U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTE TOWN HALL MEETING

FRIDAY, JULY 24, 2009

The meeting convened at 10:50 a.m. at the Pheasant Run Resort Amphitheater, 4051 East Main Street, Saint Charles, Illinois, Lee Grossman and Ellen Blackwell, 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 of America and Co-Chair, IACC Services Subcommittee

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

STEPHEN SHORE, Ed.D., Autism Spectrum Consulting

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation

MELODY STEVENS, M.A., Centers for Disease Control and Prevention (For Catherine Rice, Ph.D.)

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(10:50 a.m.)

Ms. Blackwell: Hi, good morning everyone. Can you all hear me okay? Okay, good morning, I'm Ellen Blackwell. I'm from the centers for Medicare and Medicaid services. I'd like to welcome everyone this morning, both in the room here and also from afar listening to us on the internet. I'm the parent of a 22-year-old son with Autism named Robert. I am also very honored to be here today in concert with the Autism Society 40th annual meeting. I actually founded a chapter of the Autism Society many, many years ago in Howard County, Maryland. So, it's very special for me.

The purpose of today's meeting is to talk a little bit about initiatives of the Interagency Autism Coordinating Committee Services Subcommittee. We're really excited, we don't have very many opportunities to get public input into our activities and so today is a great opportunity to have live interaction with you folks and also with the people listening remotely. We do hold regular meetings, and Dr. Susan Daniels, who's here from the National Institutes of Mental Health, is going to talk a little bit more about our mother committee, The Interagency Autism Coordinating Committee.

But we do also hold regular meetings in the Washington, D.C. area and we urge people to participate in those. There isn't at this present time, live interaction, but people do have an opportunity to come into the meetings at the end and comment and also send in written comments and if you have comments any time during the year, there is a venue by which you can submit those to the National Institutes of Mental Health. So, please we welcome your participation all year long, not just today.

I'd like to quickly introduce the members of the Services Subcommittee and then we'll let them go along the line and introduce themselves later. Today with us we have Gail Houle from the Department of Education. Gail has been a member of The Interagency Autism Coordinating Committee. She may be one of our longest members, along with Lee Grossman, who is the Co-Chair of the Services Subcommittee and the President and CEO of the Autism Society of America. Bonnie Strickland, with the Health Resources Services Administration; Dr. Susan Daniels, our liaison with the National Institutes of Mental Health; Melody Stevens who's representing the Centers for Disease Control; Alison Singer, Autism Science Foundation; Stephen Shore, who typically introduces himself as his own person with Autism, and also a member of the IACC.

Just briefly I'd like to mention that today is the 19th anniversary, July 26, 1990, of the Americans With Disabilities Act, a very important civil rights law. So, in some ways today is a very special day and I think we need to mark that. It is very important. Also, 1990, excuse me, it's been ten years. This year also marks the 10th anniversary, 1999, of the Olmstead Decision, a very important Supreme Court decision. Two women in Georgia petitioned for the right to leave an institution and live in a home and community based setting, and they did indeed prevail.

And this year marks the Health and Human Services is embarking on the year of community living. The secretary has asked for the formation of a Health and Human Services Coordinating Council, led by the HHS Office of Disability. Henry Claypool will be representing that effort, along with leadership at the Housing and Urban Development entity, and they will be looking at ways to improve access to housing for people with disabilities, access to community support and also increase efforts for independent living. HHS will be embarking on a series of listening sessions across the country to talk about how to improve home and community based services. So, look for more coming about that.

My agency, the Centers for Medicare and Medicaid Services, recently published a notice of proposed rule making, seeking comment for meaningful reform in home and community based programs, especially the development of needs-based person center programs, and that closes on August 4. So, if you're interested in offering comment on that part of the year of community living and our efforts, please take a look at the CMS web site.

The Services Subcommittee was formed to improve services and supports. That is our mission. The vision of the Subcommittee is that all people with Autism Spectrum Disorder have the services and supports they need to lead productive lives in the community and to reach their fullest potential.

We have embarked on some efforts in the Service and Subcommittee. Last fall we issued a Request for Information, asking folks from across the United States what they thought the issues and services were and we received a fairly good response, about 137 people wrote in and we looked at 500 comments. And if you take a look at today's flyer, you'll see the top categories that came in as a result of that effort. I think that the problems at this point are fairly well identified. We need to work on solutions, that's part of the reason that we're here today.

So, I also wanted to mention that the Subcommittee, in a previous life, when it was composed under the Children's Health Act, issued a road map for Autism services. So, a lot of work and effort was put into the road map. If you're interested in looking at that, it's also on the IACC web site. We are presently working on making another document that will take the place of the road map, that looks at making recommendations to Secretary Sebelius about services and supports to people with Autism.

Today we're here to talk a little bit, not only about the recommendations effort, but also about our strategic plan. And I hope that when everyone came in, they were able to pick up a copy of the strategic plan. This very nicely bound volume, thank you Dr. Daniels, is our first effort, Version 1.0 of the strategic plan. This is a strategic plan that describes research efforts within the Department of Health and Human Services, and other entities interested in Autism. And it's very important, I think it's great, a lot of work, a lot of really terrific people dedicated to Autism contributed to this.

And it's structured in a way that poses questions to families and people with

Autism. When should I be concerned, how can I understand what's happening. The questions that we are really interested in hearing from you about today are where can I turn to for services and what does the future hold. And we will be revising this plan. It will be given to the Secretary again, the target date is January of 2010, so we're hoping that you can take a look at what we have in here now and help us craft suggestions for how to make it better. As I said, this was our first effort, first time out of the gate, so it's not perfect. But, we're always hoping to make it better.

Oh, are there any, thank you. Someone just passed me a note. Are there any IACC Services Subcommittee members on the phone who would like to introduce themselves?

Okay, with that I will just acknowledge Cathy Rice. Melody is sitting in for Cathy today on the Services Subcommittee. Cathy was unable to be with us. She had some elective surgery last week, so we all hope that Cathy is recovering quite nicely and hope to see her. Susan, I'm going to turn it over to you to talk a little bit more about the IACC and the Services Subcommittee and then I'll let folks introduce themselves.

Dr. Daniels: Good morning. My name is Susan Daniels. I'm the Deputy Director of the Office of Autism Research Coordination at the National Institutes of Health, and I serve as the designated federal official for the Services Subcommittee of the IACC.

Let me tell you a little bit about the IACC. As Ellen mentioned, the IACC was originally established under the Children's Health Act of 2000, and then it was reconstituted under the Combating Autism Act of 2006.

In the Combating Autism Act, the mandate of the committee expanded to cover all Autism Spectrum Disorders and the composition was specified to be two-thirds federal members, and one-third public members. And so those federal members are representatives of various agencies that do research or support services for Autism. And the law also specifies that public members must include at least one person with an ASD, one person who is a parent of a person with ASD and one representative of a service advocacy or research organization. And, in fact, we have more than one in some of those categories.

So, these are the members of the current IACC. The Chair is Dr. Thomas Insel of the National Institute of Mental Health, and we have federal members that represent several different agencies that serve the Autism community, and public members that in various capacities are family members of people with ASD or serve in various service capacities.

The IACC mission is to facilitate the effective and efficient exchange of information on Autism activities among member agencies in the government, to coordinate Autism-related programs and activities, and to assist in increasing public understanding of the member agency's ASD activities.

The charge of the IACC under the Combating Autism Act is to develop, annually update and submit to Congress a strategic plan for ASD research and I will tell you a little bit about that later. We released our first strategic plan in January of 2009. And to develop and annually update a summary of advances in ASD research, and if you've been following what the Committee has been doing, they are in the process of finalizing the second annual summary of advances in research that summarizes various scientific papers in lay language, and it will be submitted to the Secretary of Health and Human Services.

To monitor federal activities with respect to ASD, and the Committee has recently done a portfolio analysis of ASD activities across the whole federal government and the private sector in the U.S.

To make recommendations to the Secretary of Health and Human Services regarding appropriate changes to ASD activities in the government, and public participation in decisions relating to ASD.

So, the subcommittees of the IACC are the IACC Services Subcommittee, and as Ellen mentioned, the Services Subcommittee has several roles related to services including monitoring, assessing and planning activities and providing advice to the full IACC regarding ways to improve services and supports for people with ASD and their families. And then there's a new subcommittee that just formed this year called the IACC Subcommittee for the Planning, for planning the annual strategic plan updating process. And this subcommittee is specifically charged with helping plan activities that will be related to the next annual update of the strategic plan.

So the IACC Subcommittee members are on this list here, Ellen Blackwell, Lee Grossman, Gail Houle, Jennifer Johnson, Larke Huang, Denise Juliano-Bult, Christine McKee, Cathy Rice, Stephen Shore, Alison Tepper Singer, Bonnie Strickland and soon to be joining us, Henry Claypool from the DHHS Office on Disability.

And Ellen also mentioned some of the recent activities. I'll just recap that the Services Subcommittee issued an RFI last year from August to September to collect information on what the public thought was important about services research and came up with some of the categories that are on your agenda sheet, that will be part of the subject of today's discussion.

The Subcommittee analyzed those responses and used them to guide activities such as today's meeting. The Subcommittee decided to invite special speakers to several

IACC full committee meetings and services subcommittee meetings to educate both committee members and the public on services, and they have future plans to create recommendations to submit to the Secretary on services.

This is a list of some of the services talks that have happened within the last year so including a recent wonderful talk on the CDC Learn The Signs Act Early Program and the HRSA Combating Act, Combating Autism Act initiative, as well as several on Medicare, Medicaid and other services issues. And, so if anybody from the public would like to receive copies of these slide presentations, you can simply request them through the IACCPublicInquiries@mail.nih.gov mailbox.

The first strategic plan, as I mentioned earlier, was completed in January, 2009 and it is structured around six questions. When should I be concerned, which is about diagnosis; how can I understand what is happening, which is about the biology of ASD; what caused this to happen and how can it be prevented, which is about risk factors and prevention; which treatments and interventions will help, which is self-explanatory; where can I turn for services; and then what does the future hold, which is about life span issues. And so in today's Town Hall Meeting, we would love to hear your comments, especially on numbers five and six, where can I turn for services and what does the future hold.

Recent full IACC committee activities include the annual update of the strategic plan, and so at the last meeting of the full committee on July 15th, the IACC released a portfolio analysis of federal and non-federal ASD research funding and the slide set is available to people that write in to our mailbox, if they'd like to receive that.

As of yesterday we just made

public a Request for Information for public comment on the entire strategic plan and there will be information on our web site, but we also sent out a mass e-mail to people that have been to our previous meetings as to how they can respond to that request for information, it's posted in the NIH guide.

And then we're going to be holding an IACC scientific workshop on September 30th and October 1st, 2009 in Bethesda, Maryland, and it's open to the public. You just have to pre-register to come in, and you can probably register at the door as well.

The Annual Summary of Advances on ASD Research will be released to the public on the web very soon. It's in the final stages of being processed. And, I just covered those.

For information about upcoming IACC events and materials, you can subscribe to the IACC e-mail list by sending an e-mail to IACCPublicInquiries@mail.nih.gov, you can subscribe to our Tweets on Twitter and you can visit our web site at www.iacc.hhs.gov.

And I'd like to also just take a moment to introduce my office, the Office of Autism Research Coordination, which was formed in December 2008, to support the activities of the IACC. This office exists within the National Institute of Mental Health and is supported by the HHS, and it provides administrative management and policy support to the IACC. So, we take care of coordinating and implementing various activities that are planned by the IACC and we communicate with the public on behalf of the IACC, including publicizing events, responding to public and government inquiries, including Congressional inquiries, and providing information to the public. And you can contact us at the same e-mail address.

And this is a list of our staff, Della Hann, who's the Acting Director, myself, Erin Bryant, our Science Writer, Diane

Buckley, Monica Mallampalli and Azik Schwechter, who are our Policy Analysts and Lina Perez, who is our Program Specialist. Thank you.

Mr. Grossman: I want to thank you for applauding. At our IACC meetings, for some reason, nobody ever applauds after anybody presents, and it's kind of, I don't know if any of you have ever noticed that, but it's just, I just find that a little peculiar.

I don't know if the, there are some other things I find peculiar, but I won't go into that right now.

I don't know if any of you are like me, but I'm just absolutely sweating up here. So I've asked them to turn the temperature down a little bit more. No, I'm kidding, I'm kidding. You're not warm?

Well, I apologize for the meat locker conditions that we have in here. I don't think there's much that we can do about this, so we had our Science Track Conference in here all day yesterday, and we had to thaw some people out at the end of the day. So, for any of you that are staying in the hotel, you might want to go back up to your room and bring the comforter down. And I'm really not kidding about that, it will be chilly all day in here. But that's not to say that the topics will be.

I'm Lee Grossman, I'm the Co-Chair of the Services Subcommittee for the IACC and also the President of the Autism Society of America. And I can't thank you enough for being here and I welcome you here, not only to the 40th anniversary of the Autism Society's National Conference, but also to this very unique opportunity that the IACC has presented to all of you to participate in the process to become involved, to talk about how you feel, what you believe, express your opinions, recommendations and suggestions to us so that we can hear you, so that we can follow through on what you, the people that we're trying to serve, are directing us so that we can better serve you as well.

I'm here to do a little bit of housekeeping. The way this is going to work is that everyone on the Services Subcommittee will do a short presentation and once we're done with that, the rest of the time, which will be a vast majority of the time, probably two and a half hours of the Town Hall Meeting, will be devoted to hearing from you. And we're going to ask people to queue up in front of the microphones, and to please limit your time to about two minutes so that you're respectful of others that will be there, and we want to get as many comments in as possible.

From my perspective of being involved with the IACC, and I've been through two iterations of it now, and I've been like the sole surviving member of the first IACC into the Children's Health Act, into the second IACC under the Combating Autism Act, it really has been a tremendous and a unique pleasure for me to work with so many dedicated federal officials. On the Services Subcommittee we're represented by ACF, CDC, HRSA, NIH, Department of Education, Office of Disability, SAMHSA, CMS and probably a few other acronyms I've forgotten about.

But, truly from, as a parent of a child with Autism, and as a representative of a large advocacy organization, it really is a pleasure to be able to work with the dedication, the passion, and the commitment that these federal government officials and their agencies are providing in terms of trying to truly help our community. And you'll hear, I believe, some great presentations here from each and every one of them that will demonstrate to you that they do have a commitment and we're looking for direction on how to better improve that and expand what it is that they're doing.

So, without any further ado, I

guess there is further ado. People can also, oh, okay, yes, we are, as many, I'm not sure if you people know, but this is being broadcast live on the internet, and we encourage people that are listening in the blogosphere out there, to please either e-mail us their questions, we will be taking those questions also. So, again we encourage everybody's participation in this process.

