U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

2011 IACC SERVICES WORKSHOP:

ENHANCING SUPPORTS FOR PEOPLE WITH AUTISM AND THEIR FAMILIES: COMMUNITY INTEGRATION AND THE CHANGING DELIVERY SYSTEM

THURSDAY, SEPTEMBER 15, 2011

The Workshop met in the Congressional Ballroom of The Bethesda Marriott, 5151 Pooks Hill Road, Bethesda, Maryland, at 8:30 a.m., Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

PARTICIPANTS:

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

LEE GROSSMAN, *Services Subcommittee Co-Chair*, Advance Enterprises, LLC

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

DANIEL DAVIS, U.S. Department of Health & Human Services (HHS), Office on Disability (representing Henry Claypool)

PARTICIPANTS (continued):

ALICE KAU, Ph.D. *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)(representing Alan Guttmacher, Ph.D.)

LAURA KAVANAGH, M.P.P., Health Resources and Services Administration (HRSA)

SHARON LEWIS, Administration for Children and Families (ACF)

CHRISTINE McKEE, J.D.

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

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

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

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation (ASF) (attended by phone)

ANN WAGNER, Ph.D., National Institute of Mental Health (NIMH) (representing Thomas Insel, M.D.)

LARRY WEXLER, Ed.D., Department of Education (attended by phone)

PRESENTERS:

BRIAN ABERY, Ph.D., University of Minnesota

DANIEL ABREU, M.S., C.R.C., L.M.H.C., Policy Research Associates, Inc., The SAMHSA National GAINS Center

ALISON BARKOFF, J.D., U.S. Department of Justice

GEORGE BRADDOCK, Creative Housing Solutions, LLC

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CHRISTIAN BUTT, J.D., Hawaii Department of Human Services

JUNE GRODEN, Ph.D., The Groden Center, Inc.

CINDY GWINN, Virginia Department of Behavioral Health and Developmental Services

BILL McANDREW, M.A., Community Partnerships, Inc., Anna Maria College

THOMAS McCOOL, Ed.D., Eden Autism Services

NANCY JESS MURRAY, M.S., The Arc of Greater Pittsburgh at ACHIEVA

PIA NEWMAN, Pennsylvania Department of Public Welfare

C. LEE PRICE, M.S., Virginia Department of Behavioral Health and Developmental Services

PRESENTERS (continued):

JENNIFER SHEEHY, M.B.A, U.S. Department of Education

JAMI SNYDER, Arizona Health Care Cost Containment System

STEVEN TURNER, M.S., Adult and Youth Taunton Community Crisis Intervention Teams, Taunton Police Department

NINA WALL-CÔTÉ, M.S.S., L.S.W., Pennsylvania Department of Public Welfare

KATHLEEN WOLFE, J.D., U.S. Department of Justice, Georgetown University

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PROCEEDINGS

8:42 a.m.

Dr. Daniels: Good morning I wanted to welcome all of you to this workshop today, "Enhancing Supports for People with Autism and their Families: Community Integration and the Changing Delivery System."

We are really excited to have all of you here, our distinguished speakers, our members of the IACC and members of the public who are attending, as well as our web audience and our phone audience. So welcome, everyone, we really look forward to a stimulating day.

And I'd like to introduce our co-chairs of the Services Subcommittee, Lee Grossman and Ellen Blackwell and they will be chairing the meeting today.

Ms. Blackwell: Hi everyone. Good morning. This is Ellen Blackwell. I am with the Centers for Medicare and Medicaid Services in Baltimore.

Today is our last Services

Subcommittee meeting under the Combating Autism Act. It's really hard for me to believe.

I think I have been coming to these meetings for about eight years, so today is really a landmark day for me, and there have been so many changes since I first started coming to IACC meetings.

I see a few faces in the room who were around then, Ann, and at that time, I was thinking last night, we didn't talk about services at all.

We talked a lot about the biology of autism, and there were a lot of people at my agency, CMS, who said why is CMS even at these meetings because there is no discussion about services?

So we have come such a long way. We have a Services Subcommittee and now Services has really migrated heavily into -- or did migrate, I guess I should say, past tense, into the IACC meetings.

So I just think that's a really landmark development and I am so happy that things have gone in this direction.

I also wanted to thank Gail Houle, who was the co-chair of the Services Subcommittee prior to my tenure in this role, and also Dr. Daniels, and, as usual, the great team at the National Institute of Mental Health Office of Autism Research Coordination, that got everybody here today, gets all our meeting logistics together, and we appreciate it so much.

So with that -- and also Dr. Insel, our Chairman, who has really hung in there over the long haul.

Okay, Lee, I will turn it over to you.

Mr. Grossman: Thank you Ellen. I am Lee Grossman and I have a 24-year-old son with autism. It's been my pleasure to serve as the Services Subcommittee co-chair for these past four years with Ellen.

I am the longest-tenured IACC member. I have served the full term of both iterations of the IACC. So I have been around since, really, 10 years now, on the IACC, and have seen a number of changes, particularly in services.

When the IACC first began in 2001, it -- we went a good two, two-and-a-half years without services even being on the agenda, and that wasn't for lack of fighting to put it there.

And I was very pleased that eventually it became a priority and we started the Services Subcommittee, and when the IACC was -- when the Combating Autism Act was passed in 2006, which created this latest iteration of the IACC, it was an immediate consideration and action that there would be a Services Subcommittee and that services would be at the table, and then we included all the relevant Federal agencies that are dealing with services across the life span with autism.

I want to thank you all for being here and taking the time for being here. Just so that you know, and also to thank those that are listening by phone, and on the -- and watching us on the web -- these workshops do get a tremendous web -- do have a tremendous web presence.

This -- your presentations will be viewed, if it's like what has happened in the past, by hundreds of people over the next few months, and it will -- and that's really one of the purposes of this workshop is that -- so that it has a life of its own, so this information that you are going to be providing to us, will be out there to the public and will be of value to the community.

I briefly want to talk about some of the discussions that we had leading up to this workshop, and I -- I -- what -- what I rely on is a conversation I had a few months ago.

I was at a conference in the Midwest, and I was keynoting the conference, and as I do normally with my presentations, I leave time near the end for a Q & A.

And one of the people that came up to the mic to ask me a question was a mother of a child with autism, a daughter who was five years old, and she was really concerned about the future of services, and what the future would be like for her daughter, and she challenged me to respond on what it should look like and really where we are with services today in the U.S.

And my response was that I believe the future is now, with services in the U.S., for people with autism as well as other disabilities.

And I say that because we really do know what to do. We know how to serve these people with autism. To simplify it, when we look at the service -- what is required for service delivery in the U.S. today, it basically breaks down into four chunks.

The first one is early diagnosis and intensive intervention, and getting those services started early and having a comprehensive, not only medical but educational and behavioral, and then transitioning that child into an education system and providing the supports that they are going to need throughout those young years in the education systems, so that's the second chunk.

Third chunk is transitioning that child into adulthood and starting as early as possible and hopefully starting much earlier than the prerequisite 14 years of age, so that you can develop an individual that can live relatively independently, have options in their lives and can be gainfully employed or really seek out what interests that they have, the same types of wishes that we would want for any child.

And then lastly, and most obvious,

is the ultimate outcome of what these prior services should be providing, and that is a productive, meaningful adulthood for people with autism and other disabilities.

This room represents some of the best thinking in the country around that subject, people that really know what to do now to make that work.

What we are lacking is in the services -- in the service delivery. It is inconsistent, it's not comprehensive, it's not seamless.

And what we are relying on today in this workshop is for you to present to us some of the best models that are out there and how they are working, and what it will take.

And we are going to challenge you also to provide us with some solutions on what you think that we should be doing from the Federal side to create the type of system that is seamless and is comprehensive, and really does provide for that ultimate outcome of a productive, happy adulthood, where people are not only included in their communities, but accepted into their communities, and living a fulfilled life.

And with that I want to thank you all for being here. We are going to go to our first speaker --

Ms. Blackwell: Actually we're going to take a quick minute so we can take roll call, and Susan can make a couple of simple announcements about the day's progression.

Dr. Daniels: Thanks, so I just wanted to take a roll call of the IACC members who -- first of all let's go to the phone. If you are on the phone and you are a member of the IACC, please let us know.

Ms. Singer: Hi, this is Alison Singer and I am joining by phone.

Dr. Daniels: Thank you, Alison. Anyone else?

Dr. Rice: Yes, this is Cathy Rice,

representing Coleen Boyle on the phone.

Dr. Daniels: Thank you Cathy.

Dr. Wexler: Larry Wexler.

Dr. Daniels: Department of Education.

Dr. Wexler: Yes, I'm sorry.

Dr. Daniels: Thank you, Larry. Is there anyone else?

(No response.)

Dr. Daniels: Okay, and then in the room, IACC representatives, please just announce yourselves and your organization, your agency.

Ms. Kavanaugh: Laura Kavanagh with the Maternal and Child Health Bureau of the Health Resources and Services Administration. Bonnie is going to be coming shortly. I'm just trying to confuse everyone.

Dr. Wagner: Ann Wagner from NIMH representing NIMH.

Dr. Kau: Alice Kau from the *Eunice Kennedy Shriver* National Institute of Child

Health and Human Development.

Ms. Lewis: Good morning. Sharon Lewis, the Administration on Developmental Disabilities.

Ms. McKee: Christine McKee, public member of the IACC.

Mr. Davis: Daniel Davis, HHS, Office on Disability.

Dr. Shore: Stephen Shore, Professor of Special Education at Adelphi University.

Dr. Daniels: And then Ellen and Lee have introduced themselves, and I am Susan Daniels from the Office of Autism Research Coordination at NIMH.

And now I would like to just take a brief moment to go around the room so that our speakers can also introduce themselves, and your organization or agency.

Mr. Butt: Chris Butt, State of Hawaii Department of Human Services.

Ms. Wall-Côté: Good morning. Nina

Wall-Côté, Bureau of Autism Services, Pennsylvania.

Ms. Newman: Pia Newman, also Pennsylvania Bureau of Autism Services.

Ms. Sheehy: Good morning. I am Jennifer Sheehy, Department of Education, Office of Special Education and Rehabilitative Services.

Dr. McCool: Tom McCool, Eden Autism Services.

MS. Murray: Nancy Murray, ACHIEVA.

Dr. Groden: June Groden, The Groden Center in Providence, Rhode Island.

Mr. Bourdon: Keith Bourdon, Taunton, Massachusetts, Community Crisis Intervention Team.

Mr. McAndrew: Bill McAndrew, Community Crisis Intervention Team, Taunton, Massachusetts.

Mr. Turner: Steve Turner, with the Taunton police department, and part of the Taunton Community Crisis Intervention Team.

Mr. Abreu: Dan Abreu, The SAMHSA National GAINS Center.

Mr. Braddock: George Braddock, with Creative Housing Solutions, out of Eugene, Oregon.

Dr. Abery: Brian Abery, with the University of Minnesota's Institute on Community Integration and the National Gateway to Self-Determination Project.

Dr. Daniels: Thanks. So it is great to have all of you here. Just a couple of quick announcements. We would like for everyone to go to the podium for their talk, and in front of you, you have a lunch menu. I would like it if you could all, during some time this morning, just check off what lunch you would like and then somebody is going to come up and pick them up from you. So that will help expedite the lunch because we want to make sure that we stay on time for that. So if you could just check it off or circle what you'd like, the -- some staff members will come around and get those from you. So then, I'll turn it back over to Ellen.

Ms. Blackwell: Okay. I'm going to introduce our first speaker, Brian Abery, who is -- has come today -- Brian is not the person who has come the furthest. We will get to that later. Brian is the coordinator of school-aged services for the Institute on Community Integration at the University of Minnesota.

So Brian, thank you so much for coming. Brian is going to talk about self-determination.

Dr. Abery: Well, thank you for having me here today. I really appreciate the chance to talk to you about a topic that is near and dear to my heart, and along with my colleagues at the National Gateway Project, Mike Wehmeyer, Carl Calkins, we have been doing research in this area now for somewhere in the neighborhood of 25 to 30 years.

And what I am going to try to do

today is to kind of give you a picture of what self-determination really is, why it's important, and how it really can serve as a guiding principle to the delivery of person-centered services to persons with autism, and with any other type of disability.

What I would first like to do is start out by having you ask yourself a question. I'd like you to think about one experience that you have had in your life, where you were not in control but you wanted to be, and in that situation, others exerted control over outcomes that were important to you, and just take a minute and think about how you felt in that situation.

When I ask most people to think about how it helped to not feel in control of those outcomes that were of importance to you personally, the types of responses that I get from people with and without disabilities are: I was angry; I was frustrated; I was mad; I really wanted to do something about it and felt really upset that I couldn't.

On the other hand, think about at least one experience that you have had where you had the degree of control that you desired over outcomes that were important to you, and think about how it felt to be in control.

When I ask most people that question, the types of responses I get were: hey, that really felt good; I felt empowered; I felt like my thoughts, my decisions, my opinions really made a difference.

On the other hand, I'd be remiss if I didn't talk a little bit about the fact that sometimes it is scary to be in control, and if you are a person with a disability who has had fewer opportunities to exercise control, the degree of control in life that you desire, as you were growing up, it can be extremely anxiety-producing to, in your early adulthood, all of a sudden be told that, well, now the decisions are yours.

One of the things that I'll talk

about today is how, when we think about self-determination, we really need to think about it as a life span issue.

So what is self-determination? Well, you know, while it's a $25 word that we have coined, kind of, we think in the 1990s, you know, it has actually been around for a long time, and it emerged many, many hundreds of years ago from that century-old debate about free will and determinism.

I mean, its earliest use that we have been able to document was in 1683 in the Oxford English Dictionary, where it was defined as: "Determination over one's mind or will by itself, toward an object."

Now, John Locke, one of my favorite philosophers, included the concept of self-determination in a lot of his work. I mean, he talked about the basic rights of all human beings, including freedom, equality and the power to exercise their will.

He talked about these rights being

distinguishable from people themselves, and being able to be given up to others, but only under conditions in which the individual gives their consent.

