers, speech pathologists, and the family.

So that's been a basis in working with teachers on beginning to develop a system or strategy for employing evidence-based practice in classrooms -- initially identifying the goal, breaking it down into a set of outcomes that we might expect for children and then using the identification of the goal to identify the evidence-based practice that might apply to that specific goal, drawing from the literature about those practices that would seem to be most effective.

In our evaluations we have developed family program questionnaires as a way of gathering sort of a broader awareness of how the training that we do may well impact on children or learners with ASD outside of the classroom setting.

So that content we developed over the last couple of years and when we work with states we deliver it, that is we share materials, we provide training, we give feedback to teachers in their use across the first year and also continuing on to the second year with the state TA folks taking a greater lead in that next year.

So we work with three states a year, beginning with the first year of our project, so at this point, we are closely involved with six states.

Indiana, New Mexico, Wisconsin were our first-year states and they are in the midst of their second year now. Kentucky, Minnesota, Michigan are our second-year states, or our second cohort of states, they have just started their first year.

And Virginia, Texas and California have been selected for us to work with next year. We'll be starting the process of developing a strategic plan within early into the new calendar year. We have already been in communication with them. Some are just raring to go right now, so we are figuring out how to support their efforts even before we start our formal process.

And after this year we will have one more cohort of states to work with and they will be submitting an application this next year, we will be reviewing it in June, I think and making a decision at the end of next summer about the last three states that we are working with.

So in all, by the end of our project, we have three more years left in our project, we will have worked with 12 states.

The activities for the states, I mentioned a little bit of that before. We feel like this is key. Working with the teachers in the classrooms, with state TA individuals is critical. But getting it all organized up at the higher level of the system, if anything, it's almost as critical or maybe even more critical because the professional development movements are just going to sort of wither without ongoing support from individuals within state systems, state government, state organizations.

So in order to ensure that that will happen, or at least to give it the best chance of happening, we assemble those planning -- states have to assemble a planning team as part of, they propose that in their application, so that's where we begin, sort of up at the top of that system, or the furthest part of the system, the one that's maybe most distant from individual classrooms or programs.

They establish them on sites, they identify how they're going to provide technical assistance in those states. They prepare a strategic plan clearly enough so that we can all look at it and say, well this is the next step, or oops, haven't done this yet, or this is what we, that is we, our center, need to be doing.

They participate in summer institute, conduct ongoing technical assistance, again, if there's a lynchpin in this whole process, I believe, it's that provision of ongoing technical assistance and the states take the lead in the second year.

I've talked a little bit about the application process. On this slide there's a link to our online application and I mentioned how they were reviewed.

The planning teams have been very instrumental in getting everything off the ground. The challenge for us has been to, not so much in delivering the intensive summer workshops, which are critical and important and an essential part of the process, but to develop a systematic system of technical assistance, or process for providing technical assistance.

For the next three years of our project that's the focus that we're going to have, in addition to updating our evidence-based practices, because those practices are sort of a moving target. There are new ones added all the time. They hardly ever fall out because the evidence is there. When it's there, it's there, unless somebody comes along and refutes it.

But there are new ones that come along as a result of a very active research literature. So that's one of the challenges, one of the tasks that we have, is to stay up to date on those.

But I think, for us, the focus for the last three years of our project is going to be to establish a very systematic model of technical assistance that states can follow, that use these strategies that I've talked about before.

It needs to be a model in which state TA providers can use and one which we can withdraw from because in order for it to be sustainable, state personnel need to take it sort of independently from us.

So, in conclusion, our purpose for our project has been and is, continues to be, to establish a sustainable system of professional development that states employ and use. They use it to develop high-quality programs and to promote the use of evidence-based practices. There have been nine states involved so far, with actually six involved actively so far, with another three coming online this next year, and we are going to conclude our project with those last three states.

As a center, we will be staying associated with all of our states just to see how sustainable our work is, but also to promote that sustainability if there is anything that we can do.

I want to thank you all, if you're on the webinar, and those in the room, for your interest today and your attention.

I can tell you, for those out on

the Web, everybody in the room stayed awake, which is a good sign. So thanks. I think we are going to a discussion now, is that right?

Ms. Blackwell: Yes, I was going to ask if anyone has questions. There you go. Christine?

Dr. Odom: Oh, please.

Ms. Blackwell: You go first. I have one too.

Ms. McKee: I do have a couple of questions. Who are you targeting with this? Are you going into autism classrooms? What part of the spectrum, is my question, and are these children who are in secluded autism classrooms?

Dr. Odom: Thanks for that question. The question was, who do we target for this. And I breezed through that, I think I really didn't address that.

We are focusing on programs designed for learners with Autism Spectrum Disorder, so that could be any learners, any individuals across the spectrum, from birth up to 22 years of age.

Most of our focus, just because of time and resources, has been on the age three to 22 range. It could be programs, and is actually, is in fact programs for children with a range of functioning levels, and also programs that are inclusive or that are self-contained.

So it depends on the, for us, as we begin working with individual programs within states, it depends on the programs that the states have identified.

Ms. McKee: What percentage are in the self-contained classrooms? I am curious about the self-contained group and what you're seeing as far as --

Dr. Odom: Oh, that's a good question. You know, we have those data, but I don't know. I don't have the exact figure for you. But knowing the programs that we worked in, worked with in the first year, and now going into the second year, I would say probably about half are self-contained and half are inclusive in nature.