Dr. Daniels: Do you want me to just tell people the e-mail address that you can use is IACCServices@mail.nih.gov.

Mr. Grossman: Okay, I'm going to introduce Bonnie Strickland, who is representing HRSA.

Ms. Strickland: Well, good morning. I think it's still morning. I'm from the East Coast and I haven't set my watch so I think it's lunch time. You may too.

I'm Bonnie Strickland and I'm here representing the Health Resources and Services Administration, that's a long name, in the

Department of Health and Human Services, and we've got quite a lot of work related to Autism going on in our agency. We represent the Title V program in your state, maternal and child help, it's known by different names in different states. But, we're the Children with Special Health Care Needs Programs in every state and every territory. And we've got representatives here with me, Cassie Louver, who is the Director of our Division of State Community Health that oversees the state programs, and Laura Cavanaugh, who oversees our research and training activities. They are right up there in case you want to find them.

I'm not going to spend a lot of time on the Combating Autism Act, Susan already did, and I want to spend just a few minutes though to tell you about our program, because we indeed do want to spend most of this time hearing from you.

I think the interesting thing

though about the Combating Autism Act is that it's been around since 2006 and it's taken us all this time to finally get it launched and in place. It amends the Public Health Service Act to support primarily research, training, screening, intervention and education. So, it is a fairly focused bit of legislation.

But it's enabled us to launch a rather new initiative in our agency. The overall goal, as you can see here, is to enable all infants, children, adolescents who have or are at risk for developing Autism Spectrum Disorders, and other developmental disabilities, to reach their full potential.

This slide is just to show you that in the Health Department of Health and Human Services, NIH, CDC and HRSA got resources in order to launch programs or to support programs in their respective areas. HRSA's, we are a service agency, we're sort of known as the access agency for health care. Our role in this legislation is to increase awareness, to promote evidence-based interventions, reduce barriers to screening and diagnosis and train professionals to diagnose and provide evidence-based interventions.

And when I say evidence-based, we're not talking about just data, we're talking about evidence that demonstrates that interventions are appropriate for families, that they work within the context of families, that they're reasonable and appropriate for implementation.

I've written out our name here because nobody ever seems to remember the Health Resources and Services Administration. We probably ought to change it to CDC or DOE or something. I think we think we need three words, rather than all these, but anyway.

Okay, our purpose in the program, and we call our program the Combating Autism Act Initiative, but for the purposes of this presentation I just want to call it HRSA's program to distinguish it from some of the other federal programs. You can see here what our focus is, screening children for possible ASD and other developmental disabilities; early, early interdisciplinary evaluations to confirm or rule out ASD, and if a diagnosis is confirmed, to provide evidence-based early interventions. And everyone in this room knows that there can be a huge gap between the time Autism is first suspected, from the time it is diagnosed, to the time that any intervention begins, and certainly to the time that an appropriate course of action is identified.

Here are some of the activities that we are engaged in. I'm not going to go into each one again. I just want to give you thumbnail sketch of what we're doing and then you can certainly see me or any of the others, Laura and Cassie who are with me, from HRSA.

Our program of Combating Autism Act Initiative, our program in Autism is divided essentially into four areas. The Combating Autism Act, if you know it, it focuses quite a lot on training and on research. A large chunk of the funds go to our training programs, to our national training program in leadership education, and they're known as the Leadership Education in Neurodevelopmental and Related Disabilities. You think HRSA's hard, if you don't know the LEND programs, knowing what they stand, what the acronym stands for, can be quite difficult.

But, it's a national network of leadership training programs in this country. And so we're using that to expand our work around Autism. We have 34 expansions at this time and five brand new programs to support work in training efforts in Autism. We have expanded our program to developmental behavioral pediatrics program, primarily for the purpose of early diagnosis and we have a national resource center at the Association of

University Centers on Disability, AUCD, as many of you know it, that we also have representatives right around there with Jennifer and, I can't see who else is out there. Oh, Sue, yes, and Katie. And they provide support to the Leadership Training Network, that whole network of LENDs and of Developmental Behavioral Pediatric Training Centers.

The purpose is to educate interdisciplinary health professionals, provide continuing education and technical assistance, and to contribute to building systems of service. That's really what we're all about in HRSA.

The second prong of this program is our Autism intervention research. Again the Combating Autism Act places a lot of emphasis on research. We're now supporting two networks, if you will, around Autism research. One is sort of a physical health network, I think we call it AIRP, AIR-P, for physical. And this group, based at the General Hospital Corporation of Boston, but it's actually a network, supports research in the physical aspects of Autism; gastrointestinal, sleep, nutrition, those kinds of disorders that can severely exacerbate other aspects of Autism.

And then the other component is the behavioral health component, AIR-B at the University of California at Los Angeles. Again, this is a network of research programs. It's not just located in those two places. They really leverage other research going on around the country. The purpose is to improve the health of children and adolescents with ASD by establishing and maintaining the network infrastructure and utilizing those networks as platforms from which to conduct research. They conduct research on evidence-based practices, develop evidence-based guidelines, they validate tools for intervention and they disseminate information on research guidelines in the tools.

The third prong of the program is not really required by the Combating Autism Act, but we are an access agency and we felt it necessary to try to demonstrate in various states, how services might be better put together for children and youth and adults with Autism. And so we took a portion of those Combating Autism Act funds and established a demonstration program, or an implementation program, we prefer to call it. We supported nine states to implement state Autism plans to improve systems of services for children with ASD and other developmental disabilities. These weren't for, these aren't planning grants.

What we're really trying to do is find those states that already have a lot going for them. They have either wonderful governors efforts, so they've already got agencies working together very well in partnership with families, but they've got a momentum going and these are grants to help put them over the tipping point so that in three to five years we will have states out there that we can turn to and say this state can do it, they can serve as a model for other states in helping to get that service system together.

To support that effort is the State Public Health Coordinating Center at the Association of Maternal and Child Health Programs. I'm sorry I didn't write that out here. That's our professional organizations.

This is the purpose of those state grants. Some of you that have worked with us around children with special health care needs programs, Amy, I know you have, know that we work from a systems perspective. And we say that in order for a child to be in a system, they've got to have these six things.

First and foremost, partnerships between professionals and families. We cannot do this job without the partnership of families, not just participation, partnership. We cannot do it. We must have access to comprehensive family-centered health care. We are a health care agency. We call that the medical home, we expect that pediatricians, family medicine docs, ought to be identifying kids earlier, helping families get to early diagnosis. Access to adequate health insurance to pay for needed services. I know that's a huge issue. Early and continuous screening, we think services need to be organized for easy use by families, not by the people that organize the service, but by the people that need to use the services. And ultimately transition, successful transition to adulthood.

And fourth is our National Evaluation Program. This is a combined evaluation effort over the other, all four components, the other three components of this program. We have a logic model that integrates all of our training, research and demonstration efforts and we're working on it now, it's actually in its first year and it's a required part of our reporting requirements for the Combating Autism Act and it will be reported in HHS Secretary's report to Congress.

This is our web site. You can learn about, more about anything I've talked about at www.mchb.hrsa.gov/Autism. Thank you very much. You can contact me, if you'd like. I'll be here all afternoon and we're really looking forward to all of your input and insight this afternoon. Thanks.

Ms. Stevens: Good morning everyone. Thanks for being here. My name is Melody Stevens and I'm a Public Health Analyst at the Centers for Disease Control and Prevention in the National Center on Birth Defects and Developmental Disabilities. And I am here on behalf of my colleague, Cathy Rice, who wasn't able to be here with us today.

I just want to tell you a little

bit about what CDC does in the area of Autism service, or Autism, excuse me. Everything I'll talk about today is conducted in the National Center on Birth Defects and Developmental Disabilities. We were established in 2000 by the Children's Health Act and our center seeks to promote the health of babies, children and adults and to enhance the potential for full and productive living.

Scientists at CDC use the public health model in their work with developmental disabilities, so surveillance of developmental disabilities feeds into research into particular DD's and their etiologies. When a cause of a particular developmental disability is uncovered, we can intervene on that disability through prevention efforts and health promotions. So, the cycle continues as surveillance is an important tool to help us evaluate prevention and health promotion methods.

And this is a review of our

programs that are specific to ASD's in the National Center on Birth Defects and Developmental Disabilities. First our major surveillance effort is the Autism and Developmental Disabilities Monitoring Network. This helps us to understand how many children are affected so that we can plan for services and can assist policy makers.

Our research effort is the Centers for Autism Developmental Disabilities Research and Epidemiology, or CADDRE. Big on acronyms in the Federal Government. This is our research body that examines risk and protective factors for Autism.

And finally, in the area of prevention, we have a campaign, Learn The Signs Act Early. And this is a major campaign that's aimed at helping parents, health care providers and early educators recognize the early warning signs of the developmental delay.

This is a map of our current ADDM

network. As you can see, we have 13 sites and another site at CDC currently funded to help us understand how many people have Autism Spectrum Disorders. And for surveillance year 2002, the most recent data that was published through the ADDM network, we know that between one in one hundred and one in three hundred people have an ASD, or an average of one in one-fifty.

So, we hope that the results can help intervention programs and policy makers better plan for the needs of individuals with Autism.

The second component of the public health research, or model, is research. And CDC has an active program, as I mentioned, in the area of research conducted through the Centers for Autism Developmental Disability Research and Epidemiology. That research body is currently conducting the study to explore early development. It's a multi-site study, it's across six sites, CDC is a site, also sites in California, Colorado, Maryland, North Carolina and Pennsylvania. This study will enroll approximately 2,700 kids who are age two to five, and their parents, and it is the largest study of its kind in the United States.

These are a few of the research areas that SEED will be exploring; infection and immune function, reproductive and hormonal features, gastrointestinal and genetic features, and investigating the broader ASD phenotype, sociodemographic characteristics and substance abuse hospitalizations, injuries, sleep disorders, and select environmental exposures.

And the third area that I mentioned in the beginning was prevention in health promotion. And as I mentioned, CDC has the campaign to help health care providers recognize the signs of early delay. And the major objective of this campaign are to raise awareness of developmental milestones, increase knowledge about the benefits of early intervention, increase the dialogue between parents and providers, and increase early action for developmental disorders.

These are a few of the tools that are available on the Learn The Signs Act Early web site. There's an interactive growth chart and there are developmental check lists as early as four months of age, to help parents, health care providers and early educators to track developmental milestones, just like they would a child's height and weight, as early as four months. And that web site is cdc.gov/actearly.

So, I just want to close by saying that we are absolutely committed to understanding Autism. CDC recognizes this as an urgent public health concern and we're committed to working with partners to improve the identification of people with ASD, to learn more about what puts people at risk for Autism and to encourage efforts to provide appropriate support for people with ASD's and their families. And thank you very much.

Ms. Singer: Always a relief when the technology works. Hi everyone. I am Alison Singer from the Autism Science Foundation. I am also the mother of a beautiful twelve year old daughter with Autism and the younger sister of a 45-year-old man with Autism.

I wanted to speak briefly about the Autism Science Foundation. We are a brand new 501(C)(3) public charity, organized for educational charitable purposes. We're only three months old. We were founded by myself and also Karen London, formerly of the National Alliance for Autism Research. Both of us as I said, are parents. Karen has a 21-year-old son with Autism and I spent the last four years at Autism Speaks.

Our mission is extremely straightforward. Out goal is to support Autism research by raising funds and providing that funding to scientists and organizations that are conducting, facilitating and disseminating Autism research. We also want to make sure that we are providing information to the general public about Autism research, making sure that the work that's done in the labs is getting out to families where it can be put into practice. And we're also focused on advocating specifically for the needs of individuals with Autism and their families. And then finally, our goal is also to promote the need for rigorous scientific standards and values with regard to research and services.

Within the science arena, there are really three areas where we're focusing our funding. One is genetics, with a focus on really understanding the mechanism of action of Autism so that we can create targeted therapeutics. Within treatment research, again we're really looking at both forma logical and educational building the research base there so that those treatment can be put into practice. And then finally the third area that we'll focus on will be to fund research into services and supports, again to better support individuals and their families.

And that's really the focus of today's Town Hall Meeting is to focus in on questions five and six of the research plan that you've heard so much about, where can I turn for services, what does the future hold. And within those two areas, where the Autism Science Foundation, well, I'm interested in getting your input, is really with regard to how can we focus on research that really builds the evidence base of interventions available for people across the life span; kids, teenagers, adults and senior citizens with Autism so that we're able to develop best practices and improve quality of life.

Our focus is really to try to conduct research that's both, is done in the real world and relevant to the real world. So we really want to be looking at actually conducting our research in a school environment, in a work place environment and in a home-based environment. And our goal with regard to this type of research is really to enable people with Autism to have a meaningful day. And a meaningful day may be different for each individual, but I think that's a goal that's really applicable to people at a wide level of function to try to enable everyone to have a meaningful day.

And then the second area of our services and supports research is really to focus in on how we can improve care giving and assistance for individuals with Autism. And when we say care giving, we also mean in the employment sector. So, how can we work with employers to create improved opportunities for individuals with Autism based on research.

So as I said, I'm really excited to hear from everyone here today and get your input. But if you are interested in learning more about the Autism Science Foundation, you can go to our web site at AutismScience Foundation.org, or to our blog at AutismScienceFoundation.wordpress.com, or take a look at some of our recent coverage in Science Magazine or Newsweek or some other publication.

So, thank you and I'm really looking forward to everyone's comments today.

Mr. Shore: I'm using a Stealth power point today. And as was mentioned before, I was, I am my own person on the Autism Spectrum, having been hit with what I call the Autism bomb at 18 months, when at that point, I lost functional communication, had tantrums, and various other autistic characteristics. And I'm so encouraged and pleased to see so many people here, dedicated to improving the lives of those on the Autism Spectrum.

So, how do our six questions relate to the lives, directly to the lives of people on the Autism Spectrum, when should my parents have been concerned. Well, they were concerned right at the 18 months when the Autism bomb exploded, or the regressive Autism occurred. However, there's now, we're beginning to see that there's research in determining whether someone is at risk of developing Autism in the first few months of life. So, that's great to see.

So, when should we be concerned. How can we understand what is happening, how can we help people, such as all you parents out here, educators, people right up here, such as Ellen, Lee and Alison. What is happening, what is going on in this great research, going on with that, as well. It took my parents a full year to find out what was going on, because there was no information out there, no Autism Society of America, no Interagency Autism Coordinating Committee, Services Subcommittee, and so on, at that time.

And what happened was, as some of

you may relate to, the doctors said they'd never seen a child who was so sick and they recommended institutionalization. But fortunately like so many parents here, they advocated on my behalf and provided what we now would refer to as an intensive home-based, early intervention program emphasizing music, movement, sensory integration, narration and imitation.