And what Locke said was that in situations in which basic rights are never granted, for whatever reason, or in which the person is subjected to the arbitrary will of others, or those rights are taken away, we basically have a situation which is a form of slavery.

Now, recent conceptualizations of self-determination have basically followed that same line of thinking. Mike Wehmeyer, from the National Gateway Project and the University of Kansas, defines self-determination as "volitional actions that allow one to act as the primary causal agent in their life, and to maintain or improve one's quality of life."

A high school student from North Dakota with autism who we interviewed probably about 10 years ago, I think, said it really well when she said, "self-determination is about believing in yourself. It's about making your own decisions, and being responsible for them."

And then finally, one of my favorite people, my dear friend Irving Martin, once said over a dinner that we were having that self-determination was really about power, choice and, most important, the right to chase our dreams, the chance to direct our lives the way we want to, not the way others to expect us to.

Now, as I said, we have done 25 to 30 years of research in this area, and we have done a lot of talking to people with disabilities, and over that period of time, we at the University of Minnesota's Institute on Community Integration have developed our own definition of self-determination which I would like to share with you now, because it really has driven most of the research that we have done in this area.

And that is that self-determination refers to individuals exercising the degree of control that they desire over their lives within those areas of life that are important to them.

Again, self-determination refers to individuals exercising the degree of control over their lives that they desire within those areas of life that are important to them.

So in other words, self-determination has multiple components and it's different from the notion of personal control, and I think that's where there's a lot of confusion in the field.

I mean, a lot of people think that the more personal control one has, the more self-determined one is. I would argue that it isn't quite that simple.

There's this concept of shared control that all of us experience. You know, most of us don't desire to have total control or almost total control over all areas of their lives.

I mean, we really expect to and appreciate being able to share control over tings with trusted others. I mean, think about those of you who are parents, when you were bringing up your children. You probably didn't want to make all parenting decisions on your own. You wanted to share those decisions with your spouse, with your significant other.

Second, sometimes we can agree to cede personal control to others. In some areas of life a person may not feel that they have the necessary background to make choices or they may just not value making decisions in those areas.

I mean, I think I'm a perfect example of that. You know, I am very proud to admit that I have absolutely no control over my family finances. My wife, who has her MBA, makes all the financial decisions. I have an allowance, and you know something? That's fine with me. I mean, I take up a lot of other responsibilities at home, specifically to avoid having to make financial decisions.

Now, does that make me less self-determined than my neighbor who is an accountant for Price Waterhouse and would love to have his spouse make financial decisions, but she doesn't want to?

I don't think so, because having control over family finances is not necessarily something which I value. It's not something which is important to me, and I realize after many years that my wife does a much better job at it than I ever could do.

Now, of course, that desire to share control, cede control to others or exercise control over something yourself, changes over time.

You know, areas of life which we value having control over at one phase of our development are not things we necessarily want to have control over, or at least complete control over, at other times during our development.

The other piece of this kind of notion of what self-determination entails is that self-determination really has to do with having the degree of control you desire over both day-to-day decisions -- what to wear, what to eat, what time to go to bed, what to watch on television or listen to on the radio -- as well as kind of those more important decisions, those long-term decisions -- where and with whom to work, where to work, what type of work to do. Oftentimes what we have seen is people getting caught up in one or the other of these two, kind of, aspects of decision-making and personal control, and we believe that self-determination entails both of those.

As a matter of fact, our research indicates that for most of the young adult and adults with disabilities with whom we have worked, who have taken part in our studies, is that if you don't have that day to day control, you really don't feel very self-determined.

Now, I would also be remiss if I didn't spend at least a minute or two talking about some of the misconceptions about self-determination, because when we go out and work with residential providers, or individuals who provide work-related supports to people with disabilities, oftentimes, you know, the first response we get about "let's work together to enhance the self-determination of the people you serve" is, oh, we could never do that, I mean there's no way we could do it, there are just too many problems that we would have.

And those kind of reluctant responses tend to be tied to kind of, some myths and misconceptions about the construct.

The first is that self-determination implies the independent performance of behavior. It's the either/or argument -- either the person makes all the decisions and all the choices in their life alone, without supports, or I make them for them.

I mean I think we have come a long way in really taking a look at self-determination as also including shared control.

Secondly, self-determination is primarily about making choices. It's much more complex than that. I mean, we differentiate between making choices in which alternatives are specified for you, and making decisions in which you generate the alternatives yourself.

But self-determination includes a lot additional aspects of functioning, including goal-setting, self-regulation of behavior, advocacy and self-advocacy, and so it is a complex construct and we don't want to oversimplify it.

Misconception number three: that there is a specific set of skills, knowledge and attitudes and beliefs that are necessary for self-determination.

The key word here is necessary. What we found out in our research with individuals with even the most significant support needs is that if we provide sufficient supports, that just about everybody is capable of exercising self-determination.

Well, having a certain set of skills, having a certain set of attitudes and beliefs and a knowledge set can help you, and certainly allow you to exercise self-determination even when the environment isn't supportive.

I would say that there are very few skills, there are very few, kind of, aspects of knowledge that are essential for self-determination.

What we need to do a better job of doing is providing those environmental supports, so that people at all levels of ability can exercise self-determination within the context of their lives.

And misconception number four, and this is a popular one, is that self-determination is a program that you can implement.

It's not a student-led IEP. It's not person-centered support planning, and it's not an independent budget. I mean, self-determination is about supporting people to make the things they want to happen in their lives actually happen in their lives.

Now, over the last 25 years, we have developed what we refer to as a tripartite model of self-determination. In other words, it has three parts.

I mean, we look at the exercise of control that a person has. I mean, how much control do they exercise over various aspects of their life?

We look at whether those areas in which they are currently exercising control are areas that are important to them.

And finally, we try to determine whether they have the desired degree of control over those areas. And really what self-determination is, is when those three circles intersect, when the individual exercises the degree of control that they desire over those aspects of life that are important to them.

Now, obviously, this tends to change over time. Those areas of life that are important for a seven-year-old to have control over, are not the same as a 25-year-old, and oftentimes I think we forget that when we are working with people and supporting people with disabilities.

Now, that doesn't mean that competencies, personal capacities don't support self-determination. Mike Wehmeyer's group, Denny Middaugh's group at Columbia, and our group at the University of Minnesota, has spent a lot of time over the last 25 years taking a look at some of the skills, attitudes and beliefs and kind of knowledge bases that support self-determination.

And we found that there are many things, again, getting back to this notion that self-determination is a relatively complex construct.

I mean, skills alone, the research clearly indicates, of goal-setting skills, choice and decision-making skills, problem solving, self-regulation, communication, social skills and independent living skills, all contribute to an individual's self-determination.

That doesn't even begin to tap into the importance of that set of attitudes and beliefs, that sense of self-efficacy, that sense of having an internal locus of control, and how that contributes to a person's self-determination.

And then, finally, knowledge, I mean, knowledge of resources in the system, in other words, how do you get what you want.

Now, one of the problems I have with a lot of conceptualizations of self-determination is that they place total emphasis on those personal capacities, and then oftentimes it's used as an excuse. It's used as an excuse to not provide people with disabilities with the opportunity to exercise self-determination over their lives.

The missing factor here is the environment, because without opportunities for self-determination, the individual loses their motivation to exercise personal control over their life.

We have also found in our research that many of the skills, much of the knowledge, and those attitudes and beliefs that are supportive of self-determination sometimes are very difficult to develop or acquire, except through real life experiences.

And finally, if we don't have the opportunity to exercise self-determination, okay, those capacities that support its exercise tend to wither away. If we don't use it, we tend to lose it.

So, what we have tried to do over the last 20 years is really take a look at the extent to which self-determination is a result of an interaction between the individual and their environment, using Bronfenbrenner and Garbarino's ecological model, taking a look at that person and their personal capacities, okay, the microsystems in which they spend their daily life, the family, the childcare, school or residential system, the peer group, and how the interaction and the linkages between those systems, can be used to support higher levels of self-determination.

But those systems operate within a larger context -- the exosystem -- in which decisions are sometimes made that don't include the person with the disability, or their family, that have an impact, positive, salutogenic, or negative, pathogenic, on the opportunities for self-determination that that individual is able to experience.

And finally, you have at the macrosystem level, that societal level, you know, ideological patterns, societal institutes, you know, societal attitudes and values which I definitely would say over the last 20 to 30 years have become much more supportive of self-determination.

So, what self-determination really is, is kind of an ecological process, you know, where we have that intersection between the individual and their environment, where personal capacities, environmental supports all work together to hopefully provide the individual with the opportunity to exercise the degree of control they desire over those areas of life that are important to them.

Now, as I said a couple of times, we have done many years of research on self-determination. Unfortunately, we still have a lot to learn, but we have also learned a lot.

What have we learned over those 25

years? Well, there are probably seven or eight things which I think I'd like you to take away from my presentation today that are the most important things to think about when we think about self-determination as kind of a guiding principle for providing person-centered services.

The first is that all persons desire and are capable of some degree of self-determination. Some persons need fewer supports. Some persons need more supports. But I have yet to meet a person with any type of disability, at any level of intensity of support needs, that doesn't desire and have the capability of exercising some degree of control over those areas of life that they deem as important.

Number two, self-determination exists along a continuum, I mean, because of a lack of environmental supports, and the individual having challenges with respect to those personal capacities, some individuals will exercise less self-determination, others more.

But rather than asking the person to change, what we say is we have to ask the service system to change, to provide supports in a way that an individual at any level of disability experiences that basic right to exercise control over areas of life that are important.

Number three, and this is a big problem, we currently conceptualize self-determination as an adolescent and adult issue. I mean, if you look over the years at the number of research projects that have been funded, to really better understand self-determination, you look at those projects that have been funded by adolescents and adults, versus those projects that have been funded to support the self-determination of young children, and it probably is a ratio of about 10 to 1.

Self-determination is a life span

issue. I mean, I believe that our first attempts at self-determination start from the infant cry, because why do infants cry? They cry because they want to change something in their environment.

Now obviously they need support of adults to help them create that change, but that cry is an important piece of communication.

Mothers, within a few months after bringing an infant home from the hospital, report that they can tell the difference between different types of infant cries.

And we know from the child development research that has been done, that that isn't mothers just thinking that they can make those differentiations. It's because those cries have different characteristics and tell the mother whether the child needs to be held, whether the child is hungry, whether the child is frightened.

Self-determination is naturally

reinforcing. When individuals experience self-determination, they want more. So expect those individuals whose self-determination you support to ask for more opportunities to exercise control over their lives.

Self-determination requires the assumption of some levels of risk. Whenever we exercise control, we experience risk. The key is to control or minimize risk, not to attempt to eliminate it.

Again, self-determination results from an interaction between the person and their environment. It always occurs within a social context.

And, finally, we have to understand that the manner in which people view and express self-determination is affected by their family, their age, their sex and their culture.

Now, we know from the studies that we have done and Wehmeyer and his group have done, that there are a number of mediating factors which support self-determination: social effectiveness, one's ability to use social skills and behaviors and strategies to achieve preferred outcomes. Social capital, that network of personal ties, social ties, supports and relationships that we have, whether those are affiliating with others, who share common characteristics, bonding, or bridging, affiliating with others who have different characteristics.

And finally, social inclusion, the social acceptance of persons with disabilities in school, work and other community contexts.

Self-determination is also a moderating factor. I mean, should it be valued in and of itself, or for what it helps us achieve?

We know that people who experience high levels of self-determination experience a higher quality of life, greater employment success, enhanced levels of achievement in school, that self-determination encourages pro-social behavior, and increases personal responsibility.

But when we look at the opportunities we provide for individuals with disabilities to exercise control over their lives, we find that as they grow older, we tend to offer fewer opportunities.

As a matter of fact, in some recent research that we did, we found that, of 50 items on a self-determination scale, okay, 26 of the items indicated that the persons with disabilities who we interviewed were experiencing less control, significantly less control than they desired, where only three items indicated that they actually had more control than they preferred.

The types of areas where they had less control than preferred were major areas of life: decisions about where to live, housemates and roommates and pets; decisions involving finances and money; what to do with their free time; where and when to go out into the community; time alone with a boyfriend or a girlfriend; being able to make a determination as to where they wanted to work and what they did at their work site.

So what we have is kind of this notion of self-determination being a complex construct, that it's a complex issue. I mean, it's educational because it does involve teaching skills. It's psychological because it involves motivating persons with disabilities who haven't been given the opportunity to exercise control over their lives, to take more control. It's a human services issue, you know, providing better supports and services in a person-centered manner. But it's also a civil rights issue, you know, guaranteeing the basic civil rights of people with disabilities.

Now, what we have found is that typical service planning and delivery tends to be driven by available programs rather than by the unique needs and interests of the individual.

You know, professionals are viewed as the experts, not the person with the disability. Professionals sometimes discuss prior to planning meetings, you know, what they would like as a program for the person with the disability, and the presence of the individual with the disability is nothing more than a formality.

Professional opinions tend to outweigh those of the consumer and of family members. And finally, again, while the person with the disability is present, I mean, there are legal requirements for that both in and out of school contexts, they are really supported to effectively participate.

Now, person-centered services are supposed to be based on a set of values and strategies that we can use to assist a person to create a vision for their future and to help work toward that vision.

It's a process that hopefully leads

to a greater understanding of the person's dreams and visions for the future, their core values, their gifts and their capacities.

I mean, it's a focus on persons rather than programs, driven by the individual's unique vision, likes and dislikes, recognizing a person's capacities and building on them, rather than focusing only on deficits. And it's a collaborative, community effort.

In order to deliver person-centered services, we need to understand a person's preferred lifestyle. We need to develop goals based upon their aspirations, their preferences and their cultural background.

We need to commit to outcomes that are meaningful to that individual. Far too often when I attend individualized service planning meetings, you know, I can't tell the difference between the goals and objectives at the planning meeting that took place in 2011 and that which took place in 2006.

And when I talk to the individual with the disability, they say of course it doesn't change. No one has asked me what I really would like to work on in my life.

And it involves a focus and a respect for the right of all persons to control their lives, to the extent that they desire.

So, person-centered planning and services have the potential to support the self-determination of people with disabilities, if they support the person to follow their desired paths in life.