Ms. Blackwell: Okay. First thank you Sam, for your excellent presentation. What I found myself doing was writing questions and then you answered them a couple of slides later. So a lot of my questions are moot.

But I wanted to ask you if there's a new force for those selected states to share their experiences with other non-participating states?

Dr. Odom: I am sorry, would you say that one more time?

Ms. McKee: Is there a way for the states that have been selected to participate to share their experiences with states that have not been selected to participate?

Dr. Odom: Do you know, we haven't established that, but that is a great idea. We do have a forum, a mechanism, for states who participated the first year communicating with states who are just starting out. I wouldn't, I want to say, well, it is states, but actually it's individual programs and teachers. But we haven't established a format for that information to go out any further.

But that could be, I think, a really productive future activity for us.

Ms. Blackwell: Okay and I had just one point of clarification, on one of your earlier slides, the numbers are indeed quite dramatic in terms of tracking numbers of children that are coded with an Autism Spectrum Disorder, and Gail, you can probably pinpoint the exact year better than I can, but I think the code for autism was put in place around 1991, so that was the baseline year and you know, probably, as school systems got better at identifying kids, the numbers did indeed increase. But the first year, Gail, what was the first year the code was in place?: I want to say `91 it was mandatory.

Dr. Houle: Yes, it was optional in `91, I believe, and mandatory in `92 to use that. There were zero kids identified as autism before that.

This is a count of children receiving special education services under the category of autism, so it's not an incidence or prevalence count. It's a state-reported, service delivery count.

Ms. Blackwell: Thank you for that clarification. Do we have any questions for Sam from the folks that are on the line?

Dr. Shore: None right here.

Ms. Washington: Hi, this is Deidre, I do have a question. Could you just elaborate on the concept of the community of practice? I was also with the state of Wisconsin and they have, and I think they probably got this from the project they've been working on with you all, and they have implemented what they call the community of practices. It's a little bit different because it's with the Department of Health, but I'd like to hear you elaborate on that a little.

Dr. Odom: So the question was to elaborate the notion of community of practices. We've been following it in our project, I think. Is that right?

Ms. Washington: Exactly.

Dr. Odom: Okay. I would define the way that we are using the community of practice is that we have a number of individuals that are associated with our projects, so we attempt to foster communication among those individuals around the training that we are doing.

I have to say that we are still learning about what the best approach is for accomplishing that actual productive interchange that may occur among professionals. But that is how I would define it.

We have talked with Joanne Cashman

and the National Association of State Directors of Special Education about becoming part of a larger, national community of practice network that they have established. We haven't gotten to that point yet.

So I have to say, we are still learning about the best way to accomplish that.

Ms. Washington: Okay. Thank you.

Mr. Grossman: There's going to be some, at the NASDSE conference in Salt Lake City next month, there's going to be a good discussion on that and I'm going to be on a panel talking about communities of practice through the NASDSE project.

Ms. Blackwell: Could you clarify NASDSE, Lee?

Mr. Grossman: It's the National Association of State Directors for Special Ed.

Ms. McKee: I do have one more question, I'm stepping on your toes again. You listed computer programs or technology used to help with curriculum, core academics, for children. It was in the chart that had the --

Dr. Odom: Oh yes, yes.

Ms. McKee: I mean, one of the problems that parents face with having their children in school, is that the computers are used for reinforcers. They have a really hard time getting the computers to be used for academics. And with No Child Left Behind, that encourages the use of technology for our kids, are there recommendations for specific programs, do you know what they're using in the classrooms? Any guidance you could give?

Dr. Odom: We don't have recommendations for specific programs that might be used. The practice that we elaborated on in our brief and will be elaborated on in the module focuses more on the process for how teachers would employ computer-assisted instruction in the classroom.

The evidence that we had for that, when we looked back at the studies that actually accomplished, that actually supported this practice, they primarily were around language development, language concepts, and some social concepts, which sounds a little odd for computer-based instruction.

But the potential for -- what we haven't seen in the literature is how they applied really strongly to academics and I also know that there's tremendous potential there. I wish I could give you more information about that but, at least from the literature, I think it's still emerging, it's still coming down.

Ms. McKee: I have another question about augmentative communication. You talk about voice output devices. Are the classrooms equipped with that? How do they get funding for those devices? They are very expensive. Are you finding that those are readily available in the classrooms for the children?

Dr. Odom: We have found that they are available in some places. It goes depending on which state, and really actually what community. And that's a good question.

Some states actually have centers for augmentative communication that facilitate actual access to the devices, I believe. There are issues around insurance coverage and whether insurance will actually pay for those devices or whether it's a school responsibility. And I don't think, I think that question is still not completely settled. So I would say I don't think we've seen a consistent trend. There's just been a lot of individual variability about access to devices.

Ms. McKee: I think it's just interesting to have that as a best practice. I think that that might help school districts get some more funding there. I mean what you commonly see are the GoTalks, you know the nine space things, or the old-fashioned TextSpeaks and things but not the really fancy, dynamic screen ones.

Dr. Odom: Well, by identifying it, maybe it will bring more attention to the importance.

Ms. McKee: One more question. This one probably goes to Gail. With the Department of Education, what's going to be the outcome of this. Is the Department of Education going to make any kind of a recommendation, back what they have and sell it, so to speak, and endorse it in any way? We have these training module, we get the results, and what happens then. Is there going to be any official step by the Department of Education to try to create standards for educating children with autism?