So, that brings us to we jump to question four, what treatments and interventions help. And what I found in my research is that people tend to get locked into particular approaches to the exclusion of others and to the detriment of children on the Autism Spectrum.

Given the incredible diversity of people on the Autism Spectrum, that's going to call for the fact that different people have different needs and how can we best match diagnosis to intervention.

Backing up, what caused this to

happen and how can it be prevented. Well, there's a lot of controversy about whether we should be eliminating Autism or not. And I think what we really are looking at is the difficulties that come with being on the Autism Spectrum. And I like to think that towards the future, which is question number six, how can we best provide support for people who are on the Autism Spectrum and thusly how can we use our unique strengths and abilities to contribute to society.

So, what I do, as a consultant for people on the Autism Spectrum, my goal is simple. How do I maximize the potential for those on the Autism Spectrum. And part of what I do is researching into comparative approaches to see if we can begin the conversation, start research towards matching best practice to the needs of children and adults on the Autism Spectrum. We all grow up and become adults. We spend about 70, 80 percent of our lives as adults.

I write books and articles related to Autism. One book, well let's just say I'm the dummy who wrote Autism for Dummies, and leave it at that. Education is another area that I find important. Whether it's consulting internationally on issues related to Autism, or serving on the faculty at Adelphi University in New York, teaching teachers to better meet the needs of those on the Autism Spectrum.

And finally, it's important to do work at home and in the community, and I give music lessons to children on the Autism Spectrum, because in addition to the therapeutic benefits of engaging in music, it provides a real life key in which to enable those of us on the spectrum, to get involved in society, perhaps as a performer. Plus it's just plain old fun. We need to have fun.

And finally, I haven't figured out how to teach children who aren't on the Autism Spectrum, so I'll just stick with those who have Autism.

If you want to find out more about what I do, check out my web site. The web site is www.Autismasperger, jam the words together, autismasperger, no s at the end of asperger.net.

Thank you very much.

Dr. Houle: Good morning. Let me make sure that I've figured out how to use this power point device correctly. I just go forward with it, right?

No. I go backward with it. I call Susan.

Okay. Well, thank you. Thank you for bearing with me. I'm Gail Houle and I work with the Office of Special Education Programs in the U.S. Department of Education. I'm very pleased to be here this morning and have great anticipation to listen to your concerns and your questions and your ups and your downs regarding the special education system and try to see what we can do.

I'm also very hopeful because

it's, we've had some very, very exciting things going on in the Department of Education at the federal level, which are intended to produce results, move through the states, and produce good results and outcomes at the important level where you all are working or where your children are in receiving services, in school systems, at the local, because that's where the rubber meets the road.

I'm also a, by training, a speech language pathologist and I did that for many years and worked with many children with Autism and their families and just loved every minute of that. Went on to get a PhD, got into kind of a research policy, end of line of the work, came to Washington and worked with the U.S. Department of Education, where I've been for many years, but have always, always missed the practice that I did with children with Autism and families.

OSEP's mission, the Office of Special Education Programs, is dedicated to improving results for infants, toddlers, children and youths with disabilities, birth through 21. Our legislating authorizing statute is the IDEA, Individuals with Disabilities Education Act.

Challenges, these are just a few of the many challenges. We have many successes and we have many challenges, and from a national federal viewpoint, while we know that the numbers are increasing, we're always trying to keep pace with the numbers and the skills required for adequate and appropriate personnel to provide those services at the local level for children with ASD.

And some of the instructional strategies that are effective are very complex and they require, many of the strategies require a high level of professional training. So, we are committed to see that, that we can do what we can to further that level of trained personnel who are out there to provide evidence-based excellent services for children.

The IDEA Act, and this is just the very basic, insures the right to appropriate education for children with disabilities. I'll give you just a little bit of a lesson. I don't know, you know, how familiar you may or may not be with the Department of Education and the Office of Special Education and Rehab Services. That's the big overall umbrella office that OSEP, Office of Special Education Programs is a part of, as is the Research Services Administration RSA, which serves, provides services to adults, and NIDR, National Institute on Disability and Rehabilitation Research, which is a small research arm that provides research for services for children and adults. They're birth through the adult age range.

We actually have two programs within OSEP to administer idea, and our big program is the Part B program. And that money flows, that's about, oh, it's over 11 billion dollars, that flows from the Federal Government to the states, state education agencies, and then flows to the local education agencies. And within that we also have Part C, which is the formula program that flows to states for the infants and toddlers, intervention program.

And then we have this little small pot of money set aside, and that's actually where I work, although we work in collaboration with the other programs, and that is the discretionary part, Part D, I guess for discretionary, and we have competitive grants that support technology, that support technical assistance structures, that support the best practice implementation for the Part B and the Part C programs. So, we kind of the federal model think tank part of IDEA.

Addressing the needs of children with Autism. I'm going to talk about the discretionary, the Part D, these are the competitive grant programs. And we are only about, oh, between 200 and 300 million dollars as compared to that flow through grant program of Part B, the formula that I told you that's 11 billion dollars.

So in our program though, we want to show what can be done and we cannot fund every possible teacher training program, but we want to fund the best models out there. So, we have specific to, and remember also that IDEA covers, is funded to cover all disabilities, birth through 21. So, I pulled out the projects that we're funding and these can be found on the ed.gov web site where they're targeting training personnel preparation grants for related service providers and teachers and early interventionists, transition specialists, to work with children with ASD.

And then we have a small number of research technology projects targeting, but we have a small number of those projects to begin with, because you see how small out pot of money is compared to the big formula program.

And then leadership training grants, we've had an increase at, we have eight national universities that are funding doctoral level people to provide leadership training, to provide leadership to programs that serve and universities and established programs and go out and lead efforts in providing and training evidence-based practices for professionals who work in the field of Autism.

I'm just going to give you a few examples of these personnel preparation programs, the University of Wisconsin, oh, University of Virginia, rather, the STARS Program, and they all have a unique focus. Like the STARS is focused on training of providers for rural school districts. Santa Clara is training leaders, leadership grant for individuals to actually serve in the policy and leadership capacity in that area.

And then we have a large professional training and development center for improving professional development of personnel serving children with ASD. And that's our biggest single investment of five millions dollars, one million dollars a year. And it's headquartered at UNC, and it's in collaboration with the University of Wisconsin and the Mind Institute. And, so, when you go to that, you can Google that site, or I may have it. I had to cut out some slides in the, just in the nature of brevity, but they take applications from states every year. So you could see whether your state has applied or has been selected to receive training for teams, multi-disciplinary teams, to then go out and do training the trainer within your state.

We also have several other technical assistance centers that are useful to you as practitioners and parents in disseminating best practices and finding out what the best practices are. And those are in the slides which I hope will be made available.

So, we also have, and some people don't know this, some people do, we fund parent training and information projects and community parent resource centers in 50 states. We have over a hundred projects. The web site there is TAalliance.org. So if you are a stakeholder, if you are a family member, and you are confused about what appears to be a maze, kind of navigation of a special education maze, and how appropriate services are determined, you can go to one of the parent training centers, you can find it on here, and receive information, you can meet with them, there are workshops on knowing your rights as parents. Very, very valuable to those who use this service. Here's a site from their web page, and just below cut off, which I had to take out, is the United States map where you can easily click on your state and find all the parent training.

Okay, this is sort of exciting to me, anyway, the ARRA funding, that has recently been signed and some of it's already flowing to states and it's going to double the amount of money going to IDEA, Part B. It's, states can, every state has had to set up a web site, your state education agency, to show how transparently they are flowing this money down to the local school districts where it can reach children. The idea is not to build bigger governments, the idea is to flow money to local education agencies or school districts, or Part C programs, to increase the quality and quantity of services available to children.

Yeah, 12.2 billion over the next two years and to think about our, our budget was 11 something billion for the past several years. So, this is in addition to, this is doubling.

So, either there will be nearly seven million additional children, or children who are served but may be under served right now, who are eligible to receive services through this. 11.4 billion to Part B, 400 billion to the preschool program, this is all flowing states to local. 500 million for the Part C program, and 680 million for the rehabilitation and disability research program.

Now, these are general funds that can also benefit your child or benefit you as a professional working with children with ASD, on the Spectrum, is that your state may be able to, and should be able to qualify to participate in a longitudinal data system and we expect those systems to include all children so that we can look at progress of all children as they move through the educational system in states. Teacher incentive fund, that can certainly be tapped into by states for teachers who work with children with special needs and educational technology is going to be available.

So, the Taalliance.org is the parent, that's the parent web site. IDEAdata.org is the web site, if you have any questions about how, how your state compares nationally, how many children do we serve in each category, that's kind of a data walk site that you might be interested in. It's all the data that we compile for our annual report to Congress, from the Office of Special Education Programs, and then the projects available at our ed.gov site.

One more thing before I leave, because I'm excited about this, is that we have, we are awaiting confirmation of a new Assistant Secretary for the Office of Special Education and Rehabilitation Services, that's OSERS, within the Department of Ed. And it's public knowledge that the nominee is Dr. Alexa Posny. She's in Kansas now with the Kansas State Education Agency. She was formerly with the department as our director of OSEP, that's one of the three components. Now, she's going to be appointed to, when she gets Senate confirmation, a higher level. She will be over OSERS, and there's no better family advocate, there's no better child advocate, there's no more reasonable, no more humble person in this field than Alexa Posney, so we're all anxiously awaiting her confirmation. And I think it will mean good things for you.

Did you add a slide on to mine? No, okay. Thank you very much.

Ms. Blackwell: Hi, once again, I'm Ellen Blackwell, Centers for Medicare and Medicaid Services, and I am going to breeze right through this very quickly because you've all been so patient waiting, you know, listening to us. We really want to hear from you, so Medicare and Medicaid and CHIP are not exactly lightening rod exciting, but my agency, the Centers for Medicare and Medicaid Services, essentially administers these three programs, Medicare, Medicaid and the Children's Health Insurance Program.

This is our mission, to insure effective up-to-date health care coverage and to promote quality health care. I would stress that the emphasis right now is certainly on quality. We are very interested in what's going on and I'll talk to you a little bit more in a second about that.

These are our strategic action plan objectives. I'm not going to read them to you, as Susan said, all these materials will be available on the NIH web site after we leave today.

We are basically organized through a field offices concept, which you can see here, we have four field offices. But I think more importantly, you might want to pay attention to this slide. The building on the left is where I work in Baltimore, Maryland. That is CMS's headquarters. And on the right you'll see that we also have ten regional offices across the United States. I think that these offices are interesting to you because they are really our liaison with individual beneficiaries and people who are interested in Medicaid, so, and Medicare as well.

So, if you have an issue or a problem and you have a family member who's a Medicare or Medicaid beneficiary, I strongly urge you to interface with your regional office. These folks do a great job solving people's problems on an individual level, so I think that's very important.

Medicare, the sister program to the program where I work, Medicaid, both of these programs were established in 1965. Medicare is our nation's health insurance program that supports, for the most part, people over age 65. It covers about 45 million people. Medicare provides hospital benefits, outpatient benefits, Part C is supplementary private insurance and Part D is our newest benefit, the prescription drug benefit.

Medicaid, a program with which I am much more familiar. I will be talking in fact a lot more about Medicaid this afternoon. So, if any of you are interested, I'm putting in a plug for my session. I certainly can't sum up Medicaid in two minutes. But, in addition to the acute health care benefits that Medicare provides, Medicaid also provides long term care coverage for children and adults. We presently serve almost 60 million people. Our beneficiaries are people with low income and resources.

We also have about eight million people, we call them the duly eligible beneficiaries, who qualify for both programs and these folks are, for the most part, the most disabled, you know, the most expensive. We are very concerned about them and I think you'll see, going forward, more efforts to secure quality health care for that group.

Most importantly, Medicaid is a federal state partnership. States pick up the tab for about half the program, the Federal Government pays the other half. Every state's Medicaid program is different. When you've seen that one Medicaid program, you've seen one Medicaid program. So, you know, if you come to hear me later, I'll talk more about that, but I think that's an important part of talking about Medicaid.

CMS also administers the Children's Health Insurance Program, formerly known as SCHIP, now known as CHIP. This is program unlike Medicaid that is not an entitlement program, it's funded through a grant. Some higher income program children quality for CHIP. The match, the federal match is little bit different. Some states use the Medicaid program as their CHIP program, others use it as a separate CHIP program, some of them are combined.

I wanted to mention that the

recent Re-authorization Act has a really interesting provision in it. It happens to be Section 401D, which seeks to establish a comprehensive evidence-based quality measures program for states to use and providing cost effective, high quality care for children in both CHIP and Medicaid.

So, we are working very hard with our state partners to, you know, try to put those things in place over the next couple years.

So, what do we do on the Interagency Autism Coordinating Committee, I'm the Co-Chair of the Services Subcommittee with Lee, as we said earlier. I'm also a member of the Strategic Planning Subcommittee, so I'm quite interested in what you have to say today about helping us improve our strategic plan. What do I do, I provide a lot of technical assistance to states and others who are interested in Autism services and supports.

The division where I work, the

Division of Community and Institutional Services, and I, need I say that the emphasis is on community and not institutional. We administer the home and community based waivers program in that division and, you know, I also look at programs within CMS that serve people with Autism.

I also, and I neglected to put it on this slide, have a very small program, I'm the Project Officer for some Autism research in CMS. The first part of this program which is already in progress, is an environmental scan that is looking at the strength of the evidence behind services and supports for children, youth and adults with Autism, and I expect that to be available to states and the public by the end of the year.

The second piece seeks to establish a state of the states for people with Autism so that policymakers and families will have a document to look at that will help them compare your state to other states, and so we hope to have that ready in the next couple years.

The third piece is a piece that will look at the development of model services and supports for people with Autism, children, youth and adults.

And I also wanted to mention like Gail, we actually do have a new Medicaid Director, her name is Cindy Mann. She is very committed to people with disabilities. In fact, she met with a rather large group of people yesterday, including a person with Autism and made an ongoing commitment in that meeting to continue to open, keep an open dialogue about people with disabilities. So, I think she's great, and I hope that moving forward we can continue to have these sorts of forums.

So, one other thing. Lee and I noticed, I mentioned earlier that today is the 19th anniversary of the Americans with Disabilities Act. If you're not familiar with

ADA, it is a law that was signed by President H. W. Bush. It seeks to provide equal opportunity and employment, state and local government services, public accommodations, transportation, telephone relay services, it basically hopes to level the playing field for people with disabilities. And I'm sure we can all agree that over the past 19 years, lots of good things have happened.