Self-determination also has the potential to enhance the quality of person-centered services, leading to individuals receiving more of the supports and services they desire, and helping them achieve the goals that they envision and view and value as important.

Self-determined individuals are more likely, as part of the planning of services and the provision of services, to create those personal visions of their future, to effectively articulate those visions to others, to consider the various paths they might take to achieve that vision, and to make informed decisions about the paths they desire to take.

So if we support self-determination, we will be supporting the delivery of person-centered services. People who are self-determined have shown us and other researchers in this area that they are more likely to monitor progress towards their goals and make necessary adjustments when they need to.

They can more effectively problem solve when necessary and, just as important, they are much more willing to assume responsibility for their decisions.

So, person-centered services, self-determination reinforce each other, and they are very much consistent with each other, both as values, and as goals which we as professionals need to strive to achieve, do a better job at striving to achieve within the next decade, the next 20 years, the next 50 years.

We have actually come a long way since we started doing work in this area. I am amazed at some of the residential programs that I go into and look at the levels of self-determination that people with all sorts of disabilities are being encouraged to exercise.

On the other hand, just as often, I walk into residential programs and work environments where persons with disabilities have little to no opportunity to exercise self-determination.

So while we have come a long way, we still have a long way to go. And I would like to ask anyone who has a question to please feel free to speak up, because I would love to, at least in the next couple of minutes, respond to ideas or thoughts that you have.

Ms. Blackwell: Brian that was great. Thank you so much. I don't even know how to -- I thought what you said was wonderful, and self-determination came into my house yesterday.

My son has autism. He's pretty severely disabled and I am his guardian. So I heard you talk a -- I mean, I think it's really important to recognize that even in situations where a parent or another individual is the person's guardian, that person always has to have an eye towards helping the individual with disabilities make decisions that are right for that person.

So I, you know, I actually had a situation where I had a physician say Robert can't go swimming, and there's one thing that Robert really likes to do: swim.

So I said, you know what, Robert's going to go swimming and Robert accepts the risk associated with swimming, even though he has seizure disorder, and we will put certain things into play.

So -- but it made me realize that if I hadn't been sitting in that room, that physician would have instructed Robert's staff that he could not swim, and that would really erode his quality of life and so it was just a moment of self-determination.

So this whole idea of guardianship and family members helping people make decisions I think we have to really start to integrate the concepts of self-determination as well.

Dr. Abery: That's a great point. We really need to think of self-determination not as an either/or thing, but with a lot of collaborative decision-making going on.

And we really don't have a lot of research available out there as to how to most effectively engage persons with disabilities of all types and levels of severity in collaborative decision-making.

But I have seen creative staff, you know, do an excellent job of helping individuals who even have, I mean, very limited only emerging communication skills, actively take part in decision-making. Any other questions or comments? Yes?

Dr. Shore: Yes, I think it's great that you emphasized that everybody is capable at least to some extent in self-determination.

It's something that I talk about as well and it's great to see that validated.

Dr. Abery: Definitely, we have worked with individuals with mild disabilities, and individuals who have very intensive support needs, I mean, who, I guess the best way to describe them is they have presymbolic communication skills.

I mean, but if we are patient enough, if we are able to understand the individual enough, and read their non-verbal behaviors accurately, we can get a pretty good handle on you know, what they like, what they don't like, things they like to do, things they don't like to do, and you know, support them to exercise control.

I mean, there is nobody who doesn't communicate, at least nobody who is conscious who doesn't communicate in some way, shape, manner or form.

We just have to be better at figuring out the way that those individuals who have intensive support needs communicate their wants, their needs and their desires to us.

Ms. Singer: This is Alison Singer. I am on the phone. Can you guys hear me in the room?

Dr. Abery: Yes we can.

Ms. Singer: I have a question about really the definition of self-determination, especially because of the example that Ellen just gave, which to me, what Ellen just described is an example of advocacy, where you, Ellen, as Robert's guardian, spoke up on his behalf because you were aware of his preferences.

So I -- maybe you can give us like some examples of an instance or an activity that was guided by the principles of self-determination and how the same experience might play out in the absence of self-determination. That might be illuminating, at least for me, to try to understand the difference between advocacy and maybe supported self-determination and self-determination.

Dr. Abery: Certainly, advocacy was involved in the example that was given, I mean, there's no question about that. And there are many individuals who have few opportunities for self-determination unless they have advocates -- we call them champions -- in their lives.

That doesn't mean, though, that self-determination wasn't involved there. I mean, in the example, okay, there was an individual who had knowledge of a person, who understood that person's needs, their wants and their desires, and that swimming was a very important part of their life, okay?

So what that individual did is support them in that kind of decision-making, if you want to call it, situation to get what the individual knew was something that they value.

I mean, for individuals who have more well-developed communication skills, who can articulate their needs, their wants and desires, that type of advocacy isn't necessary, and sometimes, you know, whether it's staff, whether it's parents, and when we advocate for individuals with disabilities who have the capacity to advocate for themselves, okay, we actually can interfere with the self-determination process.

But in this situation, and I would say clearly it was that knowledge and that background that allowed the individual to really advocate in a way that enhanced self-determination.

It's a problem we have in our service system because of the fact that, you know, if you look at most residential programs, you know, there is such a high turnover of staff, that oftentimes, staff don't get to understand an individual's wants, needs, preferences, desires, to the point that a parent would.

So self-determination is involved, you know, self-determination can be supported by advocacy. But also we have to be careful that sometimes when we advocate for people who have the capacity to advocate for themselves, we can interfere with that process.

In the example, you know, I think it was clear, at least it was clear to me here, that you know, the individual in question, you know, was able to engage in a behavior that they value, that was important to them, that they might not have been able to engage in, if that advocate was not present.

Ms. Singer: But if he had knowledge and was acting on his own behalf, was that advocacy or self-determination?

Dr. Abery: The important part of Robert's situation I think, was that Robert got to experience something in life that Robert values and that contributes to the quality of his life.

So in that situation, I am really looking at advocacy and self-determination as being tied together. I don't see it as an either/or issue, and I don't think that most of my colleagues would either.

So we are talking here about the process and the outcome, and while self-determination is a process, we can never kind of forget about the outcomes, and in that outcome I think it was clear that the outcome was that the person engaged in an activity or was able to engage in an activity, that contributed to the quality of their life.

If Robert was able to articulate, okay, his own preferences, his own desires, I think it's pretty clear that he would have told that physician “No, I don't want to give up swimming.”

Now, obviously, because we have a situation of a parent who understands her child, okay, that advocacy was effective.

Mr. Grossman: Brian I think this presentation was phenomenal, and I appreciate your being here. We are going to have to unfortunately move on. But I am going to exercise a moderator privilege and ask you the last question.

And that is that some people still believe that this idea of self-determination is a notion. As far as I am concerned, I think most of the people in this room, it's not a notion, it's a given right.

How -- what recommendations would you make to us to increase the awareness and acceptance of self-determination? What are we missing on the -- from a service delivery level, to -- to really enforce, to make self-determination an accepted part of society?

Dr. Abery: I think there are a couple of things. Number one, I don't think we have done a good job at communicating to any other group other than parents, the benefits of self-determination, not just to the person with the disability, but to the individual who serves persons with disabilities.

I mean, most parents know that, my God, he is now making his own decisions. I don't have to worry about those. That's a pretty powerful reinforcer.

But for somebody who serves as a direct support professional, or a teacher, okay, I don't think we have emphasized enough that your job will be easier, you will experience your job as more rewarding when the children, the young adults, and the adults you support, start making their own decisions, and those are good decisions, and you can see how it has a positive impact on their quality of life.

So I think we haven't really done a good enough job at that. Number two, I think we really haven't done a good enough job at providing parents, teachers and direct support professionals with a set of strategies that they can use to effectively support self-determination.

It's one of the things that we are currently trying to do now with our research and training center on community living and the National Gateway Project is attempting to do, to pull together strategies that research indicates are effective in supporting self-determination and making sure that we get that information out to professionals in the field.

So I think those two things are probably the most powerful interventions that we can use to kind of change people's way of thinking about self-determination and its importance to people with disabilities.

Thank you.

(Applause.)

Mr. Grossman: Brian that was absolutely terrific. Thank you very much. Our next speaker is George Braddock who is from Eugene, Oregon, who is going to talk about safe and supportive environments for people with autism and I think this is a great -- Brian's topic is a great segue into what George is going to be explaining to us, is how to create these environments where people can effectively exercise their self-determination.

Mr. Braddock: Good morning. Can everybody hear me all right? I really appreciate this opportunity to address this audience.

When I received the letter from Susan Daniels on the 17th of August, she invited me to come here and give this talk, and in reading the assignment, you know, being a licensed general contractor for 30 years and a master carpenter, I always think of things in terms of scopes of work.

And so I very carefully read the invitation and she said that she was inviting me to talk on my work at Creative Housing Solutions and how you are able to provide a safe and supportive environment to people with autism, to live self-determined lives and integrate into their community.

And I thought to myself, ever seen that actor that does Macbeth in like seven minutes? So I thought well, I wonder if I can actually talk that fast?

But it really did require that I step back from the projects that I am involved in -- we have done about 1,500 projects for people with developmental disability -- and try to think of what are the lessons that we learned, and what are the kinds of information that I might to bring to this committee that would be useful to you when you think about policies going forward around the issue of housing.

And I find it very satisfying to be talking about the importance of physical environment, because I believe that we live in an industry that underestimates and undervalues the significance of the physical environment in really obtaining the kinds of self-determined outcomes that Brian was just talking about.

We tend to think of environments as very passive, but in fact they influence -- tremendous influence and sometimes can coerce behaviors and we find that particularly with people with Autism Spectrum Disorder, we expect them to do well and to thrive in conventional environments when they do not live conventionally and those understandings of how we are supposed to act and live in our environments make no sense to them.

So, hopefully I can complete this assignment and not actually talk that fast. So as I said, I am a master carpenter. I have been doing general contracting as a licensed contractor for 30 years.

I am also a parent of a daughter, 25 years old, with developmental disability, and a stepfather of a son, 30 years old, with significant Autism Spectrum Disorder.

So the environment matters and we try to take a person-centered approach to engineering independence. You know, everybody -- if you just talk about designing houses, people just sort of begin to look the other way, but as soon as you bring engineering into it, you know, engineering has this kind of weight about it, it's like figures and facts and numbers and formulas.

So we have adopted engineering. A lot of times it's code for design.

So a huge believer in the things that I have learned from Michael Small and David Pitonyak and the O'Briens, around thinking about person-centered lives.

And my work has really tried to

take those kinds of principles that I really believe in, and wonder what it looks like to actualize them on the ground.

So what is it that we can do in a person's physical world that makes it possible for them to have that kind of self-determination, and to lead the type of lives that they want?

So all of our work comes from a place where we embrace those values in person-centered planning, and we believe that an appropriate environment must be part of an individual's planning.

And you know, I attend a lot of meetings, a lot of person-centered plans, a lot of IEPs and ISPs and the environment is traditionally left out of that question.

It just, it really doesn't come up as a factor and I think that one of the shifts that needs to happen is that as an integral part of person-centered planning, the environment needs to be part of that conversation.

And if we are going to really achieve the kind of values that we talk about, people being truly integrated into our communities, there has to be the kind of housing on the ground out there that makes it possible.

And this is my friend Emory Blackwell, and Emory Blackwell experiences very significant cerebral palsy. He and I consult together around the country, and when I am in Emory's home and we are there together, Emory is a very capable guy in his home. He gets around his home quite easily, he can use the toilet himself, he can work his computer, very, very capable in his home.

And when he and I travel together, it is -- he is a profoundly disabled person. He can't do anything for himself. He can't use his hands.

So everywhere we go, I find I have to do everything, and it's such a poignant example of how environments actually disable people.

He likes to tell the story about being in a room and turning off all the lights and he said you know, lights are accommodations, and we are all just very used to it, but you turn out all the lights and suddenly everyone in the room is blind, and a very graphic example of the kind of impact that environment has in creating disability.

This is a very odd slide and it's actually one of my favorite slides. I am going to spend a little bit of time here.

So this is a transfer platform that was built in what was touted as an accessible home and apartment in Eugene, Oregon, and this is Tracy's apartment.

In 1984, I met Tracy, who was living in a nursing home in Florence, Oregon and the state of Oregon had determined that it was an inappropriate setting for people with developmental disabilities to be in nursing homes.

And so there was a program that reintegrated those folks into community and out of the nursing homes. And I went over to meet Tracy because we had been hired to build a home for Tracy, to remodel an existing home.

And when I met Tracy, the first thing she told me was that she wanted to live by herself and wanted to have a dog, and I told her that I was there to help put a group home together for her.

But she was very determined, and over the years, she moved from a five-person group home into a three-person setting and ultimately, after a very long time on a waiting list, an apartment came available in Southtown, and it was the accessible apartment.

And I will never forget the day that Tracy and I went over there to experience wow, we are going to have an apartment.

And we got up to the front door and

there was a lever lock on the door and the low threshold and we went inside and the doorways were a little bit wider and the closet rod was lower in the bedroom and the light switches had been moved down.

That was it. That was the accessible apartment. And of course it had the requisite tall toilet with the open toilet seat, which we all know is very important in accessibility, and that was the deal, and the bars in the wall.

Well, Tracy couldn't use that bathroom herself, even though she was pretty capable. She could scoot. She had a lot of capacity. She had dexterity. But she couldn't use the bathroom herself.

So every day, for two hours a day, once in the morning and once in the evening, a staff person would come to Tracy's apartment and help her through her morning and evening toilette.

But Tracy, as I said, when I first

met her, said that she wanted to live by herself and she wanted to have a dog, and this was not living by herself and having a dog, because every day this person had to come in and provide the services.

So we thought about it, looked at Tracy, evaluated the bathroom and said you know what, we could come up with a system that would allow Tracy to use this bathroom herself, and do it independently.

And then we went to the state of Oregon, the county at that time, and we said we need $5,000 to modify Tracy's bathroom, and they said oh no, we can't do that.

And we said no, well wait a minute, every day you send in a staff person for two hours a day to help Tracy do her toilette, and that must cost something.