Dr. Houle: That's a good question too. The Department of Education has not been charged with creating federal standards and there is still a lot of discussion around states' rights and state standards.

Our standards are the regulations for the Individuals with Disabilities Education Act and that act has to be implemented by the states.

So federal standards around the practice of autism, we have to be, are not in the works. We cannot by law, say, endorse any methodology. We did fund the National Academy report on educating children with autism, which comes out with general best practices guidelines, or recommended practices guidelines and that's about the limit of the U.S. Department of Education in that area.

And what will happen with these is that we have, with our Part D discretionary grant program, we have kind of a ladder of knowledge utilization, knowledge base and dissemination. So while the center is charged with gathering best practices, training state teams around best practices, we can go to scaling up and more wide-scale dissemination after this center has finished.

So that's generally how we follow the ladder of development for practices. It's not as linear as it sounds but I mean if you would look at it in its simplest form it would be research to testing, research in terms of implementation of practices, to dissemination to large-scale dissemination.

So because we want everything done yesterday, we tend to charge centers such as this one with gathering the research on the best practices, gathering the research on the best training processes, working with the selected number of states, give and take formative feedback and then go into a wider scale dissemination based on what works with a center such as this.

Ms. McKee: I was just trying to make leadership bigger and bigger, your leadership role, but thank you so much.

Ms. Blackwell: Okay, any other questions from folks on the line? Oh, Gail has a question.

Dr. Houle: It's not so much a question as it is a comment. Because of the limits of the funding and the staffing and the center works with a number of states and brings new states on board, but they won't cover all 50 states, there are modules available, online and more coming online, through the OCALI website that was referenced in Sam's presentation.

They are working now on getting briefs posted on their website for the center and so these will be available for states that were not selected to receive the intensive training and technical assistance.

Before we go into, during the life of this project, before we hopefully are able to go into a wide scaling out, dissemination, and Sam has a comment on that.

Dr. Odom: So, for the 24 practices we identified, we are creating online modules for all of those. We now currently have the text for all 24 and we call those briefs. We are going to be posting those briefs on our website probably in about two months. Our website is going through a reconstruction and we think it's going to be ready in November.

So there will be 24 briefs, they'll have probably the term "draft" on them but anybody will be able to pull those off and use them and know that those briefs are going to turn into modules with the video clip examples and more broad information over this next year. It's just taken us a while to get the modules done.

Dr. Houle: And I wanted to endorse the modules that are done thus far and encourage people to go to the OCALI website, very very high quality modules and videos that are wonderful learning tools. I mean I've seen modules ranging in full ranges of quality and these are high-quality, well-developed modules that are well worth taking a look at seeing if they can be used in the field right now by people who are working in programs.

Ms. Juliano-Bult: Can I ask a quick question? So is this an ongoing project or is there sort of a time limit for the life of this project?

Dr. Houle: This project is funded for five years and they are just beginning the third year. So then, after the five-year cycle is up, this project as well as the other types of projects, because our funding covers all disabilities and all ages, birth through 21, we'll be reviewing everything, all the products and all the work, everything that has come out of each of those projects in the different areas and decide whether we will refund or whether we will make another announcement for the project, the learning from the project, maybe in a wider dissemination scale.

Ms. Juliano-Bult: I was just wondering if there was any thought about, like, train-the-trainers kind of thing.

Dr. Houle: Well, they do that within states.

Ms. Denboba: This is Diana Denboba. Early on in the presentation, you just made a reference to the parent training and information centers, and I just wanted you to know that quite a few of them are also family to family health information centers that are funded by HRSA.

So we're trying to, you know, make the ties and the collaboration a little bit tighter through those entities and we really appreciate what they do around education and we're just adding health to it.

Dr. Houle: That's wonderful, thank you, the more synergy that comes together and the more funding sources that can come together on behalf of families and children, the greater the impact.

Dr. Denboba: Sure, and that way, you know, we also then can disseminate information about education, because it's related to health, you know, you can't learn unless you're healthy. So thank you for the presentation.

Dr. Odom: Thanks, also in response to Denise, what we are trying to accomplish in the second year in which we work with -- well, the first and second years that we work states, is to have them take over that process of professional development. So it is very much a train-the-trainers model and concept, and we're learning what that means now, we're trying to, figuring out how best to do that.

Dr. Houle: I also wanted to mention that, I didn't mention it when I was at the podium, but in the packet of handouts that we have given out and eventually will be on the Web, there is a handout that says OSEP and that's Office of Special Education Programs, funded personnel development grants that focus on autism, and there's the name of the university, the location of the university, the name of the project director who heads up the autism training program.

And there's another column that has whether they offer a Master's, Doctorate or Certificate, and the last column is whether the degree that the person would get would be in special education, interdisciplinary, speech and language, school psych and so these are spread out throughout the United States.

I was asked to provide this list at the town hall meeting, so this is the list that we have. And I also wanted to clarify, when I probably say in one sentence that the Office of Special Education Programs funds professional development grants in the area of autism, I wanted to let people know that the university gets the grant, the department gets the grant, and a minimum of 65 percent of the funds of the grant must go to student support.

So what this translates into is money available for education for individuals who would like to go into the field of working with children with autism.