President Bush issued a statement just a little while ago that Lee and I thought you might like to hear. Yes, President H. W. Bush, the President Bush who signed the ADA back in 1990. And I'll read it very quickly. "I congratulate President Obama for taking some time today to remember the 19th anniversary of the Americans with Disabilities Act. There is no place in our society for prejudice of any kind. It was not that long ago when Americans with disabilities were often not given equal rights and opportunities. Whether the cause was ignorance or indifference, it was not acceptable. We can all take pride in how much the ADA has accomplished, which is evident every time you attend a sporting event, ride the subway, or go to work. Yet there is always more to be done, which is why it is good, not only to celebrate our successes, but to look forward at what still must be done. As long as we never forget that every life is a miracle and each person has something to contribute, we will finish the job."

So, here we are, and we would like to hear from you. So, as Lee said, there are microphones, please step up to the mike and feel free to ask your questions and Susan, if you'd like to reiterate what the web link is for folks who are participating remotely.

Dr. Daniels: Yes, for people who would like to participate remotely, you can write to the IACCServices@mail.nih.gov, and actually you can also use IACCPublicInquiries@mail.nih.gov. If you would like to receive the slides from today's presentation, please write to that same e-mail address. IACCpublicinquiries, all one word at mail.nih.gov. Yes, it's on the flyer. The e-mail address is on this flyer. Actually this is the e-mail address for today's questions. The regular IACCPublicInquiries@mail.nih.gov is where you write for slides. Go ahead, please.

Mr. Grossman: I wanted to reiterate the rules. Please queue up to the mikes, leave two minutes, please, for your comments. The Committee is here to listen and take note and we have numerous people that are transcribing your opinions, your suggestions. The Committee probably will not respond to most questions, but we want to go through as many as possible. And before I forget, we didn't applaud for Ellen.

Lars?

Audience Member: I'm --

Mr. Grossman: Yes, please

identify yourself and where you're from.

Audience Member: I'm Lars Perner, I'm on the -- faculty of the University of Southern California, I'm also on the panel of spectrum advisors. I'd like to make a very strong pitch for Autism subtype research. Autism is a very perplexing condition and we have a lot of individuals lumped into one category, but it turns out that many individuals, were, the huge -- many individuals will in fact require treatment that's the total opposite of what many of our individuals have and that creates some problems. We have some diagnostic categories such as Autism and Asperger's Syndrome, and PDDNOS, those may be useful for some purposes, but we know that these diagnostic categories usually do not project well the treatments needed by some individuals.

Now, because this is so complex again, something that would work well with some individuals could be disastrous for others. In the interest of time, I'll illustrate my points here with pharmaceutical issues, but it generalizes to other types of treatments as well.

There's a phenomenon, I'm a -- Professor and we deal with sometimes very ill-defined structures and segments. There's a phenomenon known as aggregation bias, which means on the one hand you could have a medication that works extremely well for some people and not well for others. On the average that would mean that it seems to have no effect, although that's misleading, but it also turns out you could have a medication that works very poorly in two groups, but if you add the results together, you get a false positive.

Now, there are some important reasons why we need to pursue the subtype research. We need to get to the important treatment of an individual as quickly as possible, that will both save money and also a lot of frustration. There are some serious problems in Autism such as self-injurious behavior. For some individuals -- medications may work there but they often have serious side effects. We'd like to know ahead of time if those will work or not. We know that for some individuals, very small doses of some medications will be effective. So, those are important considerations.

Now, you can also look at this from behavioral points. We want to reiterate here that many times individuals with, individuals on the Autism Spectrum lack the verbal ability to explain other conditions that they may feel. So, as a result, research and correlational parameters would be useful. There's more information on my web site. I passed out my card to the panel.

Audience Member: My name is Alex Citron, I'm from Syracuse, New York, and I teach private piano to individuals with Autism and other disabilities. And, along the lines of the diversity of therapies and approaches that are needed to cover the wide spectrum, as we say, of people on the spectrum, I'm just wondering specifically as Dr. Shore mentioned, the benefit of, for example, music instruction and other things within the arts. While these are not medical and they're not necessarily as rigorously researched and documented yet, I hope to change that, but, and just wondering, and I'm hoping that you all could consider the validity of activities within the arts and how to make some amount of funding public and private available for that. And I'll just say as someone with a private teaching studio where I teach individuals, again with Autism, I have found that certain agencies will fund certain amounts of this type of activity, but it's few and far between and I don't see uniformity in the criteria that are applied to determine whether it's valid and I don't know what the laws are in all of your agencies, but I would just encourage you to include a component for that and to continue further discussion on this topic. Thank you.

Audience Member: Hello. My name is Richard Fink, I'm from Morton Grove, Illinois. And first and foremost, I'm the parent of three children who are on the spectrum. And I probably speak for a lot of parents here, the first time they hear the word Autism is either from their pediatrician or the school system.

And then you're on your own.

What can your panel do to develop what I'd like to see, known as an Autism tool kit that is available to physicians, the school systems and then, most importantly, to the parent that gives basic steps on what a parent must do to help their child, who is newly diagnosed on the Autism Spectrum.

Ms. Strickland: Let me say just one word there, Rich, I really appreciate your comment because it's absolutely true. Fortunately, the American Academy of

Pediatrics just in June, middle of June I think, released the ASD Tool Kit. It is for pediatricians, but written so that families can use it as well. And you can access, I think that tool is on line now at www.medicalhome.org, medicalhome, all one word .org.

Audience Member: Judith Palfrey, the incoming President of the AAP --

Ms. Strickland: And is available.

Audience Member: But one of the problems is, is that there is no one set standard and it's not readily available. Even today, I have parents call me when their child is first newly diagnosed, secondly, I am President of the one of the local chapters of Autism Society. So, I field calls on a daily basis. And the information, even if it's available, is not getting down to the people who need it.

Ms. Strickland: Your point is well made, well taken.

Ms. Singer: Let me also add that Autism Speaks has a parent tool kit that's downloadable for free at AutismSpeaks.org. And that is specifically targeted at parents of newly diagnosed children.

Audience Member: I'm Gay Finlayson, I'm a parent from Albuquerque, New Mexico. I have two children on the Autism Spectrum. I also am a program manager of an Autism program at the university. And the questions of where do I turn for services and what does the future hold, my oldest daughter is 23. I have a graduate degree, I still do not understand the service delivery system in the State of New Mexico. And I have spent, since she was two years old, trying to figure it out. I don't think that speaks well for the parents who are coming after me who don't have some of the luxuries I've had, to figure out things.

The other thing that really concerns me is that we wrote an Autism road map and we're going to rewrite it before we implement it. We write so many dang plans that I'm just really kind of heartsick about that, that part of it.

Another concern I have is I come from a rural state, where we are, we've got a lot going on paper, we just got passed an insurance mandate, we're just going to roll out a Medicaid benefit. We have no providers to provide these services. So, we look really good, but we're not. And so I just want to talk about the houses of cards we might be building in some states where we're going to look good to you guys, but the families are still really struggling. And so to think when you're deciding how to do grant money, and that kind of thing, how do we add work force development to service dollars. How do we pair this with that. Because some of the grants seem to me to be awfully academic and we just need to be more practical. Thank you.

Mr. Grossman: Gay was one of the

20 experts that was involved in writing the first initial road map for DIAC. Anyone want to respond?

Ms. Blackwell: I just wanted to say that we certainly, as we move forward, have not tossed the road map to the side of the road. Our goal is to update it and, you know, make sure that we're on target for what's happening today, as Lee will attest. And we haven't finished those activities yet. So, if you have input and you want to participate as we move forward, just please, let us know.

And I also wanted to echo your comment about the adult services system. You know most supports for adults in the United States vary widely from state to state. It is simply the nature of the way that my program, the Medicaid program is constructed. So, you know, we are always on the lookout for ways to make things better. So, if you have suggestions or if you notice a particular problem in your state, please let us know.

Ms. Strickland: One quick comment to Gay. Hi Gay, it's so good to see you. Gay's been with us for many years, and when Gay can't figure it out, there's a problem.

But I did want to say to you, Gay, in case I don't catch up with you, you probably already know that New Mexico was one of the recipients of one of the HRSA State Implementation Grants that's, you know, it's not big bucks, but it's about $300,000.00 a year for three years. And maybe, with your help, they can address some of those issues that you're talking about, about the unavailability of services, even when you do have an insurance card, they're just not there. But we can talk more about that. It's good to see you.

Audience Member: Good morning. I'm Scott Campbell, I'm an active duty only officer, although I have to state right up front, I'm speaking as a private citizen and in no way related to the Department of Defense, in any fashion, for these comments. I am the son, or my son is named Ian, he is now eleven years old, nonverbal. I'm on the board or Advisory Council of five organizations in Northern Virginia. We live in Falls Church, Virginia, and I wanted to point out to the Subcommittee the significant issues that are involved with military families with have Autism. There are, we believe, and to be, we hope proven, but when the requests that were received by the, FOIA Request that we will be getting back by the end of this month, 18,000 individuals in active duty families. Another 9,000 in retired military families that are affected by Autism. That comes out to a staggering ratio of 1 in 66 active duty military families.

So, that's a very high figure that is very, very, very affect the community. And as you can imagine, as these families move, on average every three years, and have to re-establish educational services for their children, medical services for their children, and often very remote locations around the country, that is a very high impact on those families, which then turns to an impact on the ability of the service member to do their job, the mental health of the family, the financial well-being of the family and it also naturally then becomes a training retention issue for all of the United States military.

So, I just wanted to bring to the Subcommittee's attention the fact that the military specifically has a significant issue when it comes to the world of Autism and I just wanted to point that out so that it could be brought out in consideration down the line. Thank you.

Mr. Grossman: Thank you, Scott.

Ms. Singer: Could you talk a little bit about your experience with TRICARE, and how some of the changes, whether they've been effective, whether you're seeing them yet in actual practice.

Audience Member: I would love to. I just happen tonight at 6:00 o'clock, to be giving a presentation that I've been doing for about four years now, on the difficulties that service members have getting services from TRICARE. Again, we have, as of, you know, verifiable information, hopefully by the end of this month, 18,000 individuals with an Autism Spectrum Disorder in active duty families. Of that 18,000, a whopping 2,400 are currently receiving, or sorry, they are enrolled for services, to receive Applied Behavioral Analysis Therapy, specifically through TRICARE. But of that 2,400, only 900 are actually receiving any quantity of these services. So, the most scientifically validated method for helping individuals with Autism now is available to roughly five percent of the population. That's all. So, 900 out of 18,000 are receiving the services that the kids need to some quantity. I mean, that may only be two hours a month for tops. So, it is a significant, very, very significant issue.

Ms. Blackwell: I should mention that one of our activities I believe that Susan touched on is that we will be inviting folks to present us at every Services Subcommittee Meeting going forward. And we had in fact invited a representative from the Department of Defense that administers these programs in TRICARE and in other parts of the department, to come to present to us. So, we hope at some future point to hear more about the DOD initiatives in the Services Subcommittee. Although the IACC does not presently include someone from DOD.

So, keep an eye out, we'll keep trying, okay?

Audience Member: That's an excellent, excellent way to try to get the information, but I would suggest that the parent military position is perhaps not the official DOD position. So, you might want to get some parent miliary participation also. Thank you.

Mr. Grossman: Scott's presentation is on the 2nd floor of the Tower Building. Do we have a room for that?

Audience Member: The turquoise room, 6:00 o'clock tonight.

Audience Member: My name is Christine Guth, I'm from Goshen, Indiana. I am the parent of two young adult sons with Asperger's Syndrome, and my husband also has Asperger's Syndrome. I would like to plea for research into what is effective for helping adults with Asperger's, at the high functioning end of the Autism Spectrum, how can they get employment and how can they retain that employment. What is needed both in vocational assistance and in life supports so that these folks can become contributing members of our society. There's a great deal of potential there and some of them, the hurdle to get to that spot is huge and so that's my request for that population.

Audience Member: My name is Laurie Cramer. I'm from Akron, Ohio. I have an eight year old son who has Autism. I kind of have a global comment to make. Sometimes I feel like we're in Autism Whoville. We are here, we are here. I think finally people hear that we are here, but how do we, and not single handedly, knock down so many of the barriers, which is what you're hearing, to so many things, services, finances, you know, just globally.

Me specifically, my son has a great deal of medical problems, and when he was young I went from doctor to doctor to doctor and they kept saying, mom, you're trying to cure Autism, get over it. I'm not trying to cure Autism, I'm trying to get help for his, and he has huge G.I. problems, he's allergic to everything literally you can think of. It's been very difficult, because in our community I was just turned away doctor after doctor after doctor. Finally went to a conference and begged Dr. Timothy Buie to see us because I said I don't know what else to do. Nobody will pay attention to the sight of him.

We've been fortunate that our health insurance has been pretty good about covering some of those, you know, intravenous, immunoglobin-type treatments, but, that have been very effective for him.

We did participate in a study to go to the subtyping point where they tested, it was more like an oral AVIG, and I'm not a doctor, but it washed out. And I think, I'm not even a doctor, and I said I know exactly what happened here, you didn't test it on enough Phillips. Because if you tested on all those Phillips, he did great on that medication, and then it was gone. And we have no access to it except through the old-fashioned AVIG way.

So, somehow to tease out the

Phillips of the world, and even Dr. Buie said, you know, he's probably five percent. He's an extreme example, he's a perfect test kid if you need a test kid, you know, I don't mean to treat him like a little guinea pig, but he really is the extreme example of some of the problems our kids have with the G.I. issues and the autoimmune system problems. And something that's been so hard to get attention with are the doctors too. So, drilling down further beyond just the pediatricians, and getting to those immunology-type doctors and G.I. doctors to understand how those two come together so that we're not having to go to Boston from Ohio to be heard and to be helped.

I would also just quickly say for HRSA, I was thinking, that might be a good thing for you guys with the doctors, Medicaid, we've been number 70 on a list since he was like two years old, and so that's just not even a tangible thing for us. And inclusion, more information from the Department of

Education on inclusion. We're fortunate that he is in a mainstream classroom, he's not just in special ed, but the hard, another barrier for us has just been teachers who are ready to say I can do this. He's got aides, but we need that to go full circle where there's teachers know how to have a child in an inclusion environment and what that means. It doesn't mean that his aides are his teachers, that they are part of that team and more information on inclusion. So, thank you.

Mr. Grossman: Thank you. And just so that you know, and you'll probably see him walking around, Dr. Tim Buie will be here in about an hour. And he's speaking tomorrow at our Continuing Medical Education Program at noon time, and our whole program tomorrow, it's a day-long CME program, that is devoted towards direct interventions for medical conditions associated with Autism. Anybody else want to comment?

Audience Member: Hi, my name is

Holly. I am from Jacksonville, North Carolina, and I'm actually also part of the military. I'm a parent of a special needs child as well, with a diagnosis of Autism, but I also work for the military as well, with special needs.