Oh yes, that costs quite a bit a day. Well why don't we just do this and you would save that money and pretty quickly it would pay for itself?

And they said oh no, we won't do that. And it was this great lesson which was, we tend to solve problems in this industry by sending people in.

We send people in to help Tracy do her toilette. We send people in when families are in crisis to help them get through the crisis. We send in support persons and physical therapists and occupational therapists, and those are very important.

But we underestimate the role the environment can play. So we actually built this platform, and for considerably less than $5,000 because we couldn't get the budget, and Tracy was able to make that transfer.

Now, the reason I am dwelling on this, is that in the world of physical activity, you would think that that's a really obvious lesson. I mean if you spend any time in a wheelchair and you roll up and there's a two-inch curb and you can't get over the curb, pretty clear what you need to do: you have got to cut the curb out so that you can get the wheelchair over the curb.

But when you come to the issues of intellectual disability, when you come to situations where people are experiencing significant Autism Spectrum Disorder, you need things to change in their environments in order for them to live the kind of lives that they live, to deal with tactile sensitivity that they might have, to deal with some of the circumstances that are more subtle than the two-inch curb that the person in the wheelchair can't get over.

Well, our system can't quite understand that. But we would argue that the outcome is as profound if you deal with Anna's tactile sensitivity in her home as getting rid of the curb for the person in the wheelchair.

So it's a need for some rethinking about how physical environments need to respond to people with intellectual disability the same way we have actually gotten very much in our consciousness about making things work for people work with physical disability.

So as I said, you know, I embrace the principles of person-centered planning, and these are some lessons that we have learned over time in doing this work.

And the notion that the physical environment can really shift this balance so you know, somebody will say, well, you know, the idea of self-determination, and people being able to have a choice, well, what does that look like on the ground?

You know, what does it look like on the ground, you know, when Connie, with complete access to her clothes, will put them all on?

So how do we deal with that issue? How do we figure out ways that empower Connie, that help her build the capacity, and sometimes it requires that we share that control and I really resonated a lot with what Brian had to say this morning about actualizing self-determination and a lot of what the physical environment can do, is really make those kinds of values possible on the ground.

We believe that by creating environments that will -- that respond to people's needs, and also to their lifestyles and their interests, you really can shift the balance in their favor.

It's really about, you know, people being more empowered. It's one thing to say oh, you can do what you want to do, like Tracy, well you can live in this apartment, but you know what, you are going to have to have two hours of help, or we can modify the environment so that it works for you.

And we have found that if the environment doesn't work, particularly when you talk about people with significant autism, then families are needing to intervene, they are needing to redirect, they are having to take active action, because the physical environment isn't working for the person.

And the disability as a consequence of the environment, I think we have covered that pretty well. And this next point, which is that you cannot evaluate behavior outside of the environment in which it takes place, is really something that once again, in our assessment strategies and how we do person-centered planning, is all too often not taken into consideration, and our environments have, you know, tremendous impact on our behaviors, you know, how we conduct ourselves in this room, how we are in an elevator, how we are at a meeting, is oftentimes very much so prescribed by the physical environment.

And I do a lot of work in helping people leave institutional settings, and try to think about the kinds of housing that would make sense for them on the ground in community.

And I'll meet a person at the institution, and they'll have, you know, a real interesting repertoire of behaviors and ways that they are known to be in the institution.

And you try to do the person-centered plan there, and you'll got out into the community having made modifications and accommodations, and those behaviors are left behind, because they needed those strategies and methods in order to survive and thrive, in these -- in that particular environment.

So it's really important to understand that context when you are looking at it. And you cannot fix a problem behavior in a broken environment.

So, this is a project that we did in California, and the real striking thing here is the performance requirement in both of these cases, in this bedroom, were achieved.

But the notion that the family's capacity to address the issue was limited by their skill base, was limited by what kind of knowledge they had, what sort of information was available to them, in order to make the kinds of changes and the modifications to the home that they needed.

So when they were -- we argue that any time you know, you engage in a person-centered plan, just as all of the individuals that are involved in a person's life should be around that table, the other person and thing that should be around that table is the physical environment, and we call it the other member of the family.

And physical environments aren't passive. People enter into relationships with them for better or worse. You know, I think about my stepson, and he is not really -- we come in this place and we are in this room. You know, Collin would be of this room. The way he experiences this space is at a completely different level than the way we experience it, and this notion that if environments don't work, you have to intervene, redirect or restrain.

And families don't -- this is not what they wanted, and this creates tremendous stress on families, but you know, when they are feel that there are no options, this is very often the kinds of decisions that have to be made, and you see you know, bars on the windows or cribs that lock down, or keyed cylinder deadbolts on the doors.

So I am going to tell a story, and I say very often, that I owe everything to Anna. We began working with Anna when she was seven years old and she has quite a remarkable family.

And we have worked with Anna for almost 15 years now, so we have really had an opportunity to understand how, over time, a person's needs and a person's capacity, really changes, and how the physical environment needs to continue to change to meet those needs.

She had a remarkable family, and when we first got the letter from her Mom and

Dad, they were saying how they loved Anna and that they wanted her to continue to be with the family, but that they just weren't able to do it anymore, that they had gotten to their wit's end, and they wrote this line, "Vigilance and duct tape aren't enough anymore."

Anna was a person who loved water, which is why this is a particularly good photograph of her, and you know, when she was very little, she had to have water running in order to actually eat her food.

And her family were just beside themselves. Anna only slept a couple of hours a day. She would spend as much time in the bathroom as she could. The bathroom floor had rotted out a number of times and had to be you know constantly changed. Her brother had slipped and broken a tooth.

And the family was just wearing down; you know the amount of towels, 30 loads of towels a day in order to keep up.

So we did a person-centered plan with Anna involving the environment and set some standards, and I was saying earlier, how we worked from a project, we do scopes of work.

And so these were the goals that we established in the project for Anna, and the first one is always life and safety, which must be addressed at the very beginning, and reduced stress of workload on families.

You know, the state of Washington recently did a study of out of home placements. So they were stepping back and saying who is it that ends up you know, families break down and the children come into services.

And the number one cause of that is caregiver fatigue. And if you can create opportunities to support caregivers, to reduce the stress and workload on them, the likelihood that those families are going to remain together is increased.

They didn't want to have to be constantly intervening, and Anna wanted to use the bathroom in the way that she wanted to use it, but that there weren't negative consequences.

Sometimes the conclusion is, is that when the environment doesn't work, that it's somehow the person's fault, that that's the reality.

But the fact is, is that Anna loved to play in the water, and it was a very important part of her life, it's what she wanted to do.

The fact that the bathroom wouldn't put up with that didn't make Anna's desire to do that wrong. You know, it only became a problem behavior because the consequences of it, the bathroom wouldn't support Anna using it the way that that she wanted.

So if you can turn that on its head, and if Anna has a bathroom where it supports what she wants to do, then suddenly it's an activity, and that's the difference.

And provide Anna with choices to engage in activities that she wanted and that the place needed to be adaptable and change over time, as families' needs change.

And I think this is another issue we run into where -- Brian brought it up -- you know, we take a snapshot of the person, how they are today, we make it work for them, and we don't anticipate that those needs are going to continue to change over time.

So one of the first things that happened when we were called in is that Anna had begun to bang on the windows, and plate glass windows, and there was a great deal of fear, she had broken the window by her bed on a couple of different occasions.

So the family screwed plexiglass over the window, which you see in that slide up there in the upper left, and the -- it worked from a performance perspective, you know, Anna couldn't bang on the window anymore, couldn't break the glass, but the family wrote and said you know, our home feels like a warzone, and plexiglass is really soft so it scratches up and when you bang on it, it makes a great drumming noise, and you can't open the windows anymore.

So we changed it out to tempered glass, which looks just like regular glass. You can't tell it apart. But it, from a performance requirement, you know, Anna could bang on that window all day long, or kick the window by her bed, and not break it.

Her Dad, Mom, wrote that Anna had begun to experiment with gravity, which meant she was throwing things in the house and breaking the lights.

So at each case, you know, we were able to make modifications to the environment that made it safe for those things to take place and health and safety must always be the first thing.

But at the same time, you know, it

doesn't have to look weird. It doesn't have to be weird. You know, there are strategies that make a place continue to feel like and be a real home.

So this is Anna's bathroom. We spent a lot of time making this bathroom work for her. And in the upper left part of the slide, you can see the kind of constant problems that the family was having -- water on the floor all the time rotted the floor out.

And Anna wouldn't use the toilet, and she was so tactilely sensitive, that the claustrophobic environment and all the different stimulations that were occurring in the bathroom made it impossible for her to be toilet-trained.

So we came in, did that evaluation, and the bathrooms that you see, the two photographs, supported Anna being able to use the toilet herself and to use the bathroom in a way that satisfied her.

The family, you know, needed to know that Anna was okay. You know, it's the first mission of all families, is paying attention to life and safety.

And so it was important for the family to be able to do that, but they really struggled with this notion that Anna, you know, has rights to privacy, but you know, they opened the door, and suddenly she was not engaged in what she was doing anymore, she was engaged in what was happening with them.

So there was a number of strategies that came along, these kind of passive ways of being able to check in on Anna, and have it work.

The -- in the modern day, it's so simple to you know, put cameras everywhere, and to put A phones everywhere, so that our capacity to keep an eye on what's happening and to be on top of people, is huge.

But it really does require, you now, an exercise in judgment. What is it we need to know, and do we have to be that invasive about getting to it?

So one of the things that Anna would do is she would fill her mouth with water and spit it at televisions. And when I went out to the family there were seven burned-out televisions in the garage, and we needed a waterproof TV setting for Anna.

And so this one was built. But the family, once again, realized that that wasn't what -- that wasn't the end of the day, that wasn't the success that they were after. What they really wanted was for Anna to build the capacity to use the television, and use the family TV opportunity in a way that was appropriate.

So over time, now in this -- in this slide here to the right, Anna uses the regular, family TV setting.

And continue to support Anna's particular capacities, in all that time playing with water made Anna a superb pourer of water, and they turned that into a cooking skill, and she is really quite a remarkable, remarkable cook and never spills a drop.

This notion that things continue to change and that the environment supports a person in that way.

One of the things that Anna most loved to do in the world was to swing, and over time as Anna got bigger, with the swing sets needed to continue to change, at one point a case worker got involved and said you know, at Anna's age it's not appropriate for her to be using swings anymore.

And so they took the swings out, and as her Mom said, they took the swing away and Anna went off. And it was important to Anna. It brought her tremendous pleasure and so ultimately swings were built that supported Anna.

She got larger over time, began to need a wheelchair to get around, and so a ramp was created that continued to allow Anna to get to that swing which is something that she dearly loved to do.

So from a financial perspective, there were some dollars that were spent in order to achieve the kinds of opportunities that allowed Anna to live the life that she wanted, and you can see the dollars that were -- that we came to the project, the initial project at age seven, doing a remodel.

And the way these dollars were brought to the project was the state basically made the family a loan that was forgivable over time at 1/15th per year until it was basically zero, and you can see the amount of dollars that were spent.

But had Anna gone into services, and you know, as you recall, when we first got the letter at age seven, the family was pretty desperate, and these are the kinds of costs that would have been associated, had Anna been placed out of home.

As we look down the road at

changing trends, you know, where are people and what's happening in the future, and the majority of people are going to remain with their families, and that is the trend that is moving forward, a tremendous number of people remaining in the family home.

And as we look at the system and the dollars that are available in the system moving forward, we are not going to be able to afford, as a system, to support people in the kind of comprehensive care. It's just too expensive.

So we are going to have to figure out ways of helping people remain with their families, and certainly, doing modifications to the physical environment to make that possible is going to be an important tool in achieving that.

So over these years of experience that I have talked about, we have found that although each individual with autism is unique, and their needs are very particular, that there are actually some commonalities.

And we have identified six common modifications that are most often made, when you look at all of the projects we have done over the years, there is this series of opportunities.

And if you get these particulars right, the likelihood that that person will lead a more satisfying life, and that they will be able to remain with their family is very high.

So, in first addressing the needs of life and safety, and then looking at various kinds of finishes that anticipate the kinds of circumstances that we see for people living in their homes successfully.

The idea of the home as connected, visibility is incredibly important. So when you -- once again I cited the Washington study that talked about when you see out of home placement, what are the characteristics?

You know, number one is caregiver

fatigue. Number two is a diagnosis with Autism Spectrum Disorder with co-occurring behaviors or aggression.

And number three is need for line of sight supervision. And so one of the things in a connected home is making it possible for people to keep an eye on what is happening, and that will tend to reduce that stress, save steps on the caregiver.

So the use of technologies can also help monitor safety. This photograph down here to the -- at the bottom on the right was a pretty important concept when you were looking at supporting a person, you know, in a larger family setting, and we learned this from a father in California whose son had Prader-Willi, and he would lock his son's door at night and had cut an opening through the closet into his room.

So you know, before Russell would go out to raid the refrigerator, he would have to pass right past his father, who would wake up and then could redirect. And we have used that concept a lot, which is the parent at that kind of gate-giver position, to monitor and keep an eye on their children.

Bathrooms. In almost every project we find ourselves doing bathrooms. Essential elements of the bathroom including floor drains, addressing the safety, use of commercial fixtures.

You know, the idea that being able to engage with and to participate in water is really important to many people. It is a copying mechanism. And the bathroom needs to make sense.

Again, a bathroom is a place that requires a tremendous amount of energy to take -- take care of a person in that setting.

The walking loop. Something that we have discovered is really important. Large muscle movement is a very common need for people on the spectrum.

And the idea that they can move

around the house to create these walking loops enables them to engage or disengage as they wish. The idea that you can come in, you know, see what's happening, be involved if you want to, or retreat, and the -- has been a very, very important design feature.

Providing places of control and freedom, where people have, once again, an opportunity to engage. This idea that there are layers of freedom, where people can be in places safely, and be able to come and go, the notion of creating safe boundaries.

Tools for housekeeping. You know, very often this idea that parents are pretty much, they are run into the ground by the endless tasks that they face, taking care of their home, keeping it clean, and these are some strategies that have worked really well to reduce that stress.