If you qualify and you're interested, look at these universities. I would encourage you to contact the directors of the program and let them know that you would be interested in getting a degree in this area.

Mr. Grossman: One comment that I would like to make about the AIM modules is that what the Network of Autism Training and Technical Assistance Programs' partners, there are now 80 separate modules that are in development right now, and the Autism Society provided the initial funding for the AIM to be started and it's kind of taken on a life of its own where it could become certainly a tremendous resource for everyone to learn about various evidence-based practices as well as to go to receive additional training and supervision actually, because of the way that they are constructed.

But we are hoping by the end of 2010 to have that -- getting close to that goal of 80 modules up and running.

Dr. Odom: Lee, thanks for that clarification, and it's an important one too, because the resources, I believe, that AIM and NATTAP that they provide are really valuable for the field. Our modules are only a subset of the ones that NATTAP and AIM have developed. So I do encourage you to go to OCALI and look at the website.

Ms. Blackwell: Okay, well, Gail and Sam, thank you so much, that was great, and you know I think that we in the room really appreciate it and the folks on the phone and the folks that tuned in that we can't hear from today.

The materials will be available, Susan, by request, from the National Institute of Mental Health?

Dr. Daniels: Right, through the IACC public inquiries inbox.

Ms. Blackwell: Okay, thank you. So, Gail you've kind of presented us with a segue, you talked first I think about the town hall meeting because you followed through on something that you promised that you would and we sure appreciate that.

We mentioned to the subcommittee, several of you who are here, participated in the town hall meeting on July 24. But Susan, do we need to put the stamp of approval on these summarized public comments, on the minutes?

Dr. Daniels: On the minutes.

Ms. Blackwell: So, folks should have a copy of the draft minutes. I just had a couple of corrections, technical corrections, but I thought they were fine, so if there's anyone who objects to them, please speak now or we will approve the minutes from the town hall meeting.

Mr. Grossman: I have a couple of questions because I'm wondering if there was an actual count of the numbers of people that were actually in attendance at the town hall meeting and if that might be something that we can put in the first paragraph, but I'll --

Dr. Daniels: We do have a count and it can be added.

Mr. Grossman: What was that? I heard about 200.

Dr. Daniels: It was close to 200. I can't remember the exact number.

Ms. Blackwell: And do we know how many folks we had on the line, listening in, Susan?

Dr. Daniels: I don't know that number, I can find out.

Ms. Blackwell: Okay, I don't mean to try to pin you down. We did have, the Services Subcommittee, had a town hall meeting in St. Charles, Illinois. Lee, I'll let you talk about it a little bit because, you know, we do have by the way a summary and analysis of the public comments which will also be available through the link that Susan mentioned earlier.

Dr. Daniels: It should be posted to the Web pretty soon on the IACC website.

Ms. Blackwell: Excellent. We had, oh, almost 30 people come in and talk to us. We spent over about, I'd say about three hours, in a very cold room, as Lee will attest.

We started out this meeting with presentations from the folks who serve on the IACC and that worked really well. Susan gave a presentation, talked about the IACC itself and then we listened to people, mostly folks attending the Autism Society meeting, discuss some of their concerns.

I think it was a great venue in which we could have live interaction with the public, which is not something that happens very often or is even permissible under the normal IACC meeting conditions, so it was really, really nice and I hope that some time in the future we can do it again.

In fact, the comments from this meeting will be used in another activity that our sister subcommittee is engaged in right now, the Strategic Planning Process So we were extremely pleased to have the minutes available to us, Susan, in presentation for that, the larger body will be looking at revising the strategic plan and we are smack dab in the middle of activities surrounding those revisions to questions 1, 2, 3, 4, 5 and 6.

So, Lee do you have any other comments about the town hall meeting?

Mr. Grossman: Yes, I wanted to acknowledge and thank the staff who put this all together. It was quite an endeavor.

The meat locker that we were sitting in -- it was that cold -- it was freezing and it was packed. We had about 200 people in there. There, I'm sure, would have been more people that would have talked but we had a fairly long queue of people behind the mic and there were other sessions that were going on as well throughout the other parts of the conference.

But what I was most impressed by was the fact that we had people present to the Services Subcommittee that represented the entire community. We had probably every geographical region of the country represented. We had questions or concerns posed that certainly address all aspects of autism and every degree of being on the spectrum as well as across the lifespan, and that was the type of perspective that we were truly looking for, so I think for all of us it was very valuable.

The feedback that we got afterwards from those that attended the conference was very, very positive. The appreciated the IACC being there, making themselves available, hearing what the various agencies were doing -- there was a presentation by each agency at the beginning of the town hall meeting and that went over very, very well also.

But I'm also curious to hear from others that attended what feedback they may have and if we are to do this again I think there are perhaps some ways that we might be able to improve upon it. But from our viewpoint it was a success and we are very happy with the way it all came together.

Ms. Blackwell: Well, and if folks missed the meeting, it is archived on the NIH webcast so if you're really interested it's probably about 10 or 12 live webcasts back, but you can click on it and it take a few minutes to load and you can indeed hear us.

I think the presentations at the beginning are really interesting, not to say that the public participation wasn't interesting, but I think that the agencies did a really good job talking about their activities. So folks may find that first hour or so particularly helpful.

Dr. Daniels: You also may request the slides via the IACC public inquiries mailbox.