To kind of elaborate with Scott, because this is a very big issue for the military, especially in my area where people are transferring from base to base to base. The continuum of care is not equal across the board from one side of the state you know, to the, you know, from one side of the U.S. to the other. Where people are moving from California and North Carolina, especially with the military, the services are not the same.

So, some children are falling behind, especially when it comes to the military. We do move every three years. That is a very big issue. And with the educational part, we are having a great deal of resistance, I will say, in regards to allowing outside resources to be allowed into the school to assist these children.

So, like, I'm just going to use ABA as an example, they can receive it outside of school, but they are not allowed to receive it in the school. We've had a lot of resistance on that end, so I like to put that out there to at least be addressed. So, thank you.

Audience Member: I'm Stacey Hoagland. I have a son who's 13 with Autism. I also work for an agency in the State of Florida. I'm from Fort Lauderdale. The Family Network on Disabilities, I'm an advocate, family sports specialist. So I come in contact with parents all the time with varying disabilities. My heart, of course, is with Autism, I'm very active within our chapter, Broward County in the State of Florida.

The key comments that I have is in regards to the Combating Autism initiative and the dollars for Part C, I'm very active within our birth to three program that we have, in Broward and Dade Counties. And the agencies who direct those dollars for Part C are constantly struggling to keep up with our numbers. We were very high incidence within South Florida. We have within just the two counties, over 5,000 students within the public school system with Autism and when we meet with the birth to three providers, they don't know how they're going to continue to meet the demands, given the dollars that they're given and we're having to do a lot of partnerships with the school district, to try to figure out how to manipulate dollars, to provide the services for the little guys.

And I think that while the home model and the family model from Part C has been good and very beneficial, in many instances within our state it has allowed the Part C provide to sort of have a hand in saying, well, we're not going to provide ABA, we're not going to provide therapeutic interventions within the therapy center because everything is in the home. Well, if mom has a three-year-old with Autism, a five-year-old running around and an infant in a high chair, it's very hard for somebody to come in and teach them ABA. When am I going to do this with my three-year-old with Autism. So, while yes, it's been a good model, there are still deficits within that.

Also, in regards to the stimulus package, and those dollars, I find that since it's only the two years, school districts, often times, they don't even want to talk about the dollars because they're thinking, I mean, my superintendent for one, is trying to figure out okay, how can we spend those dollars because they're non-recurring funds.

So, we're looking at training, we're looking at classroom setup and design, those things that will be here for the long haul. But, it's not going to provide, you know, additional para-professionals, additional teachers, anything that's going to up and go away in two years, because we'll build up a system and then in two years where are we going to be. We're going to be full of due process cases is where we're going to be, because when the district starts pulling out, we can't afford that anymore, and the needs can't be met and we're in an ugly place. Thank you.

Mr. Grossman: Thank you, Stacey.

Audience Member: Hello. I'm Bethany McNamara and I'm speaking on behalf of the New England Center for Children, a school for individuals diagnosed with Autism. And we're proud to be an award winning program that has provided educational services to people with Autism for over 30 years. And in that time, we have become very familiar with the challenges facing individuals with Autism, their families and their care givers. And because of this, we feel that we're in a unique position to speak to the question, where can I turn for services.

The Committee has already noted the overwhelming need for greater access to empirically verified treatment and teaching procedures nationwide.

We have two main points that we'd like the Committee to consider. The first being that an effective science for teaching individuals diagnosed with Autism already exists. Applied Behavior Analysis arose from the application of a rigorous science of human learning and hundreds of scientific studies published in -- journals have validated applied behavior analysis as an effective method of teaching and treating challenging behavior.

The first sub-question in the strategic plan, where can I turn for services is, what types of services and support should I seek. Of the myriad of treatment and educational choices available, the science clearly supports applied behavior analysis. When the IACC indicates that valuable limited funds for research should be dedicated to one type of services support, they are taking a risk, hoping that these funds will result in research that improves services available to individuals diagnosed with Autism.

Because it is a proven approach, and one in which research aimed at further advancing and improving services continue, we urge the IACC Services Subcommittee, try saying that again, to advocate for the allocation of research funds to support research in applied behavior analysis and in particular, applied behavior analytic research designed to improve curricular and methods for teaching individuals with Autism.

Secondly, although effective services exist, they are in extremely short supply. And we also urge the Services Subcommittee of the IACC to advocate for research on the dissemination of empirically validated services and the training of service providers. Thank you.

Mr. Grossman: Thank you.

Ms. Blackwell: Thank you. I just wanted to mention that Lee and I have already asked the larger committee, the full committee, if we could devote some time at the October meeting. I want to say it's October 23rd or 24th, Susan. The 23rd, to have a couple folks come in and present about the different therapies which exist under the umbrella of applied behavioral analysis type treatment. In fact, one of those people was going to be Ted Carr, who we had planned to have at the meeting this week. So, if you check out our October meeting, hopefully we, our plan is to talk to our fellow committee members and have some presentations about these various types of treatment.

Audience Member: Hello. Thank you for the opportunity to speak. My name is Nancy Chronin. I'm from Maine. I wanted to answer the question where can I turn for services and twist it a little bit to how do I access services.

In Maine, you access services through going through multiple different departments, and then receiving multiple different plans. For instance, for early intervention services, you would receive an IFSP or an IEP. And then for your in-home support services, you would receive an ISP, for a service plan for afterwards. These plans are not coordinated, they are sometimes working against each other.

And it seems that the well-intended people, and there's a lot of wonderful people in Maine who run these programs, are really trying to do their very best, but they're answering to reporting requirements and funding requirements from the Federal Government. And what I'd like to ask is to find ways to provide services in an integrated model.

The other example I would give is transition services. In Maine you might have an IEP for school, an ISP for in-home services, an IPE for labor, a CP for case plan, if you're in child welfare. Each one of these plans requires the parents to go to different meetings, monthly or quarterly, where they are asked the same questions and their data is entered into different places and similar people attend each meeting. And that's really overwhelming to families and I think it's overwhelming to the people, the professionals as well.

So, I really thank you for looking at research and I ask you not just to look for evidence-based research or implementation of research, but also to provision of that research. Thank you.

Audience Member: Hi. My name is Amy Wallace. I'm a mother to a nine year old son, Hunter, who has seizures, multiple gastrointestinal disorders, is very low functioning Autism. My husband and I have committed our life to helping him and other families in our area. We're trying to live the American dream, besides dealing with Autism. We have a small business. We struggle daily with insurance issues. We've been refused insurance for our son and now must rely on Pennsylvania Medicaid.

We have plans for our future for him and we're doing everything right. We do a quality home therapy program, because we've given up on the effort that the school system has made for us. We travel as far and wide as we can to get the medical services that he needs because we're refused them at the local and state level.

We are using evidence-based practices that all of your research is about, but what do I do to pay the bills and to pay for the 30 to $50,000.00 we spent last year alone, out of pocket, on medical services, not on Autism services. We went to Penn State

Hershey Medical Center with a child who was self-injurious and aggressive, covered in bloody sores, saying help us, and we were refused care. I had to travel out-of-state, pay $4,000.00 out-of-pocket, and in one month's time my son started talking again. I should not have to pay for those services for my family.

So, all of these dollars are wonderful, but what are they doing for our families now. And there's no comments.

Mr. Grossman: I will comment, because I know how hard it is, it takes incredible courage to get in front of us and to explain that to us. And that really is the purpose of the Services Subcommittee, to look at the delivery of services. We know how important that is and services is extremely broad range of activities. And we're trying to get our footing, this Committee is trying to get its footing, to figure out how to best handle this incredibly complex and incredibly comprehensive issue. It cuts across so many domains. And we're struggling with it. You sharing your story like that is really the types of things that we need to hear, because it puts it all in perspective, how hard it is and how the families are struggling.

Ms. Blackwell: And I would add that I think that every generation of parents, and Lee and I have talked about this, makes things better for those that come after. So, there has been great progress that's been made in the past 30, 20, 10 years and I hope that your efforts will continue that going forward.

Audience Member: Hi. My name is C. K. Best and I'm an MSW Licensed Clinical Social Worker. I work in Illinois with Central Illinois Schools. I service nine school districts, 24 schools. I've been in the field over 30 years and I thank you for all your information. It's such a huge, huge job what you've taken on with Autism Society, what every agency working with Autism. Even though I've been in the field a very long time, it really hasn't been except the past few years that I've been educated myself. And I know that's similar with my colleagues, that's why there's hardly anybody here from the schools that I work in. Out of the 24 schools that I work in, there's three people here.

And I find that public relations is a huge thing, as far as, and I know this has been talked about in the workshops, but I think it will be almost a mandate that your Committee take on to continue public service announcements, not just in the month of April, but educating the public on Autism. The little shows that were on, the Today Show, the little PSA's are invaluable, and it stops at the end of April.

I called our media where I live, they weren't even interested in doing a series on Autism, even though I was going to have several people lined up. College-aged students, young people, typical students know very little about Autism. My own student said mom, if you hadn't been telling me about this I wouldn't know anything about it.

That's a whole area we need to look at is educating young people, not just people on the Spectrum, so that they know how to treat their fellow students in college and in the work place. Somebody alluded to work place, there's huge work place issues with people on the Spectrum, not just in getting hired but in not getting fired for their typical behaviors.

There was a university professor at a university where I work, recruited from the East Coast, Department Chairman for less than a year, fired. His whole family, he's still looking for a job, and I know it's because he's on the Spectrum. And he had become a friend, I wasn't able to ask him specifically, but I know it's because he was on the Spectrum, and it had probably not been shared with his colleagues. Although universities are supposed to be a harbor for Spectrum people, there's still a lot of discrimination in the work place, and that I think should be a task that maybe your committee look at.

And as many parents have talked about residential issues, I guess I'm asking you to expand your committee, hope springs upward, but mandates come downward. The education area, huge, they will not do anything unless there's mandates. And we all know that the individual teacher makes the biggest difference.

I hold my breath for all the kids I work with, with the teacher they're with. And sometimes it comes to the end of the school year and that kid is almost moved into a behavioral program, an EDBD program, and we hold our breath so that we can get till the summer so that that child gets a better teacher the next year. That's another issue.

Education, still there's a lot of discrimination in the education area towards children on the Spectrum. They are under diagnosed, they are not over diagnosed yet, at some point maybe they will be, but they are severely under diagnosed in a lot of areas.

Pre-K, we're doing a good job with. Lots of money for pre-K. Those teachers go to workshops, okay. Elementary through high school we do not do a good job with. Those teachers, and God bless the teachers again, it's hit or miss, but the principals and superintendents, where are they. Are there any superintendents here, are there any State Board of Education Directors here.

I would ask your committee to involve the Department of Education at a much greater level. Get those State Board of Education Directors involved, because teachers and principals, you have to hit them over the head sometimes and they still won't be interested. It's that compassionate teacher that makes the biggest difference in the world in that child's life. So, if we want things to change in education, it's got to be mandated.

Also, before any child is moved to a behavioral disorder program, which is now ED in Illinois, they should have to prove that these evidenced based practices have been used with that child on the Spectrum. There are too many children in our alternative schools simply because of behavior. And I would challenge this committee to do a survey of our alternative schools, not just in Illinois, but around the country, who have no checks and balances. There are no checks and balances on alternative schools that are run by co-ops, okay. Nobody's looking at them. For most school districts, it's out of sight, it's out of mind. They're in the BD program or they're in a residential program, it's out of sight, out of mind. And that has to end.

These school superintendents who do not choose to educate themselves, it used to be mandated. You will go to workshops, you will be certified in Autism, not just our special ed teachers. They are dumped on. God bless our special ed teachers. The paperwork, they get dumped on, they have to solve every problem in the world. The principals and the Board of Education, the State Board, they get off. Now again, I'm sure there's a lot of good ones, but I think systemically, again, I think your committee needs to expand more people in education.

And where's the Department of Children and Family Services here. Where are the people that put a cap on the group homes. This comes up over and over. We have, and just like some people said in the previous meeting, when you're 18, forget it. You won't even, you don't have a chance in Illinois of getting into a group home. Not a chance. You might get in-home services, maybe, okay.

Where are those people that regulate the group homes here.

We need more integration with services. It's all about integration of services as you're saying. And this is not a critical comment, but as I'm looking at all these power points, you'd think we'd have wonderful services. You'd think, wow, what a great, you know, we're so great. But, you know, I've been in the field forever, and I'm still, I still am confused by who's doing what, where, why and how.

Same with diagnostic and assessment. I was hoping to see a really good workshop here on diagnostic and assessment, and there isn't one. These is such a mix of how kids are diagnosed, what protocols are used, who's doing it, who's qualified to diagnose, what is it. You know, we had to start our own team. There is an eight-month waiting list in the State of Illinois to get a child seen at the Autism Program in

Springfield. Eight months. They have one clinical psychologist who does the evaluating. One, for like a 25 county region in Illinois. One. Eight months.

So, our school district decided, because we were harping about this, well then, you guys diagnose. And so they created an, I'm sorry, I'm going to wrap this up. I just really, really encourage you to expand, okay. And I think part of this is we're all growing in our awareness, and it used to be kind of a closed system. We need to really expand, really educate the public and really push those schools to do what parents need done and we all know it needs to be done too, it needs to be mandated. Thank you.

Mr. Grossman: Anybody want to comment?

Dr. Houle: I actually would like to hear more comment. It is a complex system and the layers and layers that are built upon the system makes it very difficult to do that.

Really, the OSEP has state monitoring teams that come out to each state and do verification and site visits, every three years to each state. And I'm going to give some of these issues to that monitoring team to see if they actually are looking at the issues that you people are bringing up education wise when they go out and monitor a state. So, I'm interested in hearing.

Mr. Grossman: Any other comments from the panel? I guess I'll comment, just because I'm still getting over the last person. Because I'm hearing a recurring theme here, and, in my position right now, standing up here, I'm representing the Services Subcommittee and I somehow at times feel conflicted in my day job being with the Autism Society. So, I'll try and bridge those two sometimes dichotomous roles that I'm playing here.

But the recurring theme that I'm hearing between these last two speakers is one that certainly in the Autism Society that we've picked up on and it almost seems as though, let me take that back. It doesn't seem as though, it is that this community is discriminated against. We believe this is of a global nature and our civil rights are being violated. For somebody to have an obvious medical problem with their child and not getting served because of the fact that they have the diagnosis of Autism, in most cases, is discriminatory. It's a dreadful act. It's inhumane. And these are things that we have to change. Listening to that person.

The second person talking, we have systems that aren't working. They're not seamless, they're not comprehensive, they don't coordinate and what happens is families struggle and the people that should be served are falling through the cracks. And we really do need to change this.