And beyond that, those six -- you can identify these very specific challenges, that there are environmental modifications to address each of these issues.

So in closing, I would like to talk about, you know, so once we have figured out and we know that we can create individualized living environments that work and make sense for people, you know, what's next? How do we create these opportunities in community, for the kind of integration that we all know is incredibly important?

And this is a project we did in southern California once again. This is a triplex, and three separate units, affordable housing owned by a housing authority.

And the -- all of the kinds of features that I am talking about, in terms of supporting people you know, with complex needs, are in place here.

But it is not a traditional group home setting, and it -- what it does is it creates that kind of fabric that really works for people in community.

And this is a project that was

actually just opened, named after me and I am not even passed away yet. In it -- once again, it's just this idea of not you know, just doing a home for all people with autism, or you know, too often, homes are designed based on the characteristics of the disability, and so they will tend to group four people with autism in the same house, and oftentimes that's not, not at all the best decision.

So here we have a situation, that is owned by the housing authority of Santa Barbara County, and it is an affordable housing situation that will be available for people long term.

And it supports quite a constellation of different needs. In one end you have a setting that supports a person with enduring medical issues, and what's unique is, is that each of these shared living apartments contains bathroom, bedroom, sitting area, that really allows people to have kind of independence, different supports, not all provided by one provider.

So it's creating affordable and available housing fabric out there in the community.

This is a beautiful setting in Santa Barbara. This is a project that was done in Maryland, once again, this idea of creating affordable stocks, belongs to the housing authority in Montgomery County. It was remodeled, supports people with both physical disability and also folks on the spectrum and very much so in the community, and available and affordable housing that is mixed population.

This is another shared dwelling where this notion of separation and kind of apartment-style living supports a man with very significant Autism Spectrum Disorder, who lives with two women, both of whom use wheelchairs.

And you know, this setting you

know, really responded to the notion of you know, people having the kinds of choice that is out there, and not always being grouped by the disability.

This is a project we did in Salem and this is trying to think about, you know, how do you create welcoming neighborhood and community.

And this particular project is 18 units of affordable housing, 6 units ground floor, barrier-free, 5 of those units are set aside for people with disability.

And the remaining units were leased to a non-profit organization who provide care in the social service industry. So it wasn't strictly people with -- that provide services to people with developmental disability, but it was people who provide services to seniors, to veterans.

And by leasing those to the organizations, they then made them part of the employment package. So a person would go to work for an organization, and then they would have this housing would be available.

And what we were trying to do was sort of engineer the neighborhood, you know, trying to create a situation where you know, people are more understanding, more tolerant, more experienced in dealing with folks with disability.

And they are also kind of criminal background checked. You know, when I watch my daughter go out with her Section 8 voucher and look for housing, I'm often very discouraged at what kinds of opportunities are available to her, and very frightened by who are the neighbors that she is going to live with.

So this is an opportunity to create a situation where there is a common thread of people that are you know, that are experienced, and it has actually worked quite well.

And this is the last project I am going to talk about. And once again, it's trying to think about how do we create these opportunities for real integration into community?

And this is a project going in Aloha, Oregon, and down here at the bottom is a center called the Edwards Center, and it has been, started out as an AHRQ, and has been a place that provides services and environmental opportunities and employment opportunities for people with disability.

And then they have five contiguous building lots attached to it, and we are doing this development on those lots, and the thinking here is, it's quite often you will see developments where they put housing together that makes sense for people with developmental disability, and then that's the only people that are living there.

And so it becomes, you know, identified by the folks with disability there and it becomes this enclave and you know, all too often it's sort of that slippery slope back to removing people from our community and putting them elsewhere, if you will.

In this case, we are thinking about the thread that runs through the project, which is an involvement with disability.

So here, we are looking at families, you know, particularly families that are continuing to support their adult children with disability throughout their lives, and they are getting older and there is this need for community and for that kind of support that would happen in neighborhood.

So this is creating a pocket neighborhood, if you will, where the thread is everyone that would be involved here, would have some kind of connection to the disability community, either a person with a disability himself, or their family, or a sibling, or people that work there.

So the idea is, is that you -- can we step away from the notion that it has to only be enclave and is the fact that we --

that the group would come together because they shared this common experience of disability that is a rich community, is really integrated and is workable for people.

And I think that these are the kinds of alternatives that we need to be thinking about, our system, particularly those people that are providing affordable housing, are not really I think responding in the kinds of ways that are going to create these kinds of opportunities for people to be integrated into their communities.

And does anybody have questions? I'd be happy to answer.

Mr. Grossman: Well we're a little bit late. So George, if you can hang around until the end --

Mr. Braddock: Yes.

Mr. Grossman: because I have a number of questions as well, and I'm sure others do here, and I want to thank you very much. I appreciate the challenge that you face with taking this presentation, which I have seen you give over multiple hours, into a 30-minute time frame, and I certainly, I think a lot of us have questions about -- about how you do this.

Certainly later I -- during the Q&A, just so you can think about it, I'd like you to address what you have seen in terms of the people that you have served with disabilities and with autism, how, by putting them in a mixed environment, that's not diagnostic-specific, how that's affected their lives.

Thank you very much.

Mr. Braddock: Thank you.

Mr. Grossman: We are going to change the schedule a little bit, because I am sure that people would appreciate a break right now. So we are going to do that and we are going to shorten it from the 15 to 10 minutes, so if you can be back here in 10 minutes we are going to continue. Thank you for your patience

(Whereupon, the Subcommittee members took a brief break starting at 10:13 a.m. and reconvening at 10:27 a.m.)

Ms. Blackwell: So I'm going to actually introduce our next speaker. I am going to hope that the Justice Department wakes us all up after lunch, okay?

So our next panel is a great topic that we have actually had a lot of discussions about in the IACC Services Subcommittee, but no presentations on.

So we are really happy to have with us today Dan Abreu who is with our partners at SAMHSA. As Dan knows, Larke Huang is our IACC member from SAMHSA.

Dan also works for Policy Research Associates, Inc. And he is going to talk with us about the National GAINS Center work and diversion.

And then following Dan we will introduce our next presenter, who is also -- I am very happy to have with us today the Taunton, Massachusetts Community Crisis Intervention Team, the people who do a lot of the on the ground work for criminal justice diversion, including diversion of people with disabilities.

So, Dan, I leave it to you.

Mr. Abreu: Okay. Thank you very much, a pleasure to be here, and thank you very much for your invitation.

I am with policy research and policy research operates the National GAINS Center, the SAMHSA National GAINS Center, which is funded -- funded by SAMHSA to provide technical assistance to states and communities around co-occurring disorders, people with co-occurring disorders in the justice system.

So we provide technical assistance. Right now, our current project is we are providing technical assistance to 13 states who have veterans -- diversion programs for veterans, and developing veteran diversion strategies in the justice system.

A little bit about my background. I have worked for the GAINS center for about five years. I have worked within the criminal justice system for my whole 30-plus year career, working in mental health centers, working in jails, training police officers, working in prisons, and running mental health services in prisons, and then and then also overseeing reentry for people coming out of state prisons in New York back to the community.

And I have good news and bad news about that. The bad news is I actually don't know an awful lot about autism in the justice system, but that's also the good news because the prevalence of autism in the justice system is low, and I think obviously the main reason for that is that the prevalence of mental illness in the general community is much higher than autism and pervasive developmental disorders.

And so people with mental illness, there's more people and they get -- and because of a number of factors, there's a higher prevalence of people with mental illness in the justice system, but I don't know that we can say the same about people with pervasive developmental disorders and Autism Spectrum Disorders.

What I do know about autism in the justice system, there are intermittent cases and I will talk about some of them in the course of my presentation.

But mostly what I know about autism is as a result of my wife, who is a retired speech pathologist who worked in elementary school education for her career, and worked within school settings with special needs programs.

And I have tremendous respect and appreciation for what's going on in school districts across the country to provide services consistent with the goals and visions of some of the previous speakers, programs that have self-determination, programs that speak to the highest levels of independence that somebody is capable of.

But it's -- I also appreciate from her experience what a tremendous challenge that is, both for the school districts, and also for the families, who have to advocate constantly and have their own levels of diligence, vigilance, not only about their children, but about how systems interact with their, with their family members.

So, and that's certainly going to be true of any criminal justice contact that people should become involved with.

So, I am going to talk about something that was developed for the National GAINS Center by a psychologist, Patricia Griffin from Philadelphia, and a Dr. Mark Munitz, a psychiatrist from Ohio who has done a lot of work around criminal justice populations and people with mental illness.

And whenever we go into a community we find that you know, the police have one set of problems with people with mental illness, the courts might have another, and then the jails might have another problem and then reentry from prisons; there's a while completely different set of issues very often in the community, and so services to people with mental illness in the justice setting tend to be very fragmented.

What Dr. Griffin and Dr. Munitz did is they developed the sequential intercept model which really is a paradigm for communities to plan a set of services around people who, with mental illness, who come into the justice system.

And this same model, I believe, and actually does apply to people with any developmental disability that might be involved in the justice system.

So it's, the justice system, one of the good things about the justice system is that it's fairly linear. People move through it in fairly predictable fashions.

So in intercept one, the first intercept is police contact. So what happens at that police contact -- first police contact, and there are different strategies, and diversion strategies that will occur.

And I'm really fortunate today to have my colleagues from Taunton Massachusetts, who will be talking more specifically about those interventions with police. They are a nationally recognized program, and very innovative in their approaches. And they will be talking about that.

If the charges are too serious though, the police -- or they don't have resources available, then they will be, then the second intercept point is intercept two, which is after the arrest, there's an arraignment court and there are diversion strategies there.

And in intercept three, then, if

people move through the justice system, then there's a disposition court, where, which would be either a felony-based court or a misdemeanor-based court, and also there's engagement points in the jails and I'll talk briefly about them.

Intercept four comes reentry; it's again another engagement opportunity when people are coming back from the justice system, back into the community, different strategies there and then lastly, under community corrections which would be probation and parole -- another engagement point.

So we will talk a little bit about that. I am not going to spend as much time as I would have ordinarily. I want to try to help get us back on schedule and leave time for my partners from Taunton.

The basic goals of the intercept model is, number one, to keep people out who don't need to be there. Certainly, people commit crimes, even sometimes people with mental illness might commit serious crimes, and they are going to penetrate into the justice system.

But to the extent that people can be diverted at the earliest point in the sequential intercept model, that's the goal with it.

The second basic goal is that if people with special needs are in jail, to ensure that there's constitutionally adequate services in those jails, and that they can get the kinds of treatment and management that they need in the correctional institutions.

And then the third is to do the -- is to provide the linkages from the justice system back into the community, and that creates partnership.

And that requires partnerships between both the criminal justice system and local providers and government -- and government folks.

And then the last, you know, on the

mental illness language, you know, we are promoting recovery. We want people to achieve the highest levels of independence that they are capable of.

So, the first intercept is intercept one, the first police contact. Now again, the prevalence of people with Autism Spectrum Disorders in the justice system is not very high.

But to the, the first contact is going to be with police. Generally there will be a report of a crime, and these contacts with police might not always end well.

You know, I've done -- I did a quick Google search just because there's very little research about it, so I did a quick Google search, and these were some of the headlines I came up with.

Stafford County woman confronts issues of race and autism after her son's arrest.

There was a report of a suspicious

individual around a school. School resource officer went looking for possible suspects, found a black man sitting on his stoop who would fit the description, and the officer approached the man who had -- a young man who had autism.

The person, the young man was frightened, attacked the police officer, didn't know what he had done, and attacked the police officer, which resulted in the officer injury, which brought him -- really sucked him quite quickly into the justice system.

An 11-year-old autistic boy arrested in a middle school after he assaulted two school administrators.

Mother furious after autistic daughter was arrested. A young woman, 17, who had pinched a student and an administrator, the police were called and the young woman was arrested.

Another police chief says he will apologize for mistaking an autistic teen as drunk. So just see, a young man walking down the street with some gait problems was -- could not respond appropriately to the officer who was questioning him, and arrested the young man.

And then this is probably one of the more interesting cases that you will find. This actually occurred in New York. Asperger's sufferer jailed for posing as a subway supervisor. Young man -- well, he wasn't so young, when he was arrested he was about 35, but he had memorized the New York City subway map by the time he was 11. By the time he was 13 he hijacked his first train. This behavior persisted for 20 years. He ended up in prison finally as a result of this behavior because there was actually probably an anti-social component to it also.

So these things happen, but most of the time police are going to get involved with a developmental person -- disability person because of a situation like this.

A missing boy spends 11 days in the New York subway. He had a problem in school, ran away and hid in the New York City subways, riding the subways for 11 days before a transit officer finally identified him from posters that the family put up.

So these things happen, and while the prevalence is not high, they can be devastating for families and individuals if they are not handled properly and there's not appropriate interventions.

So the -- I am not going to spend any time talking about the law enforcement piece of it. I am going to let my colleagues do that.

And I am just going to talk quickly now about some of the different interventions and the other intercepts, intercepts two, three, four and five, just to kind of give you a brief flavor.

And if people want to talk to me about any of these issues after, I'll be available for a brief period, but certainly contact me from my website.

So, in intercepts two and three, I'll combine them, this is where people appear in court. Now the resources if a family member does get arrested and they do have to appear in court, there are probably over, I don't know, 1,000 diversion programs across the country at these different intercepts.

Many communities have them. They have mental health courts. There are mental health courts, or jail-based diversion programs.

Not every court-based diversion program is a mental health court. Many courts, in the course of their regular duties, will bring in service providers from all kinds of networks in order, to, in order to provide alternatives to incarceration for people.

And so there doesn't necessarily have to be a mental health court in order to have a diversion decision made within the court processes.

But if there is somebody with a developmental disability arrested, probably the first contact should be through the attorney that will be assigned, so in many communities that will be a public defender's office, or a legal aid office, or a private attorney, could be a private attorney, to let that attorney know what the circumstances are of the disability.

Many attorneys don't want the court to know anything about a disability at their first appearance court because it can jeopardize a bail decision.

And depending on how serious they think the charge is, they might just want to get the case pled out or dismissed outright. So they don't always want to let that information out.