Ms. Blackwell: And when Susan says slides, she means all the slides from all the presenters.

Dr. Daniels: The entire presentation is available.

Ms. Blackwell: How many? How many is it, do you know?

Dr. Daniels: About six presentations or so it's 80 pages, so if anyone in the public is interested in receiving those, please write a request to IACCpublicinquiries@mail.nih.gov.

Ms. Juliano-Bult: I just wanted to say, I was on the videocast of it, and the quality of it was great. There wasn't the problem that you have sometimes of the delay that's so annoying.

But the other thing that I found

really interesting was the public comment section and I made a little outline, I mean, people covered a really impressive array of important issues that I know, like from our side, was just sort of an outline for areas for research basically. So in that regard I found it useful.

Ms. Blackwell: Well, and they literally are an outline for research now, Denise, because we are, as Christine will attest, I mean we are co-chairing one of the panels for the strategic plan and they are being used as program materials so we take public comments very seriously and it was great that people came out and took the time and waited and you know it really was, we all left with a good feeling, and we do truly appreciate all the hard work that staff put in to getting all of us to Chicago and getting the whole thing put together. The technology is pretty amazing.

Dr. Rice: Ellen, this is Cathy

Rice, just to make it clear, that that connection is made, that this summary is being provided to the workshop chairs for each of those questions, too. You may have said that but I may have missed it being directly stated, that this information is being considered by those that are revising each of those research priority areas.

Ms. Blackwell: Yes, Cathy, I may not have made myself clear, but yes, Christine and I made sure that the materials went to our team a couple of days ago and in fact we had our first call yesterday, so they are indeed part of the materials we will be looking at.

We also put out an RFI last fall to ask what was important to people in terms of services and support so we have that summary as well and also NIMH recently issued an RFI to solicit comments on the strategic plan itself, so shortly all of the teams working on the questions will have that information to consider in terms of revising the strategic plan.

Dr. Rice: Yes, I think that will be invaluable, because I think one of the challenges has been with the current research plan has been really figuring out how to integrate services issues into research and there were many excellent suggestions.

Ms. Blackwell: And we have a fantastic team working on questions five and six, some really excellent professionals from across the United States, and a couple of parents. Christine and I are both parents. So we had a very spirited discussion yesterday and four more hours to come, which culminates September 39 and October 1 in a meeting here in Washington when we will be talking about all of the revisions that the Strategic Planning Subcommittee might propose to the larger group.

Dr. Daniels: Right, and all of those conference calls are open to the public. It's on our meetings and events page of the

IACC website and you can see conference calls schedule under the IACC scientific workshop section of the website, and the meeting is also open to the public and you can register through the website.

Ms. Blackwell: Susan, did you say where the meeting is, I'm sorry, maybe I missed that.

Dr. Daniels: The meeting is going to be taking place at the Bethesda North Marriott Hotel in Bethesda, Maryland, on September 30 through October 1, all day both days.

Ms. Blackwell: Thank you. We wanted to talk, Lee and I wanted to talk for a second about our next meeting and I think we have a request for a presenter, Stephen, it is you, if you're still on the line.

Dr. Shore: I think I am, yes.

Ms. Blackwell: If you're not we're going to volunteer you anyway.

Dr. Shore: I don't know if you

can hear me but I am here.

Ms. Blackwell: Okay, yes, yes, we can hear you and we are asking you if you would be kind enough to present us at our next Services Subcommittee meeting, date to be announced.

Dr. Shore: Sure.

Ms. Blackwell: Great.

Dr. Shore: Yes.

Ms. Blackwell: Excellent.

Dr. Shore: Yes, I'd be honored to do so.

Ms. Blackwell: Excellent, well, we look forward to that, and I guess we can take a second and go around the room for a round robin, oh, I'm sorry, Christine.

Ms. McKee: Ellen, can I ask one more question, I see you packing up, I don't want to -- the research behind the supporting research sites for what you determine to be evidence-based practices, is there any listing of that? I think that would be a wonderful resource for parents to go in, to give to schools, to say, "Here's what defines this criteria so well."

Dr. Odom: Okay, the research will be identified, I mentioned before, the briefs that will serve as bases for the modules, it will be identified there, so we have the individual studies that we picked out that fit the criteria that support the practice.

Also, and then when the modules get up, they will be identified there. So those are two locations. Yes, we are hoping that the briefs will be up in about two months.

Ms. McKee: Wonderful, thank you.

Ms. Blackwell: And also, I wanted to mention that in each attendee's packet there are a couple of items. There is a notice of the AFAA town hall meeting scheduled for November 13, some information sent to the subcommittee from the foundation for autism support and training and also some information sent to us from an organization called InventSuccess.

And I wanted to draw your attention to another print-out in here. I had a recent conversation with a representative from our sister agency, the Agency for Healthcare Research and Quality. I was quite interested to see that AHRQ has published an interest in doing a comparative effectiveness review of therapies for children with Autism Spectrum Disorders.

So they published, and you can find on their website, their draft key questions in this respect, and some of the background about why they are interested in doing this. It closed I want to say about two weeks ago, but I think it's interesting and just something that the Subcommittee will probably want to stay on top of and it's good that we reached out and that we have an autism contact at AHRQ.

Dr. Rice: So Ellen, how does --

this is Cathy Rice -- how does that work, they solicit this from anybody, is this like a request for information, or is this a literature review, or what?