I appreciate the comments that are coming forward because this, again, it's the feedback that all of us here, the public members, the federal representatives, need to hear so that we can start correcting this, so that we can coordinate it. And we do have numerous conversations about how we can do that. It is rather daunting and it will be something that can't be changed immediately. I know it gives little solace to those families that now have a child with Autism. It certainly gives a little to myself with a 21 year old son with Autism, that the problems that exist now aren't going to be ones that we're going to change immediately. I've usually taken the tact that it will take about a generation for us to implement the types of services that need to be in place, to really, to make a meaningful difference.

The problem is, is that we have to stop treating Autism like it's the weather. We can't continue to talk about it and do nothing about it. We have to do something about it now, and start immediately to make these systems change so that they do work for all of us.

Ms. Blackwell: Lee, I mentioned earlier our announcement of notice of proposed rule making, but at CMS, we are committed to serving people based on need and irrespective of a diagnosis, and we are moving very swiftly towards creating a system that, you know, is person centered and really looks at needs to deliver services. That's where we're headed and certainly hope that we're not discriminating in any of our programs based on disability. It isn't even possible under the statute. So, anyway, we are really working hard to transform our system to look at how services can be linked to need.

Audience Member: Hi, my name is Tyler Whitney, I'm a Clinical Psychologist, from Boise, Idaho. And I sit on the Continuum of Care Subcommittee for the Medicaid redesign in the State of Idaho. I also have probably one of the largest practices with a university style center for treatment of Autism. And unfortunately, have not been able to bridge the gap between Medicaid and private funds. And so the majority of my private practice or center patients are insurance. I want to talk about two experiences that I've had. One just this last week. I work also with ICFMR Homes, and those are intermediate care facilities for the mentally retarded. And they seem to be the dumping grounds for some of the more moderate and severe, profound individuals with Autism Spectrum disorders.

One observation is that I had the distinct displeasure of Monday night receiving a phone call about a 13-year-old in acute crisis. Now, this individual is a ward of the state, does not have a guardian, and that's how he ended up in the ICFMR Home.

But he was having some medication changes and because ICFMR primarily are required to disclose the DD diagnosis. In the emergency room we called every psych facility in the Treasure Valley population in a 40 mile perimeter of about 500,000 and as soon as they heard DD, no one had a bed available. So, we called the state hospital and they have a crisis team with crisis beds that is available from eight to five and this was not falling between those. And then when we called the next morning, they said it's really not a crisis team. We would like to support this individual in a home. Well, when you have an individual that's having severe reaction to medication and coming off of medication, another medication, it just wasn't acceptable.

So, I'd like to make a pitch for using that example, as well as the following example. More understanding in terms of Medicaid and other federal agencies of dual diagnosis, because it's been my experience over the past decade or so, since my fellowship training, that as individuals decompensate and their Autism becomes more and more unmanageable, and I'll just mention two of the very, very primary types of developmental factors, socialization and communication. They can flip diagnostically into a psychiatric primary diagnosis and a developmental delay, secondary diagnosis.

I had a call yesterday from a 24 year old young man who informed my front office staff that he was sitting in his tub with a toaster and if he didn't get to talk to me, and this will be his third inpatient hospitalization because we handled it as a crisis call.

But, I would implore the Committee, I understand the difficulties with bureaucracy, and I deal with that trying to be supportive and helpful being duly licensed in Idaho and Utah, I understand that it's going to be 2011 before our Medicaid redesign is finished, but I would tell you that there are not enough providers and there are not enough individuals that understand the significance difficulty with dual diagnosis and that if people don't get their needs met and they do have specific disabilities, that they very quickly decompensate and become what I would consider critical and in crisis and at that point, not to have a place for these individuals to go is appalling to me.

Ms. Blackwell: At CMS, I should just let you know that we do not only have an internal mental health team, and we talk a lot about people that have dual diagnoses. I'm a social worker, we have a number of other mental health professionals on our internal mental health team. We also have a mental health technical advisory group where we meet with our state partners about once a month to talk about mental health issues. So, there may be a liaison at your state mental health agency that you might want to talk with to see if that person could also bring those issues to the technical advisory group, because these are the sorts of things that we talk about.

Audience Member: Lastly, I just

wanted to thank ASA because I really feel like I benefit by coming to these conferences and hearing what other states are doing. Thank you for your time and for your effort.

Audience Member: Hello everyone. My name is Chris Filler, and I'm from Ohio, Ohio Center for Autism and Low Incidence is where I work professionally as Transition to Adulthood Coordinator. But I also have a son who's 25, who has Autism and so my comments are really from both personal and professional.

First of all, he is one of those individuals that qualifies for Medicare and Medicaid, and so we're entering into that area. And even thought I am Transition to Adulthood Coordinator, it is incredibly difficult to manage all of the variety of service systems that we need to. And that's not anybody's fault, in fact, I appreciate the services that are available to him and the potential services and supports that could be there. But managing it is incredibly difficult.

And, across the State of Ohio, I hear the same thing from a variety of people, including and probably more so, the education folks. Our transition coordinators, intervention specialists, they truly do not understand the adult services that they're transitioning individuals into. Not that they don't want to, it's just difficult. It is incredibly difficult.

And so even though we have some road maps and we have a number of web sites that give good information, they are incredibly difficult for families and other professionals to navigate.

One of the things that I'm wondering, suggesting is, in looking at the variety of individuals in different agencies that are there to help coordinate services, they do very well coordinating services within their agencies, but not necessarily the ones that they are also having to coordinate with.

And so looking at sort of that cross-training and developing capacity and understanding of those individuals within those different agencies of their coordinating bodies, that would be incredibly helpful. And that does include our education folks as well.

I think that on a state level, I see that understanding developing. But as some of our colleagues here pointed out, the trickle down to families doesn't seem to be there. And so as you start looking at how do we get that message out, I really would encourage you to look at that trickle down.

One other quick point, and I hear this moreso from my colleagues around the state, from various agencies, is that one of the areas they run into that are difficult in adult services is the definition of disability, and how that varies from place to place in terms of eligibility. Whether you are disabled, if you cannot work, in some cases, and other cases we're looking at functional ability. And so, sometimes that gets in the way of folks being able to access the multiple services and the work incentive.

So, I just want to put those out there. And once again, I am appreciative of what is being done in an attempt to give the services and supports to our transition aged youth and adults. I think it's the coordination that is so difficult. Thank you.

Dr. Houle: I just wanted to thank you for your comment and, you know, each agency has to do their part to make this transition thing work better. And from a parent point of view, I know that our parent centers have been focusing a lot of resources on the transition to adulthood work for families of children with disabilities, so I would encourage you, they do conferences, they have specialists available. So I would encourage you to go to that Taalliance.org web site and find out what the parent training and information centers have going on that might be able to assist from our agency's point of view in collaboration with the other agencies.

Audience Member: My name is Phyllis Shingle, I'm from Albuquerque, New Mexico. I have a 16-year-old son with high functioning Autism. He was fortunate to have some very good early intervention programs that have helped him to be able to function on lots of levels and to do some really, really cool things.

I do have some concerns about both of those questions that you have up there. My concerns have to do with where can I turn for services and what does the future hold, because those are the things that we're focusing on with my son.

As I start looking at his future, what's his future adulthood going to look, I find that the service system for adults are not set up for individuals who have Aspergers or high functioning Autism in any way. So, as we start looking at his adulthood, we start looking at a life without a lot of services. Fortunately he is on a waiver program. We've very fortunate in New Mexico to have a self-directed waiver, which we're, the -- program which has been a wonderful blessing in our lives and in the lives of many families.

I do find concerns, though, about where are the services. A lot of the services aren't there and I see concerns when I also work as a social worker with the hot line where I answer questions from families around the state about where do they turn for services. And I'm hearing a lot of families who have children with high functioning Autism and Aspergers who are unable to qualify for the waiver programs. And I hear it over and over, we were denied again, I appealed, we're denied again, over and over again. And I have concerns about that and I would urge you as a committee to look at that and how our children and our adults with high functioning Autism and Aspergers are not being provided services. And they're kind of caught in the middle between, you know, not needing maybe extensive services, but still needing those supports in place. So, that is my plea to you. Thank you.

Ms. Blackwell: Medicaid, as I said before, was designed in 1965, so although we have come a long way, in 1981 Congress changed our statute to permit home and community based services to be substituted for institutional services under some circumstances, including waivers. Medicaid has many different waivers, but for the, instant discussion, we're going to talk about home and community based waivers, and you are absolutely correct. There is a requirement that to receive services, a person must be at institutional level of care. So, it makes it quite difficult for states under the way that the statute is constructed to serve people that are not at institutional level of care.

There are some mechanisms in place. There was a law passed by Congress, the Deficit Reduction Act that included an option for states to provide home and community based services under a different part of the statute to people who are not at institutional level of care, but few states have exercised that option to date and so it really again harkens back to where do you live. There are some states, Connecticut, perhaps Massachusetts, that have created state based programs to serve people who are not at institutional level of care, including people with Aspergers Syndrome.

But I do understand that it is a very fragmented system and I think that perhaps one way to approach it is through your state legislature and also to continue to lobby the Congress to change the law so that people can be served based on need and not institutional level of care.

Audience Member: Well, and I'd

certainly encourage you to continue supporting the self-directed services that I've been an advocate for, for a lot of years now, is because that does seem to be a way that lot of our individuals are able to access services that they weren't able to get on --

Ms. Blackwell: And I wholeheartedly agree with you. Most states are moving in that direction. I think it's a, and I will talk more about self-direction, but agency based do not always deliver services the way agencies deliver services, so self-direction and participant direction are great ways for families and people with disabilities to grab that brass ring and hire, fire, just really increase the quality of their services, and do it more cost effectively. So, it's great that your state offers that and if folks are living in a state where those options aren't available, I urge you again to pay attention because you can control what happens in your state.

Mr. Grossman: We're going to stop, to keep our promise of addressing internet inquiries and Dr. Daniels is going to read a question that came in.

Dr. Daniels: We have a comment from Dave Hoyda, the state was not mentioned. Why do you not require individual states to put federal matching Medicaid funds back into where they are used and not into a state's general fund. Why do you not require individual states to put federal matching Medicaid funds back into where they are used and not into a state's general fund.

Ms. Blackwell: I guess I'm a little bit confused by the question, Dave, but I will harken back to the Medicaid statute which requires that states pay for half the cost of the services they provide, generally half the cost, actually it comes through a very complicated formula called the Federal Matching Assistance Percentage, FMAP for short. But I'm not, I don't quite understand.

States are generally required to pay half the cost of these programs and then the Federal Government pays the other half. CMS, my agency, has to approve the services and the state dollars have to come from state appropriations.

Audience Member: I want to thank the committee members for all the important work you're doing and thank you for the time listening to us here. My name is Amy Whitehead and I'm from Wisconsin from the Children's Youth with Special Health Care Needs Program, University of Wisconsin, Madison. And I'm also a parent of a 25-year-old with a developmental disability, not on the spectrum.

And I'd like to just address my comments to the two questions there to say the more that you all can think about building an integrated system of supports for families so we don't create and encourage more silos across disability and condition lines. We are fortunate to have a Combating Autism Act initiative grant in our state and I just want to commend HRSA for that because it's, the way they designed it, is we're really required to integrate education, health, insurance, everything together and I think that's so important when we're designing services to make sure that we're not creating silos.

And I want to say I've just, I'm working with this Autism grant and I'm learning a lot as a parent of a child with a developmental disability, cerebral palsy, I'm realizing that actually the issues are so similar and everything I'm hearing is so applicable to my own life as a parent, which just again reinforces to me the importance of creating integrated services of supports and not separate services for separate disabilities or conditions. Thank you very much.

Ms. Strickland: Let me just take this opportunity, thank you, Amy, I really appreciate that. As Amy said, she's one of the Directors of Children with Special Health Care Needs Programs that exist in every state and territory. Amy also said she was the, that Wisconsin is the recipient of one of the Combating Autism Act grants that we support. And I just want to take this opportunity to let you know the other states, because I neglected to do it when I was speaking, but they are Alaska, Vermont, or I'm sorry, not Vermont, sorry Vermont, Wisconsin, Utah, Illinois, Washington State, Missouri and three new ones in Rhode Island, New Mexico and New York. And that's in addition to Wisconsin. There are only nine. We're really hoping to expand that program because as Amy said, it's an opportunity to try to integrate the different service sectors so that we don't have these silos.

Mr. Grossman: Thank you for bearing with us too. I've noticed since less bodies are in the room, that the temperature has dropped, the ice is growing precipitously in the pitchers up here, so, just bear with us here. Sorry.

Audience Member: Hello. I'm Lisa Kowalski and I'm from Michigan, and my comments are about people with disabilities as a whole and children in special education. It's really not specific to Autism, although it would serve everyone with Autism.

And it's about this theme of integrating services starting in education, but then working in the transition planning with agencies and community services and local businesses to employ people.

Everyone in Michigan, by law, has to have an educational development plan, and that means the word everyone, all. And yet so many kids in my son's Autism programs, it's kind of not used because they don't see the benefit and how helpful it would be. But that's because of the way it was written and is currently used, which is what this, I hope you guys could do to help change.

There's a national program that's widely used by schools called Career Cruising, and kids go into this data base and they put their interests in and then it tells them what career opportunities might fall in that plan and then they can continue to change that year after year. But, did you know that there isn't even one career that is not at least a high school diploma. Now, that to me is discriminatory. My son goes in there, he is not going to get a high school diploma. He has an IEP, he's going to be in the system and he will not graduate with a Michigan high school graduation requirements. We know that. Well, what good is Career Cruising if it isn't going to show you anything that doesn't have a high school diploma.

So, I would really like, it would be great if they could receive some kind of a grant, and they probably don't even realize they have the problem, okay, of using career choices that don't require a high school diploma. Now, think of the consideration then of how a teacher might decide to actually do transition planning and then agencies would already have a heads up on the careers to put that kid into, which is Michigan rehabilitation does and community mental services, or whatever it's called, CMH, all that sort of thing.

Now, in conjunction with that, there are some other barriers that we have, the way the laws are written in Michigan for education to work outside of the box. There's a wonderful idea going on locally in my community for transition planning into a college. These are for the higher functioning kids who will get their high school diploma but may not be very successful in college due to social issues, the Asperger kind of problems.

So, they have like a two-year transition program to teach the kids how to be successful on campus. They are not getting college credit, they are learning how to be on campus, how to be socially correct, how to get everywhere they need to go, how to use the transportation to get there and back. It's all independent skills so that, and how to be in a classroom successfully, the whole bit, at the college level.

That's a wonderful idea. There shouldn't be roadblocks to making something like that happen, but there are a lot of them. And again, that would help feed to successful adulthood abilities.