So it's important to let the attorney know what some of the issues are so they can guide about the legal ramifications.

Other key partners at that first intercept would be pretrial services. Many communities, not all, but many communities have pretrial services whose main goal really is to make sure that -- is to assess whether or not the person will reappear in court, not so much to find out if there's problems that need treatment, but to assess whether somebody will appear in court.

So it would be appropriate to contact the pretrial people and say, as a family member I will make sure that he appears in court. I'll make sure he gets the help that he needs so that he'll appear in court, and that would be very helpful.

Moving on into intercept three, where there are more significant -- where there's a more significant charge more than likely, if there are diversion programs -- again, these diversion programs are set up generally for people with mental illness, but I know most of the diversion programs, if they find somebody with more, like a brain injury, and Asperger's syndrome that might, that might come into those courts, they will take, they will make arrangements to include those folks also in their diversion programs, and set up the kinds of programs that they need.

If the person ends up in jail, it's critical that the jail staff know what they are dealing with. There are screening procedures in jails to screen for suicide, to screen for mental illness, not so much for developmental disabilities.

So depending on what the officer is able to observe, they will make a referral to mental health for a more thorough assessment.

But if they don't know that a person is coming into the jail with some impulsivity issues or tactile defensiveness, those kinds of issues that you'll find with a pervasive developmental disorder, they'll treat them like any other inmate and they don't tolerate much -- any rule infraction.

So it would be important to get to the jail quickly and let them know exactly what some of those issues are.

And the jail's also a good place to learn a little bit more about the diversion programs. I also want to make a quick, put in a quick plug for the National Alliance for Mental Illness.

They have been tremendous advocates for people with mental illness around justice issues and diversion issues. In many instances they have been the catalyst for development of crisis intervention teams in the country.

So again, it's a grass roots support if there are issues with the justice system's involvement in a family, NAMI -- the local NAMI chapters or the state NAMI chapters can be terrific advocates, really help you through the justice system.

They have gone to great lengths to get their associates trained on these issues so that they can -- they can help respond to these issues.

Moving on to intercept four and give, this is -- again, in many communities they have very sophisticated reentry programs. In other communities not so much.

So again, depending on the kinds of services in the jails, then, you may have to advocate with -- you have to do more advocacy for a person than for programs that have very sophisticated reentry programs.

And then the last is probation and parole. Now, many probation departments, because of the numbers of people with mental illness and special issues in -- on their cases, have developed specialized probation case loads.

And in those communities, those case loads are smaller, those officers are better trained. In other communities probation caseloads will be over 150 people and they just don't have time for special needs issues generally, and it can be a problem, and so advocacy would be very important in those issues, in those, in those circumstances, should somebody end up on probation.

I am going to cut my talk -- stop my talk there and I am going to turn it over to my esteemed colleagues from Taunton.

Mr. Turner: Well, I'm sure that you are going to be more interested with Dan than from us, but we appreciate it.

My name is Steve Turner. I am with the Taunton police department. I have been a police officer for 23 years. Prior to that I was a special education elementary teacher, in Taunton, for five years.

So I have always had a passion for working with the special needs population. I first want to say that just, you know, the talks beforehand, with Brian's talk, we tweak our training all the time and I really think that we are going to go back and tweak it some more with self-determination.

I think that that's something that police officers really need to grasp, and even myself, who probably is more ahead of most officers.

But I think that was a hot topic and I really gained a lot out of it. George, I'd love you to come to Taunton. We could use your passion and your talent. That was a remarkable presentation as well.

And other -- we have gone into housing but we are going to be looking a little more into that as well.

And Dan is just a wealth of knowledge, speaking to him prior, you know, again I was hoping he took the whole hour so we could just sit here and watch but --

(Laughter.)

So as a police officer, I don't like to be around other people. And so it's kind of intimidating to be here with other people who aren't police officers.

We are a different crowd. You'll

see that through my next 10 minutes or so. So bear with me. Don't throw anything at me. I do have backup in the hall.

So I want to thank the committee for inviting us and recognizing us with the passion that we have. We think we do a great job. We don't do a great job at getting our name out there and probably getting the word out to other communities and throughout Taunton and its area as well as Mass and regionally and even nationally.

So, we thank you very, very much. I am going to talk about just the CIT, which is now called the CCIT from Taunton. Originally it was -- it started very informally back in Taunton.

I was involved with a social services provider, CPI it was called, and they asked us -- they asked me if I would come to a case conference for lack of a better term at the time.

So I came, there was a consumer

there that was having some difficulty in the community, with people bullying, using his house as a drug, as a drug lord and a place to -- a drug haven and a place to sell drugs.

He was being bullied. He was being -- his money was being taken. So I happened to go there. There were some other people at the table. Bill was at the table at the time.

And we came up with a plan. We did extra checks. I went to the police department. We did extra checks with this gentleman. And he became a friend of ours.

It was very impressive how it turned out. So CPI put some money together and they sent five us out to Portland, Oregon and we were trained under Major Sam Cochran at the time on the CIT model.

We came back. We were then sent down back to here which was Montgomery County, under Chief Charles Moose, and we were trained on the CIT model, train the trainers.

We went back to Taunton and we came

up, we gathered players that we thought would be appropriate for our CIT team, and it's continued and really molded into a great organization.

Like I said, we have changed many things. We have tweaked them. And the core group has been together since the late '90s.

So we gathered our group together and we started the training, and we talked about it, we got the court involved which no other organization that we had found at the time, or even still at the time on the CIT, brings the court involved with it.

And that was the vital part. The police, certainly yes, the intercept, most of the time, with the consumers. But the court was a vital piece and that's when we added the extra seat for community so it's a Community Crisis Intervention Team.

We put together our training. We do three trainings a year, two adult 24 hours, and then do a youth training. Again, we tweaked it that we really needed to deal with youth, and we hadn't. So we added the two-day training for the youth.

So our training was, as a police officer we usually get trained by ourselves. And you professionals here, don't make fun of us, but we are usually -- the training is from 8 to 4. We arrive about quarter of 9, get our coffee, about 9:30 we are in the training, and take a lunch from 12 to about 1:30, come back and we are out the door to 3.

Not a bad gig. But this training here is from 8 to 4, and a lot of times it goes after 4. We have people that come in, and Keith is going to talk about who comes in and trains, but it's really, from a police officer's perspective, it's a great training.

And the police gain empathy towards other mental health issues, which we are not good at that. We are not trained at that when we are in the academy. We are not trained to do that. We get street smart, a little bit, some of us a little better, some of us not so well.

So that was something that we liked to do. We trained, there were what, 30 to 35 people in our training at a time, and we have about half police and half other professionals.

And it's like an eighth grade dance with the police officers on one side and the mental health professionals on the other. About day one and a half we start intermingling and get the guts up to go ask someone to dance, and we start talking with other people.

So our goal was to train one third of our police department. We wanted, again, the passion. We wanted someone to have that passion, to volunteer to come to the training. We don't want to mandate it and so we ask for volunteers.

In Taunton we have about 45 percent officers trained, and other towns around us are about the same, and hopefully we would like to get to 100 percent but we are happy that we have reached that 25 or 33 percent goal.

The trainings have strengthened the police in the community. We have lowered repeat calls to consumers' houses, which was -- that's a big problem with police departments.

We are very short-staffed right now in Taunton and probably everywhere around the country, so the repeat calls, we spend a little extra time that first or second time with the consumer, and maybe grasp a little bit of a rapport with him or her, and we spend some time with them.

And that probably will make us not come back as often. We still might get called back there but we are hoping that it's not as often.

It's citizen safety, not just for the consumer but for his neighbors. For anyone that's dealing in Taunton, we have a state hospital, we have a mental hospital and we have a lot of halfway houses, and there are a lot of consumers that have been integrated into the community, which is a great thing.

And police officers have probably dealt with it better than most police departments because we have dealt with that for many, many years.

We have a better-trained police officer because of this training. The mentality and just the ideology of the police department and the police officers that go, we have seen a big change in their mentality and how they deal with consumers, again, the self-determination, that's something that we really -- I am really going to go back and I think talk about.

We have a better understanding of mental health issues and mental health professionals. We talk with other professionals, we learn their limitations, we learn their weaknesses and their strengths, and we take that back and now we have a person that we can call.

If we want to call, a lot of places we have a crisis unit, that I didn't know anything about, being a special ed teacher I should have known, I didn't know anything about until about 12 years ago. This place is open 24 hours a day, has an on-call 24 hours a day that you can call while you are at a police call.

So they have police officers that are using that. And just officer safety. We have talked about escalation and de-escalation techniques in the training and taught police officers.

We are lucky. We get to go to calls with guns. Other folks, they go to calls, they don't have guns. They go in there with maybe their cell phone and a piece of paper and a pad of paper, a pen and a piece of paper. That's all they have.

So we teach them as well escalation and de-escalation -- escalation techniques as well as officer safety and agency safety.

So, we now have other options than arrest. We do interact. The sequential intercept is we could meet them -- we could meet people at 2 a.m., at 12 noon, any time of the day, and we are 24 hours a day police officers.

So there will be a sequential intercept. When we went to Pittsburgh we learned that term and we were like that's what we are doing. It's a great term and we learned a lot at the Pittsburgh training and we think that that's important, to get that intercept at that time.

Unfortunately there are times when we have to arrest, because it's mandated, because there's just no other, no other, no other option.

So then we have go to the court. Keith is a former probation officer as well as

Bill, and what we do is we will put a little sticky note or some kind of an addendum into our report, and send that over with the arrest report.

That's -- first thing in the morning the court officer as well as the probation officer will read the report and they see that, and so now it transitions into the court system, which again, I think is the vital part of the Taunton CCIT.

So I appreciate the time and thank you very much and I am going to hand it off to Keith.

Mr. Bourdon: Thank you Mr. Turner. He is always a tough act to follow. But we are going to give it a shot.

First off I would like to thank Ellen, Susan and Lee for inviting us down here today, as well as the rest of the IACC folks. It's always informative. I think a lot of times we get more out of this than you probably do from us.

Just a couple of things to pass along. In the past I have had positions with Mass Department of Mental Health, Mass Department of Children and Families, formerly known as department of Social Services, the Mass trial court and the probation department.

I am also an adjunct instructor with Anna Maria College, and I think a lot of what we utilize in the CCIT applies to the classroom and it provides a lot of information for students.

I want to talk about three things starting off with comments on the court component then going into the trainings, and then brief comments on our case conferences.

From a court perspective, I think anyone that goes through the court process, it can be really scary, and for a first-time person or someone with a developmental disability, or a mental illness or a co-occurring disorder, it could be off the charts.

It's a very, very tough experience. What we have tried to do is to have the court staff, especially in the probation department, be aware of, I should say how to manage situations and how to come up with positive results to make the best of a bad situation.

Wanted to outline five of the points that we really try to stress in our trainings and on a daily basis with the court staff.

The first is when someone does come into the court, to understand the functioning level of the client. So you want to have an idea what are their limitations, what are their resources, their backgrounds and so on.

And you are trying to do this at a very high speed I guess you'd say. You don't have a whole lot of time to pull this together.

So you really rely on the information that comes in from the family, from the case manager, from the police department. It's very important to gather as much as you can as quickly as you can.

Second, you want to maintain realistic expectations. What do you want to do with this situation? What can you do? Is this a brief intervention and the person will never be seen again by the criminal justice system?

Is it going to be something that is going to be dealt with over the long haul? Also in terms of what, what do you really -- what can you really expect to do for the person, with the person?

Third one is provide close supervision. Obviously you want to spend a little more time with individuals, once again in a fast-paced environment.

Fourth, utilize graduated sanctions, as we call it, kind of going up the ladder. If the person needs further intervention to prevent them from once again going deeper into the system, what can you do?

I think George mentioned this morning something about making modifications, kind of in the environment. Well in the same way, we do that in the court, in terms of maybe you want to modify the treatment or the supervision plan that you are doing with the individual.

So you want to take a look at that. And then lastly, probably the most important one here and I'll put it in capital letters: communication.

Family, treatment workers, prosecutors, defense attorneys, the judge, the individual, you want to have those lines of communication open and gather as much information and update it as you go along and make sure everyone's in the loop.

There's nothing worse than, as the old phrase, operating in a vacuum, when you do that it makes it very difficult. If you have that information, you share it, have everyone on the same page, everyone pulling in the same direction, everyone benefits. I think that's key.

So, and moving along, I know we are limited here for time, our trainings. I think in your handouts there's a one-pager that up at top, it's entitled Community Crisis Intervention Team training.

It gives you an idea of the types of professionals that have come through the training. Usually you are talking classes of roughly 30, 35 people, varied background, and the amazing thing is that they come in, it's a three-day training, we have a great number of speakers that present and there's also a list I believe in the brochure of those types of speakers that would be presenting.

Folks get to really see what the other side is like, what their experiences are, what their limitations are, what their resources are, so they gain a much better understanding, so when they, later on down the road, they are working together, they have a roadmap in terms of where do we want to go with this, what resources are available so it's very important.

Trainings go on for three days. At the beginning usually people are kind of, you know, they don't really know one another, they are not too familiar with what is happening, and by the end of, you know, the second day or so, things are really beginning to open up.

We have interactive pieces for them to do. They do a visit to a state hospital. They do some exercises. We have a hearing voices exercise.

We do some scenarios. We do some role-playing, we have some panels. It's, you know, once again, very, very informative.

So the trainings, hopefully, over the long haul, when you come out the other side, you go back to your job and then when an incident happens, or a situation comes up, you have a contact person.

If you need information, you want

to relay information, it's very, very worthwhile just in that regard. So the networking aspect is extremely important.

Just moving along quickly, our case conferences. And this is where we really can be proactive. We can hold a case conference on any individual within the community, at any checkpoint in the system. I think the sequential intercept model was spoken about.

We can deal with someone before they enter the system, we can deal with someone that is in the system, we can deal with someone that's hopefully leaving the system, and come up with a game plan, what's the best way to keep this person from going any deeper into the system.