Ms. Blackwell: Cathy, my understanding is, and I hope that I don't mangle this, because I don't have my personal notes in front of me, that they work, AHRQ works with certain folks, a group of Medicaid directors and some outside organizations, I believe in this instance it may have been Autism Speaks or another stakeholder group.

These groups go to AHRQ and ask them if they are interested in doing certain types of evidence-based reviews. We take a similar approach at CMS in the world of Medicare when we go to look at what coverage is reasonable and necessary.

So this is very similar to what we do on the Medicare side, but I understand that they were asked by internal and external stakeholders to take a look at early intervention therapies for children. So I was curious too, you know, it kind of just popped up, it was something that I ran across and I was really glad because the IACC has been interested in, and we have a contact at CMS that we typically work with on our quality-based initiatives but I have not been able to find anyone who is interested in particular in autism so this is great.

Dr. Rice: Yes, very helpful.

Ms. Juliano-Bult: Who is the contact?

Ms. Blackwell: It is Karen Siegel. I also wanted to mention that at our next full IACC meeting -- I feel like in between all these strategic planning meetings it will be here in no time -- that meeting is October 23 and Dr. Tony Charman will be talking to us a little bit about the same topic, early intervention strategies for children with autism. So we're looking forward to having Tony. We had planned to have Tony present with Ted Karr, who unfortunately was killed with his wife in June, Lee?

So, it's really sad that Ted will not be with us but we're hoping that Tony can do a yeoman's job covering this material. That meeting schedule is very busy but I think the committee will be very interested in what Tony has to say.

So with that, I guess we can do a round robin. Denise, do you want to go first since you're at the end?

Ms. Juliano-Bult: Sure, and I'm going to have to duck out in a minute anyway. Just to update folks, the activities that NIMH has had related to the stimulus package money and there was an announcement that was the umbrella solicitation for research that included services research in the autism area and we are in the process of funding four grants, four services research grants, under that announcement and two services research grants out of the Challenge Grant mechanism.

So until it's final I'm not allowed to give more information about it, but it's a good start and we already have folks who applied and were not funded working with us to revise and resubmit, so we're encouraged by that.

We have several of these that address access issues related to minority folks and several that are looking at technology for disseminating and implementing and training in broader areas of the country.

We also, in our -- we have a biennial services research meeting that happened this past July. We had a think tank that Sam Odom actually participated in that was looking at, or discussing how can we foster more interest in services research in this area, either encouraging junior people to pursue it or convincing more senior people to come over and work with us.

And we also have planned doing a

similar kind of think tank at the American Public Health Association meeting in November, where David Mandell -- it's in Philadelphia and David Mandell is going to host that. So we are trying to keep the research flames going on our end.

Ms. Blackwell: David is one of the folks that is participating on our strategic planning exercise, Denise. Lee, do you have anything?

Mr. Grossman: Yes, at our conference last month, where are we, September? It's actually two months ago, sorry about that. Time flies when you are having so much fun. We announced that there are professional competencies that have been approved by the CEC and the NCATE and those will be part of the AIM modules as well.

Basically what this means is that any academic institution that has teaching, any university-based teaching programs, that are going to be teaching anything on autism, that they have to meet these competencies and have to teach to those competencies.

And through the NATTAP partners that I referred to earlier and the AIM modules it's our intent to take those competencies that are now part of an accreditation process and deliver them back to the school districts so that those teachers that are currently in place will be aware of them and hopefully will teach to the competencies as well.

We think this is a big breakthrough in teaching methodologies for the students because the school districts are also asking for that type of not only standardization in their curriculum, but what is best practices and this certainly sets the standard for what those best practices will be.

And it was mainly because of what Christine brought up, the questions that she was asking, I wanted everybody to be aware that this is ongoing right now and it's something that you'll be hearing much more about.

Ms. Blackwell: Okay, thanks Lee. I really don't have too much. I spoke a little bit about the Year of Community-Living initiative that our partners at the HHS Office on Disability are undertaking.

So I think that when our newest member joins us in October we'll be hearing a lot more about community-living initiatives within the Department of Health and Human Service.

I also wanted to mention that we have issued a new RFP for a project that will actually fulfill one of the objectives in our strategic plan, which is to assess autism activities in the 50 states with the intent of having that go forward on some regular basis, whether it be annual or whatever, so that should be closed in a short time.

So that's it from me today. Gail, do you have anything?

Dr. Houle: Yes, I do, thank you. I wanted to say that, everyone's probably aware that our Secretary of Education is Arne Duncan, and on the ed.gov website we have posted guidelines for states to use in the use of the ARRA funds that states have received for the IDEA, the Individuals with Disabilities Education Act.

And basically it will say that those funds can be used by states for any purpose for which the IDEA funds that have been appropriated for years, are used for. So as long as they're following the IDEA regulations, the ARRA funds, the additional funding that is coming to the states, can be used for the same purpose. It's not for supplanting, but it's for enhancing.

So if you're interested in the federal guidelines for states to use with the ARRA funds for children with disabilities. I would encourage you to go to the ed.gov website where those are posted.

We also have in development some new partnerships with HHS, and education, and certainly we have a new federal collaborative for young children early learning collaborative among the two agencies and we have a new assistant to Secretary Duncan and the assistant is Dr. Jacqueline Jones and she's special assistant for early learning and we have been having inter-departmental meetings with the HHS special assistant Dr. Joan Lombardi, around how to coordinate efforts for the whole child health and education.