And then the final one, there's another really great project going on throughout the United States called Project Search, and if more of these kinds of programs, or something along what Teach does where it's vocational skills systems being taught by people, that would be great as well. Project Search works with a local business, the school and community agency all pool their resources and they train kids how to do a job that is a full, regular job, but has a real high turnover rate. A lot of complicated but repetitive tasks, like in a hospital setting where you have to sterilize equipment, it has to be done right every single time, but it's really boring, but our kids thrive in that kind of a thing, and they get complete full wages for those jobs. Everyone benefits. If you go and look up Project Search and all their success stories, more things like that should be happening. Thank you.

Dr. Houle: I wanted to say that I totally agree with you and one of the things bearing out evidence-based effective programs and practices that are available in the era of transition. And the decisions on which programs to choose are usually made by a local school board and so I'm thinking about it, and you may have already done this, you know, gathering some groups of parents who feel the same way as you do, and present some options to those programs that aren't working for your kids for the school board to select. There is a fair amount of research going on and there's universities that are testing programs and you've gone on and identified some. So, I would encourage you to advocate for the selection of really effective tools in a group with possibly other parents, with your school board or whoever is responsible for selecting those kinds of programs.

In the Higher Ed Act, when it was re-authorized recently, has some provisions in it for expanding access to higher education, which is not exactly what you were talking about, in that the program that you wanted some more vocationally oriented or job oriented programs for children who were not going to have a high school graduation. But the Higher Ed Act is getting out there, there's some provisions in the Higher Ed Act that universities are paying attention to community colleges, any accredited higher ed institution to enhance the access for people with disabilities.

So, this is a great area for parental advocacy. We can do some things at the federal level, but we, by statute and law, are prevented from selecting or mandating a particular method or program for a state or a school district to use. It's all set up, you know, schools have local controls and the states have local controls and nobody wants to give that up to a federalized system at this point in time, but our politics is local and so that might work to your benefit, to get some of these changes implemented. And the ARRA money, this is the other point I wanted to give, can be used for those things, and I think there is some information on Ed web site for states and how to select, and I know in professional organizations like ASHA and other web sites have how to select materials and programs to buy with ARRA money. So that would be perfect, as well as improved, I mean, it would be a great expenditure for your school district, when they flow some of that ARRA money.

Audience Member: The money is already spent. The school district used it because of the non-supplanting part that got put in there.

Dr. Houle: It's available, the money for special ed can be used for anything that's allowed under IDEA and there are some non-supplanting clauses in the law, so I'm not sure how that really worked out for them.

Audience Member: Hi. I'm Liz Roth and I'm from Montgomery County, Maryland. And I guess the first thing that I want to say, and it's going to hit the life span of people with disabilities, Autism and other disabilities. So, I really, like somebody else spread over all of the disabilities.

The words are continuum in education and options, that we need to have various options in our education. And as school systems are closing down various options for the students, we are already seeing those students falling behind from where they were the year before.

In this continuum, a lot of parents really want inclusion, but inclusion with proper supports, not just put into the classroom and say, gee, he's included because he's sitting there in the classroom. That is not really inclusion. We need people in those classrooms to help those kids and to help the teachers, and the other kids in the class to work around these children who are being included.

I want to make sure that the option of learning centers stays around and a lot of school systems, including my own, are trying to close out learning centers. And I will fight to my dying day for this to stay as an option. This is where our kids are king of the hill. I mean, they do everything that kids in other schools do. When you get included in a regular school, you aren't afforded all these options. You're given the promise, yeah, your kid will be a part of it, but my goodness, if you're not really on top of it and shove it down their throats in the different schools, you lose those particular options, the child loses those options, not you.

But I know all of these from experience, and we want our kids to be in schools where they're respected, and not bullied or made fun of because they have a disability. But for some of our students it is very good for them to be included all the time.

Our son Andrew is an adult and he's 29 years old and we have had very good services. Andrew has run the whole gamut of services. He was in very segregated classes, schools, separate schools, classrooms that were included in separate schools, classrooms in regular schools, and he was in his home high school for high school. I never thought he would be there, but they wanted to program for him, so we did this.

Andrew did not graduate with a diploma, he graduated with a certificate. Andrew is one of these with splinter skills, as so many of our kids are, that he had never taken tests before, but they taught him to take a test and to fill in a bubble page. And he started passing the Maryland State tests for graduation, and one of them, I said, there's no way, how could he ever. He did. I said, he can't take the fourth one because it is our choice that we don't want him to have a diploma.

I feel, unfortunately, that having a diploma could hinder some of our kids who need services for the future, from getting some of the services. And I know Andrew is one of those who really needs support. He can't go out and be on his own, never, never. So, that was a choice we made. He did graduate and walk across the stage and all this, and it was great. But these are things that we have to choose.

Andrew lives at home. That is by our choice and his choice. We've asked him if he'd like to move to where his friends are, that he grew up with, we visit them in their homes, and he says no, he'll go home. But, on occasion, he tells us he wants to go live at the Comfort Inn in Gathersburg. And I do not have any idea why this Comfort Inn, because I've never stayed in a Comfort Inn. But, you know, they come up with weird things.

But, another thing that I do want to say about the adult services, because I've been working for lifespan services for people with all disabilities since Andrew was ten years old, and working to get different classrooms in schools for everyone, to get new service providers. And we really need a lot of help with getting more service providers out in the community so that our kids can be in, or adults can be in the community, but get the services. And we've got to some way get to other people to start new service providers.

Andrew is with a service provider and he has vocational services and supported employment, and he has part-time paid employment, which is a pain in the neck, if you really want to know, and sometimes I say I'd rather everything be all volunteer. Because then you have to deal with your SSI, filing your papers every month with Social Security, and then you're constantly getting notices from Social Security saying we're changing this or you're going to lose services because we don't have any information on a year and a half or two years, or whatever, when one, everything's been filed with them, every single month, that's one thing.

You go down for your meeting with them and there's nothing in the computer and so they say we'll sit here and we'll put all this in, you come back and they go over it with you, give you the computer run out of all of this year and a half's worth of information, so everything is set, you know. So you won't lose services, don't have anything.

Four months later, you get a letter. You have to come in and have a meeting because we don't have any information in the computer for over two years. Bring everything with you, you have to bring originals, do not bring copies. We keep a copy of everything and we keep originals and whatever. So, my husband always has, you know, a packet like about like that, and takes it with him.

So, before he gets to go to that meeting, another letter comes, you have a meeting, and it's going to be the following week on the same subject and gives you all the same information. Okay, go for the meeting, sit in Social Security for an hour and a half and the guard says, they'll call your name, you have an appointment, whatever, whatever. So, finally somebody comes and takes pity and says well, didn't you have an appointment. Yes. Well, who's it with. They go get Mr. So and So.

You don't have an appointment with me. You aren't in the computer. I don't know anything about it, but come on back here and let's look in the computer. All the work that was done four months before, which we have the computer run out from Society Security, none of it's in the computer. Not one piece of information. I mean, so much time is wasted. So, they do this again, but he's not in the computer for having a meeting with this man this day, at all.

So, we get everything done. This man says I'll put it all in and we give him the packet and everything fine. And no, you don't have an appointment with me again for next week. They send out so many letters and so much money and time is wasted for them and for all of us. And it's really a shame that we can't help them to get their act together to do this.

So, that's what our life is about. And, I mean, I live my life and my husband lives his, for helping people with disabilities and older people to get through the Social Service System. So, I think we live at Social Service and Social Security most of the time.

So, I just want to tell you about how our experiences are there so that if there's any way you guys can help on this, and I'm happy to help anybody, I live near Washington, D.C. and Silver Spring and NIH and everything else. And thank you, but just please make sure we have options in the school system too for our kids. That is so important for them to feel good and be respected all the time. Thank you.

Dr. Houle: You deserve a round of

applause. Thank you for everything you do.

You probably remember, you've been around, our former OSEP Director, Tom Hare, very dynamic guy, and he always said, and it has to become a practice, he always said, inclusion is not a place. Inclusion is access and services. We always have to remember that. So when, you know, a child always, he's included. Well, it's really not determined by the place, it's not a place.

Audience Member: I know, and unfortunately we're seeing, I mean, we, Montgomery County, Maryland, was Mecca. Well, Mecca is not Mecca, okay, anymore.

Thank you very much.

Ms. Blackwell: Hi Liz. I've known Liz a long time. I've known Liz since I was a young mother of a child with Autism. Now I'm an old mother of a child with Autism. I just wanted to say that I, you did flag one issue that I think is really important, and it is the issue of provider training for children, youth and adults with ASD, and certainly that is an area where there are a lot of unknowns.

I wanted to mention that CMS sponsors something called the Direct Service Worker Program, and on our web site there are some very interesting papers that you might want to take a look at because it is a challenging issue, especially in the adult services system, not just in schools. But, we are doing some work in that area that I think is exciting.

Audience Member: Thanks Ellen. Take care.

Mr. Grossman: Thanks, Liz. We're going to miss you, but don't go too far away.

Audience Member: Hi. My name is Peggy Helm-Quest and I work for the Wisconsin Maternal Child Health, Children in Youth with Special Health Care Needs Program. And in the work that I do, I look at integrating many of our services with children with special health care needs within our Department of Health Services. And recently the GAO Report on Seclusion and Restraint, I would like that to be addressed as it is a disparity among the federal and state statutes in regard to the use of seclusion restraint in regard to children and adults.

And what I'd like to address is the aspect of Medicaid and the guidelines on seclusion and restraint for the adult population as opposed to the seclusion and restraint for children in residential treatment, foster care, day treatment facilities, as opposed to schools. Children are receiving school based Medicaid covered services in the school system. Medicaid is paying for these services, yet at the same time, schools are exempt from the seclusion and restraint regulations under Medicaid. This is a disparity.

The GAO Report highlighted ten children in that report, and probably more than half of those children had Autism. Many states are looking at seclusion and restraint within their own state statutes and Wisconsin is one of those. And recently the Wisconsin came out with a report, my son was highlighted in that report, as he was secluded and restrained in school.

This is something that I would like the Autism Society of America and all of you folks up on the panel, to really look at the issues of early brain development, trauma informed care and the issues of seclusion and restraint being done on our young children and how then they are progressing into teenage years and adulthood with anxiety, trauma and how that then affects their life, and especially for those who have Autism, where anxiety and person relationships is damaged at a very young age.

So, I would certainly like the issue of federal legislation for children in the issues of seclusion and restraint to be addressed. Thank you.

Mr. Grossman: That's a very important subject. As you know, the Congressional Hearing that Congressman Miller had hosted went on addressing the issues in the GAO Report. I'm going to refer you to Jeff Zell, who is in the beige suit in the back, who's working, literally on a daily basis, with Congressman Miller to draft legislation to address these problems with seclusion and restraints.

Ms. Blackwell: I also read the report and it certainly was, you know, for those of us who saw it, extremely disturbing. I just wanted to touch base with you on your comment about Medicaid. It is in fact true that some Medicaid services are provided in school settings. Children who are enrolled in home and community based waivers cannot receive Medicaid services through a waiver in school settings.

And our home and community based

waivers have very strict quality requirements that we go through with our states to make sure that children are safe. Children who are in institutional settings in Medicaid are generally in settings called PRTF's, psychiatric facilities, treatment facilities for children under 21. And we wrote a very strict set of regulations and conditions of participation for those facilities because we knew that children were being restrained and secluded, and in some cases dying.

So, you know, we are absolutely committed in our programs to making sure that our beneficiary's health and welfare is assured.

Mr. Grossman: Okay, we're in the last 25 minutes of the Town Hall Meeting, so time flies when we're having fun and freezing our, I won't say off, but thank you.

Audience Member: I'll try to be concise. My name's Gail Chodron. Are you shivering? I am cold.

I work with, I'm a training and outreach specialist with the State of Wisconsin for the state's demonstration grant. I'm also family faculty on the MCH LEND Program at the Weissman Center, at the University of Wisconsin, Madison. I'm the parent of an eight year old, almost nine, diagnosed with Autistic Disorder. He's very high functioning. We've done well at getting services for him. We have good access in Madison. So that's sort of the perspective that I'm coming from.

When I look at your questions, where can I turn for services and what does the future hold, I notice in the aspirational goals, the words community, and obviously family is a basis for, family and community is our basis for individuals with Autism getting access to what they need.

And I suppose that I want to share a perspective that shifts the focus a little bit. I think it's easy to think about services for individuals with Autism, how a family can access the services for individuals with Autism, how we can get our professionals trained to provide services for children with Autism.

But, when I think about, what does the future hold, I really think about the families and the communities and the states, the whole country, having the environment and the contacts that enables us to support. In reality, people have talked about what works in reality, what's really going to make a difference, that enables these individuals to be supported thoroughly.

And I learned a hard lesson, a lasting lesson. In my parenting experience, my son is very high functioning, very bright, he also has the, an astounding capacity to bring a whole school to a standstill and accomplish getting one on one support for himself, if that's not written in to the plan.

So, I have done doctoral work, I

thought I was well prepared to sort of research what works, I can to it, no problem. So, it was easy to look at the material and figure out what would work. I've worked as an educator, so I also know how to teach. But I found that there was one determining factor in whether I could support my son or not, and it was how I was doing, where my well being was.

When I was doing well, well, let's start with when I wasn't doing well. When I'm not doing well, it really doesn't matter what best practice or evidence-based practice, whatever visual schedules or whatever I might use in the home, it wouldn't really work well.

And when I was doing well, when our family was doing well, those things could be helpful, and even beyond that, my own creativity and insight and being able to listen and look and learn from him, enabled me to come up with things I hadn't heard of before. And I think that's really important.

When I think about the Region 5

Meeting in 2007, the Medical Home Autism State Planning meetings that we had, I was really struck by, you had all these stakeholders around the table for each state, and what really mattered the most, it wasn't just the ideas that were coming out, it was can these people sitting at the table work together and fell okay. Do they feel hurt, do they fell like they can make a contribution, do they feel okay, or does it feel adversarial, is it just rife with conflict instead of cooperation and teamwork.

As faculty in the LEND Program, we're very concerned about people being able to actualize their own capacity to learn how to work with teams, to learn how to support a family so that the family is able to do what they need to do.

My own personal lesson is extended to our team with my son. After I learned the lesson that I needed to care for my own well being, we went forward with the teams that my son had. And when they didn't have access to what they needed, when we were in a year, for instance, where we were afraid the school would be closed because of budget cuts and the teachers didn't know if they were teaching in this classroom or they'd be moved to different schools, what was going to happen.

We totally failed to do anything supportive. He didn't succeed, the teachers weren't happy and there wasn't success there, and it was certainly much more difficult at home. I think the lesson I took from that is that we're all in a boot together, even though sometimes it feels like, you know, we're opposite opponents in a boxing ring or something.