The case conferences, they are called, we have a -- basically it's interchangeable parts, the folks that will come from the various backgrounds, probation, the police, the clinical folks, the state agencies, and everyone will kind of throw their cards on the table and come up with what's a good plan for this individual.

What's unique about this, there's a very high trust factor. So people aren't kind of playing it close to the vest and protecting their resources, they are willing to share them, come up with some good ideas and implement them.

That's something you don't see too many times anymore, especially in this day and age where the funds are drying up and people are, well, we don't want to spend too much on that.

The other thing is when people fail to share their resources, an individual can wind up incarcerated. That's the bottom line agency, I guess you'd say, you know, for someone.

So, by utilizing things on the front end we can keep people from going any deeper into the system there.

Case conferences we have had, we

have been doing them for roughly 10 years and we have had some great success stories -- you know, we could certainly share a lot of those -- with folks that -- developmental disabilities, mental illness, the co-occurring disorders, we have really done, done a lot in that regard.

And when you look at it from any perspective, no matter what agency you are coming from, I think you will really see results and I think that's, that's what counts, that a lot of families come back and say, you know, gee, it didn't look good in the beginning, but it really turned out, turned out well.

So I think I will stop there and turn it over to Bill McAndrew who will take it another step further. Thank you.

Mr. McAndrew: Good morning all. My name is Bill McAndrew and first of all I want to thank Ellen and all the organizers for having us here today at this very important conference and symposium.

As Steve Turner, my colleague Steve Turner from the Taunton police indicated, the police over the last several years have been going through a culture shift in terms of dealing with individuals that they encounter at the street, if they are summonsed to by dispatch.

And it's not necessarily just clear the call and move onto the next call, but how can you spend more time to resolve what is going on so that there is no next call, or at least the number of next calls have been significantly -- been reduced.

And part of our training, we provide all of the participants with a -- and particularly useful for the police officers -- with a laminated card of a whole host of agencies that a police officer can have in his or her vest pocket and then if it's appropriate, to deal with the situation, provide resources to the individual, to provide resources to the family, so it's not necessarily saying I need to summons this person in, I need to arrest this person.

But if there was some type of pre-arrest, which is the whole notion that Dan spoke about and the first stage of the sequential intercept model, is to either stop penetration into the criminal justice system, or certainly the goal, our goal, collective goal is to lessen that penetration into the criminal justice system.

So now police officers are equipped, as a result of participating in this Community Crisis Intervention Team training, they are equipped with the resources of the community and with names of individuals who are at those various agencies.

Keith talked about the heightened awareness of the court system, and that only comes through, as he suggested, through communication.

We have sat down with the presiding

justice of the district court or the community court, we have sat down with the associate justices, to make those folks aware of what the resources are in the community.

Judges are a neutral body and certainly need to be that neutral body in the community, to resolve disputes. But they also need to be aware of what's available in the community to assist them in either setting some pre-trial supervision issues, or some post-trial or post-plea issues that will benefit the individual before him or her.

Some communities, as has been said, are experimenting with mental health courts. Massachusetts is currently experimenting with mental health sessions of district or district courts or community courts.

As a sequential intercept model, we are very fortunate that Massachusetts, the Department of Mental Health in Massachusetts, has funded for a number of years a forensic transition team.

And one of our partners in our Taunton initiative is a forensic transition social worker who is going to the jails and into the prisons looking at those folks who are at the stage where they will be released shortly, and have had some prior experience with the department of mental health, to ensure that their medications are in order, to ensure that their housing is in order, and to ensure a successful transition.

We know from our experience in the court system that if there is no interaction early on after release from jail or from the person who is in a court setting, if there is no supervision plan set up, then the likelihood of that person failing in the first 30 to 90 days is very significant.

So what we try to do is work with all of our partners, including the forensic transition team, to ensure that services are available for a productive transition to the community.

The Taunton CCIT model, our Community Crisis Intervention Team model, is a community-based model. We are here today as -- at an Interagency Autism Coordinating Committee.

And that's what we are. We are an interagency model. We feel that it's -- we have a core team of about 12 individuals who meet monthly , and we feel that it is very important to have that -- to have the sustainability we need to be at the table.

So we have an eight o'clock meeting and over the last several years, those meetings have been at the local community general hospital.

We just transitioned two months ago to the state hospital Steve spoke of in Taunton, but for a number of years we met in the cafeteria annex of a community hospital, to bring our community partners together in a setting where, oftentimes, many of those folks that we are seeing are experiencing emergency room services.

We are very fortunate to have a Community Crisis Intervention Team intervention team coordinator, Kathy Lalor, who worked at Community partnerships Inc., that's CPI, Inc., Agency that both Steve and Keith spoke of.

It was a non-profit community agency that a dozen years ago brought Steve from the police department and me from the court system together to start talking about an individual who was involved in both systems, and also involved with this developmentally disabled non-profit agency.

And police have worked with the courts for a number of years. Police have worked with schools. The courts have worked with mental health agencies.

And we all have these segments, where we talk to different people but it's kind of interesting that it took a non-profit agency to bring all of us together and to start talking about how, collectively, we can improve the quality of life of the individuals in the community that we work in.

So we have a committee of about 12 core members, but we also have, as part of that committee, a steering committee of five members.

So as a true community model, it's not the Taunton Police Community Crisis Intervention Team. It's the Taunton Community Crisis Intervention Team.

And one of the members of the steering committee is a representative from the Taunton police department. One of the representatives from the steering committee is from the district court probation department.

But the Department of Mental Health, the Department of Developmental Services, formerly the Department of Mental Health in Massachusetts, and one of our community provider agencies, community counseling of Bristol County, those are --

that's the makeup of our steering committee that sets the tone and sets the opportunities and direction where our team should be focused.

We have a number of different individuals who participate at various segments of our larger team. The school system is involved, the department of social services is involved. The hospital is involved. The district attorney's office is involved and a number of other partners.

When we first started our training back in 2003, which is before we were aware of the formal sequential intercept model, we brought a number of partners together for our first training.

Steve and Keith in 2001, in September of 2001, participated in training in Portland and then, as Keith alluded to, came to Montgomery Country for additional training.

In 2003 we held our first training, and we provided coffee and Kathy Lalor, our coordinator, and colleagues of hers at the time, made some pastry goods and we literally had our first three-day training with zero funding from any agency other than the non-profit.

Over the years, we have been very fortunate to get some limited funding from the United Way, of the Greater Taunton/Attleboro agency United Way, from southeastern Massachusetts NAMI, and from the Massachusetts Department of Mental Health with their jail diversion program.

There are five jail diversion -- initially there were five jail diversion programs funded in Massachusetts, four with a ride-along social worker model, and then the Taunton model, which is the training of police officers who are on duty 24 hours a day versus perhaps a 40-hour or 32-hour shift of ride-along social worker with a police officer.

So we have done what -- trainings over the years with very limited funding, and we are also now looking at some bank foundation -- some limited bank foundation funds. Oftentimes the commitment of banks, the foundations, bank foundations are three to ten thousand dollars so we are exploring that so that we can sustain our training efforts.

We are constantly evaluating our training format and our training curriculum. All of the participants who complete our program, we have a manual for our three-day training, and from day one, from our first training, we have provided a manual.

And as a result of our initial three-day training, the evaluations that we have conducted over the years have all said that's great, but what are you doing with youth issues? Because youth issues are so different from adult issues.

So as a result of those comments, we have -- this will be the third year that we have hosted a two-day youth program. So we have some of the core members from our adult

CCIT are also core members of our youth CCIT, and also there are some different members who are in the youth than are in the adult.

So right now it's a five-day training, three days for adults, three consecutive days, and then a few months later we have a two-day youth component to give people an opportunity to get back to work and do the things that they need to do at their work site.

But we are constantly evaluating our manuals. When we participated in the Pittsburgh conference, our team was at dinner, and we started talking about the sequential intercept model, which was the focus of that conference.

And it dawned on us that the issue of housing, which George spoke about, was completely missing in our, in our training.

And we know, those of us on the criminal justice side of the house, know that when folks enter the criminal justice system, and more often than not, with a developmental disability, or a substance abuse or co-occurring disorder, are held in a local jail, held without bail in a local jail.

And what happens? They lose their housing. They lose their Section 8. They are back on the street, looking for transitional housing and need to provide some type of roof over their head.

So as part of our training package now, we are dealing with the housing authority and the whole notion of stabilized housing for individuals.

We also realized that we did not have a component on state and Federal entitlement programs. And interesting enough, the agency that Kathy Lalor worked for at the time is a rep payee agency for individuals with social security.

So that is now a component. So what we do as part of our monthly meetings, and in dealing with our partners, our community partners, is to take a close look and to ensure that the trainings as we go forward, have all of the components that are necessary to have an effective training program.

And we certainly understand that homelessness is a big issue and we are dealing with that as well.

The -- if anything, dedication and commitment are the hallmarks of our team. We have a number of partners from a variety of agencies, who participate in our monthly meetings.

This organization is -- CCIT is basically a pretty much volunteer organization. Kathy Lalor is a four-fifth person, four-fifth time slot person who coordinates our efforts.

But the police department's participation, the courts' involvement, the psychiatrist from Morton Hospital in Taunton who does two back to back modules of our training, the local district court judge comes over, assistant district attorney, NAMI's participation, the school department's participation, the other alphabet soup state agencies, all of those folks provide their contribution for gratis.

So it is -- our collective participation is basically an effort in community participation and partnership building.

Brian spoke earlier of providing supports in his comments, and we are fortunate that we do have some supports in our community.

We have a mobile crisis team that unfortunately, at this time, just works with youth. We would like to see that expanded to work with adults.

But we are very fortunate that Mass DMH provides a youth crisis -- mobile crisis, and we are very fortunate that Community Crisis of Bristol County provides a school-based counseling program for individuals.

So we are not removing individuals from the school system, either during the course of the day where they are missing academic work, or where it's -- it becomes a stigma for that individual to be removed from the school, but counselors are available at the school to do school-based counseling.

In his comments earlier, Lee spoke about you know, what's the future of services, and part of what we do is advocate for services.

One of the major concerns of ours is what's considered boarding status of individuals who are held at the local community general hospital.

They are brought in for a psychiatric issue, and are held in boarding status for more than a reasonable period of time, more than a day, oftentimes more than three days, sometimes more than seven days, and we can tell horror stories of 17 days.

And so what we are very much concerned about is creating enough of conversation to get the powers to be to have the services available, and not just in other pockets of the Commonwealth, but to have services available regionally, so that parents can maintain that close relationship, that daily close relationship, particularly with their child, in a local psychiatric facility.

So part of what our team doe as well, is advocacy. I spoke about the need to meet monthly. We -- part of our outreach has been to other groups, and some groups feel that they can meet quarterly or semi-annually.

We feel that in our 10-year plus existence, we feel that it's very important to meet on a monthly basis on a given day at a given time at a given facility, and it just becomes part of our routine. People bring a cup of coffee. We sit down for an hour. If there's a case conference we schedule that.

Immediately after, certainly we

have emergency case conferences. But we have an established time for case conference after every, every meeting.

If I can give you a little visualization. When we first started it was the police and it was the court and it was the community agency.

And for those of us who do some recreational bicycling, if you can -- if you can think of your bicycle wheel, it's comprised of different spokes.

And if you are missing a spoke or if you have a loose spoke, it's not a comfortable ride. It's a wobbly ride or the wheel is hitting the brake and you are going forward and it's jerky motion.

But if those spokes on the wheel are tight and aligned correctly, then it becomes a smoother ride, and we look at what we do as adding spokes to our wheel.

I talked about the housing issue, we talked about the entitlement issue. So we are constantly looking at what we are doing, and how can we add more spokes to the wheel.

And it's not just adding spokes to the wheel. But one of the critical things we need to know is “what is our mission statement of each of our own agencies? What do we know that we can bring to the table?”

And then we need to communicate. We need all of the partners to communicate to the other folks around the table what they can do.

There are certain things that the Taunton police can do and there are things that they can't do. So they can't make promises that they can't keep. The court can’t make promises that it can't keep. Agencies can't make those promises either.

But it we all know what our own individual agency can do, and if we know what the limitations and the opportunities of other agencies, then those folks of the wheel, are going to be aligned and the services that we are going to provide to those individuals, whether they are other institutional leaders, whether they are agency partners, or whether they are consumers, what we will be doing going forward will be a lot smoother transition or a lot smoother, smoother ride.

So we are constantly looking at strengthening partnerships and expanding those as well.

Education of community partners is key, so part of our monthly meeting is to -- if we bring new partners in, it's to keep the court informed of what we can do to keep the defense bar informed of what we can do, to keep the, the prosecutorial arm informed of what we can do, so that we are operating on a common knowledge base.

One of the things that we have done is to assist other communities in establishing similar programs and to strengthening their partnerships and we are happy to do that.

We have provided a brochure and it's in your manual. Unfortunately I do have to correct an email address, but if anyone is interested and you don't take the correct address down now, I am sure that Ellen can get in touch with us.

But Kathy Lalor's email address is klalor@communitycounseling.org, not yahoo.org, and she is also kathylalor@yahoo.com.

So Kathy is our coordinator, and is ready, willing and able to assist anyone in providing more information and access to what we do.

In a word, as we close our training programs, and I think -- George talked about concern for safety in his remarks. I have the opportunity to close our three-day and two-day training, and I try to capsulize what the whole focus of the training is.

And the first thing I say is be concerned for your own safety, whether you are a social worker, you are a police officer, a court worker, whoever you are, if you are in a situation and it's not a safe situation, then it's not going to go well.

So we all need to be concerned for our safety and the safety of those around us.

The next key component is communicate. We need to communicate with each other what our limitations are what opportunities we can bring to the table. We need to let other folks know what our specific agencies can do, what as individuals we can do, and how, collectively, we cannot lateral the problem away, and not be the police officer that says hey, I'll make the arrest and clear the call.

But not to lateral the problem to the court system, but to deal effectively with what's going on, or for the court not to lateral the problem off to the county jail, but to deal with the correct resolution of that problem.

So what we are suggesting is be concerned for your own safety, communicate and above all, do your job. If we do our job, and not lateral the problem, we are going to have less police calls, we are going to have less criminal court arraignments, we are going to have less -- less individuals incarcerated, and we are going to have a better outcome of what is before us.