We also, in the Office of Special Education programs -- we fall under the Office of Special Education and rehabilitation services. We have an assistant secretary who has been nominated and we are awaiting her confirmation, Dr. Alexa Posny. She was formerly with the department so we are waiting for her to be confirmed and come back to head up OSERS.

And within OSERS you will find OSAP and the idea implementation in the administration of the Individuals with Disabilities Education Act program. So that's the news from the Department of Education.

Ms. Blackwell: Do we have anyone on the phone?

Dr. Shore: Yes, I'm here. I've got to dash off to another meeting at three so I guess I'll speak up.

Ms. Blackwell: Thanks Stephen.

Dr. Shore: Sure. Things have been busy over here. We're busy building an autism graduate certificate here at Adelphi University and I look forward to employing those new competencies that are about to be released.

Ms. Blackwell: Great, is there anyone else on the phone?

Dr. Rice: Yes, hi, this is Cathy Rice from CDC.

Ms. Blackwell: Hey Cathy, thanks.

Dr. Rice: We have our next autism prevalence report in print and we hope that that will be out by the end of the year.

In addition there's another paper coming out in pediatrics in early October, led by HRSA, so I don't know if Georgina wants to say anything about that, but they will be looking at the National Survey of Children's Health and parents' report on autism so that should be out early October.

We continue our activities with the study to explore early development looking at early risk factors for autism. In addition I think in our June IACC Services Subcommittee, that's when Dr. Georgina Peacock presented on the Learn the Signs Act Early campaign, the activities continue there, working with parents and healthcare providers and early childhood educators to get information out on the early milestones that need to be monitored to identify autism.

In addition, we continue the Act

Early summits which is bringing state level and regional leaders together to come up with state plans to address service needs for children with autism and developmental disabilities.

More information about those summits: the next one is going to be in October, the end of October, I think the 29th and 30th, in Atlanta, and you can find out more information about those summits and the campaign activities at the aucd.org website, the Association for University Centers for Disabilities, aucd.org. That's about it for right now.

Ms. Blackwell: Thanks Cathy and I should you know, once again indicate the materials from that June meeting, we've had a lot going on in between, so I apologize but HRSA and the CDC gave us a great presentation and those materials are also available through request from NIH.

As Cathy said the Learn the Signs

Act Early campaign that was also a really great presentation, so I urge folks who are interested to take a look at the materials.

Anyone else?

Ms. Washington: Yes, this is Deidre. As Cathy mentioned we do have, there is an article in Pediatrics coming out led by her so with a lot of collaboration, CDC is going to be over there, as well as a couple of other folks, and it's data, new data, from the National Survey on Children's Health and the prevalence and impact of Autism Spectrum Disorder. And we are hoping as she said that that will be, that should be coming out in early October.

However we are doing a sort of unveiling this data, just at the HRSA level on September 29, here. We will be unveiling some of that data here, HRSA.

So there's that and in addition to that we have as of September 1, three new state grantees that have started regarding our commanding autism act program as well as seven new research intervention grantees that have started. Two of the seven are secondary data analysis and the other are sort of your typical authorities working on evidence-based practices and interventions regarding autism. And that's in on my end.

Ms. Blackwell: Great, thank you Deidre. Deidre also presented along with Dr. Peacock so her presentation is also wonderful and you can learn more about the grants and programs that she just referenced in those materials.

So, Lee, do you have anything else? He says no, so I guess we are adjourned.

Dr. Rice: Ellen, before we adjourn can I make a suggestion for some future topics for us?

Ms. Blackwell: Yes, of course.

Dr. Rice: One thing we mentioned, or talked about briefly at the June Services Subcommittee meeting was that the Combating

Autism Act recommends that each state have an autism plan I think particularly for services but it doesn't really have much teeth to it in terms of implementing or how that would work.

But in that vein, I know a lot of states are putting together autism plans, trying to address the various levels and so one thing that may be very helpful, we had talked about could we be a repository for if there is a state autism coordinator or a governors' council or something, it would be very helpful for the IACC Services Subcommittee to know about that and is it possible to consider the website as a place to link to those programs, those collaborative efforts for each state.

So one thing I'd like to propose to the committee, is that something that folks are interested in pursuing and that we hear more about some of these state collaborative plans and then we consider how we can be a source for gathering that information for other states that are interested in learning from what others are doing?

Ms. Blackwell: I don't know if we can be a repository Cathy. Susan can talk more about that, but I can definitely say that there are a lot of states that have these sorts of plans and I use plan in quotes because they call them different things, but if you're interested in a particular state I've found that just like googling them.

So Pennsylvania has a really good one and I'm trying to think of another one that I saw more recently and it's just escaping me today but there are quite a few. Lee, are you aware of any other newer ones?

Mr. Grossman: Well, there's, well, as you rightly stated and as I think you pointed out in that last meeting, it seems as though each of the states has multiple teams that are working on autism and that there's many players on different teams that are working cross-collaboratively in many, many different areas.

So it is hard to pin-point who is doing what. Not only are some of these federally sponsored, some of them are state sponsored. We have a group through the NATTAP partners and working with NASDSE for example, similarly there's two separate programs there pulling state teams together.

At the Autism Society we are trying to put some concreteness behind this and we've started to compile the information that's out there and put it together in a micro-site so that we can get a handle on what's actually being presented there.