But I guess I would really encourage, just like we've done the State Demonstration Grants, which allow us to take a look at the state level and say, okay, what makes it work here. What enables a state to move forward and support these individuals and their families, to look at those concentric circles that surround an individual, the family and the community, and maybe with a strength based approach, looking at what's working, to allow. What's going right in different places and what can we learn from those as models so that we can support everybody and ultimately support these individuals with Autism through their life span. Thank you.

Mr. Grossman: Just looking at our time here, we do have a hard stop at two because we have to clear this room for a program that starts afterwards. So, we're going to take the people that are in line now, I think there's somebody behind Marsha. She'll be the last one on this side and because of the, here we go, there is somebody there. It's hard to see because of the spotlight. We'll stop on, whoever's in line now is what we're going to take.

And if you could please, so that

we can get everybody in by two, be a little bit more concise please. Thank you.

Audience Member: I'll be quick. Thank you for all listening to us, that's great that you're here to listen to us. I'm Susan Morantes, I'm the Operation's Director at the Dan Marino Foundation. I do have a son that's 19 years old with Autism.

Just quickly one of the things I want to talk about, we run a summer steps program for over a hundred young adults 15 to 21 years old, for eight weeks. They get paid minimum wage, they work 30 hours, they work five days a week. The self-esteem level in those eight weeks rises phenomenally. It is funded in part by CSC and the Foundation CSC's Children's Services Council. And this year we worked in collaboration with Work Force One through the ARRA stimulus money to add 20 more interns.

The thing is, the problem is is that some of them go back to school, but a lot of them do not. They call us in October, asking us when we're going to start, you know, having our program, when are they going to interview and everything else. So, the things that we need, plus we get 300 applicants, and we have a hundred positions, so what we need is more programs like this. Then we need a continuation year round of these programs. There are some like Search, but in Broward County, it's a very, very small number that are able to be accessing those programs.

And then we need to know the research of does this work. We see on a very limited basis that it does, but you know, we try to get jobs past that program during the fall and, you know, continuing on into adulthood, but it's tough. And so we do know it works because kids have gotten jobs, but we don't know that it will work in a, you know, wide variety of positions and locations.

The other thing with those jobs, they're actual jobs, they not carved jobs.

They do, they are on duty, so some of them have gotten hired in those positions.

The other thing is we would like to see, you know, more school programs, like Project Search that do continue that. And just one other things, the SSI, we run into major problems with that with our kids. Every year they work eight weeks, they have to go back into the offices and that kind of thing, so I certainly see where that's coming from.

And the one other thing, diploma options. We, I have a child that could possibly have gotten a regular diploma, but I had to choose not to because then he would not be eligible for services any more, and he needs them. He's bright, academically, but needs those services past that. So, it's really a catch-22 with the schools. If you get a diploma, you're kicked out the door and if you do, you know, if you don't, then you might not be able to get a job like someone else had stated earlier.

So, I want to offer the foundation support, input, anything that we can help you with. We're very interested in moving into the adult arena, which we have. Michael Marino is now 21 and doing great. And out kids from the center have grown up and they're all adults, so whenever we can offer our support, we would love to. Thank you.

Ms. Singer: Could you just describe briefly the types of jobs that the kids in your program have over the summer.

Audience Member: There's 24 sites, it goes from clerical to custodial and everything in between. We have some computer programmers, but we have, my son loves animals, the work he can do. We have libraries, a lot of hospitals, so the positions there range from everything, you know, filing, data entry, custodial, cafeteria.

We have the YMCA, so we have several different camp programs which many of our kids love working with the other children, and we do have Camp DNC, which is where the interns are actually working with younger children with Autism. So their perspective there has been really phenomenal because those kids really do look up to our interns. And so, it's, you know, it's a phenomenal program, but I don't know of another one and everybody needs one. So, that would be a good thing.

Audience Member: Hi, my name is Alan Kurtz, I have a brother with Autism, I have a good friend who's an adult with Autism for whom I guardian, and I'm a former special educator, and I work for the, right now for the Center for Community Inclusion and Disability Studies at the University of Maine.

And when I think about what does the future hold, one thing that concerns me, and this is related to the issue of research too, is that I spend a lot of time in schools, I spend a lot of times with adults with Autism Spectrum Disorders, and in some ways it seems like there's a narrowing of the options in terms of educational strategies that are being used. And I'm on a state-wide committee in our state, looking at evidence-based practices and I'm not speaking for that committee certainly, but we've been working on this for a year and I guess, one of the conclusions I think seems pretty clear is, that we don't know what works for all kids. That there are those kids in certain sub-groups for whom certain approaches aren't going to work and who, then those who those approaches will work with.

I guess my one concern I have is there have been four peer reviewed studies that have come out in the last year, looking at early intensive behavioral intervention, and I think they all pretty much come to the same conclusion, and that is that, and I realize the ABA is certainly much bigger than EIBI, Early Intensive Behavioral Intervention, but we know that it works well for a number of kids. But I think those studies all came to the conclusion too that there are a number of kids who it doesn't work for.

And I think a third conclusion in all those studies was that we really don't have strong evidence comparing comprehensive interventions. And so, what I'm hoping is, what I hope to encourage is that as you're promoting research, that we begin to do some really high quality research, comparing comprehensive intervention so we know what works and for whom it will work. Thank you.

Mr. Grossman: Thank you.

Audience Member: Hi. My name is Amy Dawson, I'm from Minnesota, and I have a son on the Autism Spectrum, who also has a lot of special health care needs. He was medically fragile for first couple of years and luckily has gotten much, much better physically. And in fact, his Autism has also gotten better. He turned six a couple weeks ago, and looking at you specifically, Ellen, because I really want CMS to hear this message.

One of the presents that he got for his birthday was a book by Archbishop Desmond Tutu called God's Dream. And he asked me about it, he says, what does this book say on the cover, mom. And so I read it to him and he said, he sort of looked thoughtful. So I said, what do you think God dreams about. And he thought for a second, he says, ducks. And I said ducks, why ducks. And he says, because God loves ducks.

What's amazing about this story is two years ago he couldn't talk. He had less than 30 words that I could recognize. And now, his full scale I.Q. has gone up 26 points in two years. He's talking, we can go to church, we can go to the grocery store. He's on track for best outcomes. Forty-eight percent of the kids, according to this study, have achieved best outcomes, typical I.Q., don't need supports and services at school, and no longer meet the diagnostic criteria for Autism.

And I really hope that CMS will become a leader on this issue. I know that the National Institutes for Mental Health, on their web site and in publications, affirms IBI as evidence base. So does the Material Child and Health Bureau, so does OSEP in a study that it funded, so does Autism Speaks and so does Autism Society of America. And I hope that the IACC, that's a lot of acronyms, will not shy away from resoundly affirming IBI as evidence-based.

Also, I want to make this last point. You can't answer the question where to turn for services without answering the question, how can families afford the services. A lot of my work is helping families figure out affordable access to the treatments and therapies that they choose for their children, after looking at the body of evidence. And again, we need CMS to be a leader on that.

I think there's too much talk about shifting this burden to schools, they can't afford to do it. They do stand to save a lot of money, but the really, the biggest stakeholder here is CMS. The average lifetime cost of an individual is 3.2 million dollars, and we can reduce that by two-thirds with effective early intervention.

So, CMS is the biggest, stands to win the most and we really need you to be a leader across the country on this issue. Thank you.

Mr. Grossman: Yes, sir.

Audience Member: Thank you. I'm Robert Nausif, I'm the parent of a 29-year-old with Autism. I've been through all the wars. He doesn't talk, he lives in a group home. But I'm speaking to you as a professional psychologist as well.

Mr. Grossman: Where are you from?

Audience Member: Philadelphia.

So, he had good services, you know, ever since he started flapping. So, I wouldn't cast aspersions on our educational and medical community.

But I have some concerns about the research going forward, particularly in terms of family strengths and what the realities of the challenges are. We see widely reported in 90 percent or 80 percent divorce rate in the Autism community, but that's actually a myth. There's no source for that.

I think it wouldn't be hard to look at some of the family variables in the longitudinal and population studies that are going on. I think to add those variables would give us, you know, important information.

And from the point of view, I have another interest in men in fathering, and I think if people believe the divorce rate is 80 percent, then they believe men are leaving their kids, and abandoning their kids and don't care, and that's just not true. That is just not true.

So, I think to get the evidence on this is not that hard and would really help our community and our society. So, I'd really urge that and, you know, that's my piece. Thank you.

Mr. Grossman: At 4:15 today, myself and Dr. Jim Ball will be doing out annual father support group and we'll be exploring exactly that and the reason why these marriages generally do fail. It would be great to have you there to give us, to add your voice to the room.

Hi, Marsha.

Audience Member: Hi Lee. Hi. I'm Marsha Eichelberger. I am a parent of two children with disabilities, one who's on the Spectrum, he's 16 years old. I wasn't going to speak today, so I don't have my comments and I'm kind of nervous, so I just want you to know that. But I wanted to say a couple of things.

People often times think Santa Barbara is this very affluent community and we do have that population. But we also have a population of very low income mono-lingual speaking families. And culturally, I kind of looked around the room today in this Autism study conference, and as you can tell, we don't have a lot of folks of color here. And I forgot to mention, I'm the President of the Autism Society in Santa Barbara we well. And we have difficulty reaching out to those families.

I just want to tell you a little bit, a real quick synopsis of my history. We moved to Santa Barbara and my son was diagnosed and we immediately took action to try to figure out to do and wanted to go after a research evidence-based program, which we did.

And tried to work it out through the schools, were unable to do that. Ended up having to go into a due process situation that took us two and a half years, fighting, it was probably the most grueling, emotional thing I've ever dealt with in my life and I really didn't want to go there again, and it appears that I may have to with my other child now.

But, interestingly, and this is kind of for the OSEP lady here, what's happened in Santa Barbara is we won our due process, we had this great program, and they were afraid to give it to us originally because they thought it was going to be very expensive, everybody was going to want it and guess what, people really didn't want it because the wealthy people don't want to argue with the school, so they just go out and buy it. And then the mono-lingual, low income families are afraid. Culturally they don't want to step up and ask for the services.

And so it's kind of this weird, these middle income families who finally this year, came together our of frustration, and went to the school board meetings. And we've been going since October. The families had to ask to have an outside investigation of our special education department. Why did it have to get to that. I mean, why did it have to get to that. And so, the report has come back, the Fiscal Crisis Management and Assistance Team did the report, over a hundred pages, over a hundred recommendations. And I think that the key phrase in there was systemic dysfunction.

So, here we have, we have no Autism services in our district, And we're this little insulated bubble, and now we don't know where to turn because pretty much we have no administration right now. The administrators have left for a variety of reasons and we've had seven special ed directors in eight years. And we now have an interim administrator, that just was hired last week. I was asked to be on the interview committee and we can't find anybody with enough skills to take over what's going to be a, I mean, this is it. This is going to be their job description, you know.

And so, I guess with between being very worried about the California budget, because all hell is going to break loose here because this thing, we have no money, and the services, they're going to start going away from the schools, they're going to start going away from the regional center side and I don't know what's going to happen to our kids.

But I'm very worried that we're not even going to be able to find leadership to come in because our district's been messed up for so long and with the state that our state is in, is anyone going to come from outside the state into California to do this.

So, I'm just worried for our kids. And I think we have to, I agree with everything everybody has said today, and I guess the last thing I wanted to say is one of the reasons that I was afraid to stand up here is because, and this is the white elephant in the room that a lot of parents face is retaliation. And it's not just parents, it's teachers and it's staff and it's DIS providers who want to do good for our kids. And this isn't just where I am, I mean, this is I think a problem across the country where if people do stand up and advocate for children, a lot of times they do get slapped down.

And so I don't know how that happens, I don't know how you have, I know California has legislation to protect teachers. I don't know how you protect parents from that situation, but these are just weird comments and things that didn't come up. But I'm thinking about our mono-lingual speakers, I'm thinking about the retaliation piece, I'm thinking about it should never have to get to the point that we've gotten to in Santa Barbara, now hoping that we're going to find some white knight to come in and take charge. So, that was it.

Dr. Houle: I agree with you. It sounds extremely dysfunctional. I don't know what kind of school boards you have there, elected, appointed, I don't know how the local government runs, but one thing that I am going to do is try to connect you with the parent training and information centers at your, in the greater Los Angeles area. And I know there are some community parent resource centers as well that specialist in providing services to mono-lingual families. And so, and they also do advocacy, so it's not, it won't be you as an individual per se, it will be a federally funded parent training and information center coming in to advocate.

Mr. Grossman: Wow, our last person, and thank you for your patience.

Audience Member: Hi. Thank you guys for being here and for listening. My name's Christy Steel and I'm a student at Northwestern, interested in pursuing a career in the Autism field and so turning the question around, where can I turn to to become a service. I've had a lot of trouble finding resources about what kind of Autism therapy trainings there are, what kind of opportunities there are for young people who haven't fallen into it because their parents and kind of stuck to where they are with their family.

So, earlier Richard Fink suggested a tool kit for pediatricians and for parents and so I just wanted to throw the idea out there of a tool kit for young people who may be interested in pursuing a career in this field and what kind of options and services are available, rather than just being aware allies, but people actually working in this field.

Dr. Houle: If you will use my e-mail and e-mail me your contact information, I will e-mail you the list of programs that provide student support and funding for students to get Master's Degrees specializing in working with children on the Spectrum.

Ms. Blackwell: I think that Towson University in Maryland also just announced an initiative to help train college students to prepare specifically for working with adults with Autism.

Mr. Grossman: And there's some very good resources here as well. I don't know if you saw, I think Barbara Becker-Cottrill was speaking either yesterday or today. She's from Marshall University and she started the first Autism specific program in a university many years ago. And she was giving a talk on exactly that, and how to prepare people with Autism, to go into college, but also how to prepare college students to enter into Autism services. Barbara Becker-Cottrill. It's at 2:30, oh, okay. Thank you, Ruth.

Just to do a little twist on the old Mark Twain saying, what he said about San Francisco, I can now say that I've spent the coldest, I spent the coldest winter of one summer in Chicago. And with that, I appreciate your time and patience and for closing remarks, I'm going to turn it over to Ellen.

Ms. Blackwell: Well, I'm going to make this really short. I hope that everyone who came today got a copy, this lovely bound copy of our strategic plan. It's also available on the NIMH web site, and please keep your comments coming. As Susan said, there's now a special link to provide comments on the strategic plan. As we said, we have regular meetings of the IACC and regular meetings of the Services Subcommittee.

They're all available live on the internet and we take comments for those too. So, I hope that everyone going forward will help us and participate in those meetings and last, but not quite last, but I'd like to thank the support staff from the National Institutes of Mental Health, not just Dr.

Daniels, but every one who came with her and provided us with lights, camera, action, computers. What a great job and what a monumental endeavor and also last, thank Lee for being our host.

(Whereupon the above matter was concluded at 2:00 p.m.)