And we have an intern in place right now that's coordinating all that. But we'll be reaching out to the agencies here fairly soon to get a better idea of what they're doing. But there's multiple agencies even working on that. SAMHSA, HRSA has their group, AUCD has another group, I know CDC has people that you're working with, and so all that is in addition to what some of the states are doing on their own dime in putting these together.

Dr. Rice: Right, those are all, you know, wonderful efforts, it's just you know, as a coordinating committee, can we play a role in terms of trying to disseminate that information or help people connect with each other. If one state is looking for what others are doing and searching on the Web -- can be done, but that is a lot of redundancy and how can we as a committee help states learn from each other.

Dr. Daniels: Well I would suggest, this is Susan Daniels, that if you as a subcommittee have a specific recommendation for the full committee and you'd like this to be considered as a particular project, that you need to propose it formally. So I would like for you to --

Dr. Rice: Well one easy way would be either any federal- or state-sponsored efforts in terms of coordinating services state-wide could be something that we would start to focus on. And identifying those projects and at least having, you know, those folks come and present to the committee and hopefully some sort of resource lists of those activities would be something I would suggest for the committee to consider.

Dr. Daniels: Right, so I would suggest that you discuss it by email as a subcommittee and if you want to propose a formal project that you propose it and bring it to the full committee.

Dr. Rice: Okay.

Ms. Blackwell: Well, I think that calls it a day for the subcommittee. Oh, Christine has one thing. I'm sorry.

Ms. McKee: I've one more thing to say and after our last meeting, and all the information I have about this is second-hand, after the last IACC meeting, it adjourned early, and there was a person who brought someone, their son to speak, and the message that I read from the public comment was that the mother wanted to have the IACC, people who don't have daily contact with people on the spectrum, to see a person with classic autism. We have a wonderful presentation from the Autistic Self-Advocacy Network, you know, they get up and speak and give us wonderful guidance and it's very appreciated.

But autism is a spectrum and there are many, many people in the middle of the spectrum and at the low-functioning end of the spectrum and how do we bring that reality to the IACC, the people who sit on the IACC, who don't live this in their daily lives.

So early on I brought up the suggestion of a reception and just for people to bring their family members or for the -- and I'd love the public to be there as well, so that people from the public don't have to fly their family members -- I love that they do and I would be happy to have that public comment period have representation, but I'd also like to make it a little easier, a little more user friendly.

And I do not know what the real idea is here other than to have a place for there to be contact, for us to have more interaction with the public, in a more, without microphones, you know, where people don't have to speak into microphones.

And I don't know if this is even possible within our budget and like I said I brought this up early on with Joyce and at that time we didn't have a budget, we didn't have funding, we didn't have an administrative office and it just seemed too big with where we were.

I don't know if it's worthwhile now or how the committee feels about it but I think that this is the place to kind of start to discuss it.

Dr. Daniels: So something we want to consider, if the subcommittee decides they want to do that as a project, they might want to look for a non-profit partner to help, because there might be limitations on what the government can do in terms of throwing receptions and so forth. So there may be parts of such a type of activity that we could organize but parts that we would not be able to fund with federal money.

Ms. Blackwell: So it might be useful for Christine to take this up with the full committee? Sounds like Susan is another --

Dr. Daniels: You could propose it at the full committee meeting. I don't know if you want to have more discussion here with the subcommittee first, but then if it's something that the full committee is on board with, to think about partners that might be able to help.

Ms. Blackwell: Because there are more partners.^^At the full meeting there are even partners in the audience who aren't at the table, so there might be folks who are interested, maybe if you brought it up in the morning, you might.

Ms. McKee: What do people here think about this? I mean, is this is a worthwhile endeavor or not? I was very moved by what happened and when I went back and read the mother's statement and I felt that she had a very good point.

Mr. Grossman: Well, I think that we've always advocated that however we can make the public more involved in our process we should take advantage of that.

When I refer to the public I'm referring to people on the spectrum at all levels and all ages. So again, whatever we can do to make the meetings much more accessible for people I think we should try and do that.

I don't know what the limitations are regarding how they have to be presented. We have to have this available to the general public as well. But wherever we can hold a meeting, so that people can be more available and we may have to become more creative to make that happen.

I know in my own experience that we always encourage and we generally will have meetings that will have, that fully includes people on the spectrum. And certainly I would love to see the IACC do the same thing. So I'm fully in support of what you're saying.

Ms. Blackwell: And I think that even in terms of, I don't want to speak for Susan here, but even in terms of our regular meetings, if anyone has a special need, they are always encouraged, to not just, if they can't identify a staff person, come up to an IACC member and say oh, I have this special need, and could you help me find someone to help me with this and I'm pretty sure that any one of us would be willing to try to figure out a solution.

So certainly at future meetings, I

mean, all of us are very sensitive to the needs of people with autism. That's why we're on the committee. We're here to try to make things easier. So, okay. All right, well thank you Christine and we can talk more about it, and maybe at the next meeting we'll have some other partners in the room who might be willing to help out with the things that government can't do because sometimes our hands are tied, as Susan will attest.

So, all right, well thank you everyone for participating today and we'll let you know when our next meeting is and Stephen, thank you for offering to present. Okay.

(Whereupon, the above-entitled matter went off the record at 3:12 p.m.)