So the whole notion of the sequential intercept model is intercept at any point, even if it's a probation surrender hearing, the case could be two years old and the person is -- has been on probation, has been doing fine, is now acting up.

That doesn't mean, okay, the person is on a suspended sentence, let's refer him to the county jail for a period of incarceration.

But let's revisit what's going on. Let's bring those community partners back together again. Let's expand if we need to the number of and variety of community partners to have effective resolution in what we do.

So we appreciate the opportunity to

be here to showcase a little bit of what we do and we'd be happy either today or some future day to spend more time with you.

Mr. Turner: And if I could take two seconds just to state that as again, we tweak our training all the time. About three or four years ago, we tweaked it with autism. The school that called us, they were having a lot of issues with autistic students.

I work in the school department as one of the truant officers, so I was key on bringing this autistic piece to the training.

Approximately one -- maybe six months after the training had occurred, an officer got called to a middle school in Taunton, and a boy had pulled a firearm and I guess it was his second or third time to do it, and he was autistic.

And the school principal wanted that student arrested. Luckily, the officer was one of the ones that had gone to the training, and he articulated to the principal, that that's not where this boy belongs.

And luckily, who knows what would have happened if he had gotten into the criminal justice system. We trained, and a lot of the criminal justice system has come to our training, so hopefully we would have gotten one of those or two of those people.

But you never know. That student could have had a record. He could have been placed some other place. But no, we got him into the appropriate, we took him down to the police station, he sat in the front of the police car. We brought him to the police station, had his parents called, had his social worker come down, and it worked out very, very well.

So again, but that's a piece -- we talked about the self-determination. That's a piece that will be brought up, but the autistic piece was -- it just seems like more and more -- maybe we were ignorant to it in the past, but it seems like more and more, we are dealing with autistic, especially youth, but even on the adult side.

So thank you. I know we have probably have run a little long. We apologize.

Mr. Bourdon: I'd just like to add another little situation, that we actually had a director of an agency that we work with, that's part of our group, and he had a son that was autistic. I believe he was 19 years old at the time when he came in.

He was actually arrested, brought into court, and so on. We did some interventions. It went very well. He went on, actually, went up to Maine, went to, went to school up there, graduated from college and is leading a successful life now. So just a little story that goes along with it. Impacts everybody. Thank you.

Ms. Blackwell: Well, thank you guys, Dan, Keith, Steve, Bill, I mean this was a great presentation and our committee has been really wanting to hear what happens at the community level, and I think that what you guys from Massachusetts described is just a wonderful example of how, with very little resources, you can do a lot.

And you guys didn't really talk about this, but I can guess that there are immense costs that are saved down the line by implementing these sorts of models.

So this has actually happened in my family too, and there's nothing more terrifying as a parent than to get the call from a police officer.

So you know, it is extremely common. So --

Mr. Turner: And because it happens in Taunton, it really can happen anywhere -

Ms. Blackwell: Oh yes.

Mr. Turner: And that's the -- there are people, there are hubs out there that will be the Kathy Lalors in each community. It's just the having the intuition to go and find that person and having the guts to go and approach that person.

Police officers are weird, we're different, but we are approachable.

(Laughter.)

Ms. Blackwell: So does anyone have questions on the phone or in the room for our panel?

Stephen.

Dr. Shore: I heard some very encouraging things going on in my home state of Massachusetts. That's great to hear. Great to hear that.

And what I was wondering is, you know, if you could give me some, if you could provide some more specifics as to what training is being done for -- related to people with autism in general, and I think at the very end, when you were talking about the situations, that was very good.

Because you know, based on what I have seen, often the reactions of a person with autism, even from the very beginning, at the initial contact, if you get the person with autism who has a sensory issue, and is reaching for an officer's badge, or all those shiny objects around the belt, it's a very different, potentially, situation, than someone who may have a different type of disability.

And then what type of representation, what's being done to assure that the person with autism has representation, and then as you move on, if it goes that far, into incarceration or the court system, just the different ways that -- ways that people with autism think, and to that point I think of a video clip that was produced by Denis Debbaudt where a judge asks the person at the stand with autism where do you live, which is a very standard procedure.

The person with autism, who is hyperlogical says well, you have got the records, you know where I live, why should I have to tell you?

And that could be, you know, a person with another condition, or someone without autism, that would be interpreted as being a wise guy. But instead this is hyperlogical thought which is --

Mr. Abreu: So let me just, just address your question naturally, and it really pertains to some of the comments that Mr. Grossman made at the beginning.

I think that training and awareness is inconsistent across the system as you probably would guess, and that you shouldn't assume that your community is informed about developmental disabilities or that your police department is informed about developmental disabilities, unless you check.

I mean it's over, I forget the number I heard, 2,000 CIT programs, they are guessing, across the country. Many of those will have a developmental disability module but because they were set up for people with mental illness, some of them won't.

So it's important to be, to be advocates for your constituency, which is your family and people that you are working with, with Autism Spectrum Disorders.

On my slides, which I didn't go through, Maine for example has an autism checklist that they provide the officers who are on the streets so they can actually question somebody about their disability and learn a little bit more about them.

A number of police departments have developed, like Taunton has these little resource cards, with a quick little checklist, just to get some quick information, because in the street you don't have a lot of time to make decisions or do a lot of questioning, so that again, to -- so that the awareness is out there, and then resource numbers about who to call, and those kinds of things.

But you shouldn't assume that it's in your community. NAMI would be good partnerships in terms of -- because they may have already established the training linkages and to investigate those issues.

Mr. Turner: And just on a local aspect, again, about three or four years ago, we just saw the growing concerns with autism.

There is an officer of a neighboring town who has an autistic son who is nationally recognized as an autistic instructor, and he is part of our core team now, this instructor.

We have always had development disability parts of the training, but this is just another aspect of it, and the knowledge that he brings, in talking to me with a Masters degree in special ed., I thought that I knew a lot of things which I really didn't.

And just in the hour that he presented, and then talking to him later on, he just was a wealth of information. And many officers in our town and our surrounding towns have reaped the benefits of having him.

So that is something that we will continue to strengthen and again, probably tweaking some other things as well.

Mr. McAndrew: And I know that Massachusetts has, as I suggested earlier, has started some mental health sessions, not necessarily mental health courts.

Chief Justice Linda Conley of the district court department of the Massachusetts child court would be overseeing that.

And advocacy is a role that we all need to assume. So I think it's a fair question to her, is what training a judge is receiving and court employees, so that when individuals come before them, is their awareness heightened and what services are available.

Mr. Abreu: Just to back up on Bill's comments, judges in many communities are champions around these issues.

Mr. McAndrew: Absolutely.

Mr. Abreu: And they actually will

chair mental health criminal justice task forces in their communities. So if you have a task force like that in your community that includes the judiciary, they are very good advocates and partners around these issues.

Mr. Grossman: Thank you, gentlemen. This was quite informative, an excellent presentation. Unfortunately we have to move on to the next group.

(Applause.)

Mr. Grossman: Thank you for being here. That truly was remarkable, what you are doing, and I want to thank you on behalf of the autism community for your work.

We are going to have a -- our next presenter is Ellen Blackwell, which we all know well, and we are also going to have C. Lee Price and Cindy Gwinn present on home and community-based services, Federal precepts and the state delivery system.

Ms. Blackwell: Okay, I am not going to waste any time. Today's presentation is actually by special request. Alison Singer of the Autism Science Foundation, who is one of our IACC members, has been asking if I could explain waivers in a way that people can understand.

So I had to really think about this a lot, because it's a hard question and I wanted to have a presentation where we could talk about what the Federal role is, and also what the state role is.

So with me today I have Lee Price and Cindy Gwinn. They represent the Virginia Department of Developmental Disabilities, but so I am going to let them talk about what this looks like at the state level.

But I do think it's very instructive for all stakeholders to try to understand you know, because there's -- these are very complicated concepts.

So I am going to try to explain them in a way that everyone can understand. And the question wasn't really, to me, can you explain waivers. It's “how are home and community-based services provided through the Federal government, what are they, how do states provide them, and how do I get them?”

So those are the -- that's sort of the way that I conceptualized this. And so what does the Federal government do? We talk a lot about long-term services and supports these days, and home and community-based services are inclusive of long-term supports.

Medicaid, the program that I represent, provides a lot of home and community-based services. Medicaid is a state and Federal partnership so, Lee, we are partners.

And how do we pay for Medicaid? States receive matching dollars from the Federal government. Most states get about 50 percent -- some get more, some get less -- to pay for the cost of long-term services and supports.

So a little bit about Medicaid. In

Medicaid, some services are optional and some services are mandatory. And I said that backwards, because most services in Medicaid are optional.

Home and community based services -- optional services. Kids enrolled in Medicaid, they get different services, or they get more services than adults.

Also, important point, Medicaid pays for a lot of services that are provided in schools.

So when the Medicaid law was passed in 1965, it mostly provided physical health services. States began to offer long-term services and supports probably beginning in the 1970s and '80s, and some states offer some long-term services and supports to everyone enrolled in Medicaid.

So by the '80s, people started looking at the Medicaid program and talking more about this institutional -- idea of institutional bias, and also the fact that institutional services cost a lot more than home and community-based services.

So how could we start to rebalance the system in a way that people liked better?

So why did that happen? You know, again, mostly because home and community-based services cost less, and because it's the right thing to do.

The only institutional benefit in Medicaid is nursing homes. And also, the other things that changed were the passage of the Americans with Disabilities Act and the Supreme Court's Olmstead decision, which you are going to hear more about from our Department of Justice colleagues at one o'clock, really asking states to support people to live in community settings.

So, what are home and community-based services? On the left side you see the statutory services. The last statutory service is other, so I am just listing on this slide some examples of what other services could be.

Other services are just simply services that help people live in the community.

So how do states provide home and community-based services? They use different parts of the Medicaid statute. Almost all states use -- here comes the alphabet soup -- Section 1915(c) home and community-based service waivers.

There are lots of different kinds of waivers. What that means is that the Secretary waives the usual rules and the rules change according to which statutory authorities states pick.

So what do states do to come to their partner, CMS? They have to fill out long applications where we ask them a lot of questions.

And then, in the regional office, we have colleagues in our 10 regional offices, we work with them, to look at these long applications and make sure that they are congruent with the law.

Usually we approve them. Sometimes we disapprove them. Not very often. And waivers are active for only certain periods, usually two, three or five years.

States also have the ability to come in and change something about these waivers during their period of approval.

So who drives waivers? States. States drive their entire Medicaid program. States get to decide where services are provided, who gets them, what the services are, how they are delivered and how many people get them.

And that's really important to understand, I think, that as the Federal part of this partnership, we are at the receiving end. We don't tell our states what services to provide or how to provide them, for the most part.

The second point here is really

important because even though, for example, a developmental disabilities agency may be running the waiver, the state Medicaid agency is totally in the driver's seat, and it is our partner not the operating agency.

So people participating in these home and community-based services waivers, again this harkens back to the early days of Medicaid, are required to be at what we call institutional level of care, and meet other eligibility criteria that the state gets to decide.

So what sorts of things are in the application? The state has to tell us who it wants to serve. State has to attest that the cost of this program will not exceed the cost of providing care in an institution.

The state gets to describe what services it wants to provide, who is going to provide them. The state gets to decide if it wants to put families more in the driver's seat in terms of delivering the services.

And lastly, and probably most importantly, the state has to say how people are going to be healthy and safe in the community.

So there are also other ways that states can provide home and community-based services. A few years ago, after -- in 2005, the Congress decided that you know, there would be a different way to put home and community-based services in the Medicaid program.

It's called Section 1915(i). It has different rules from the waiver programs. Under this statutory authority, states can't have waiting lists and lastly and most importantly, states can serve people who are not at an institutional level of care, unlike in the home and community-based waiver.

So it's sort of a different group of people but again, different set of rules. So there are all these different ways these services can be provided.

In addition to what statutory authority states use, states are -- have a lot of leeway in terms of how they pay for services.

So for example, in a fee for service system, states pay, based on the service that's delivered, by hour, by unit, by day, by month, and we are going to talk a little bit more about this this afternoon, but states are also looking at using managed care delivery systems to provide home and community-based services, mostly to save dollars, improve this whole notion of care coordination, and be able to better project costs.

So we call that managed long-term services and supports, and the way that looks is, for example, the state might decide that it wants to pay $500 a month for a particular person, and then the provider organization would deliver a certain package of services based on that set rate.

So there are some other authorities that can be used to provide this sort of managed care Section 1115 demonstrations, and you see a few examples of states here that are using that authority.

We are going to hear from a couple of those states later today. Section 1915(b) waivers, Section 1915(a) contract, again, we will hear from our colleagues in Pennsylvania later so I won't dwell on that.

So how can you learn more about what is happening in your state, because we all understand -- I think we have talked about this exhaustively in our meetings -- that the biggest predictor of the services you will receive is the state that you live in.

So I would recommend you go look at your state Medicaid agency website, and I put a link here. I think at least with the -- in terms of people with autism, it's also really important to look at your state DD website. There's usually a lot of good information there. So I have a link for that here.

And also, I can't emphasize this enough, read the waivers. They may look incredibly boring, and difficult to get through, okay, but that's really where the juice is in terms of understanding your family member's services, not necessarily in something that -- and no disrespect Lee -- that the state developmental disabilities agency might say, but that's where the rubber meets the road, in the language that's in the waiver, and they are all up on the CMS website so I would really urge you to take a look to try to understand that.

So how do you get these services? They are not mandatory in Medicaid. So again, you have to look at what your state offers. You have to understand the difference between the different waivers that the state may offer, and that could -- again, it goes back to looking at age limits and eligibility criteria, and it gets pretty deep.

But if you look at the waivers, you will be able to tell the difference. You also need to understand the waiting list process for home and community-based services in your state.

States are allowed to have waiting lists for these services. The government really doesn't get involved other than to say that waiting lists have to be fair.

I think it's good to advocate for home and community-based services in your state, especially in this fiscal environment, and most DD agencies have a way to sign up for bulletins. So I would suggest that people do that as well.

So plan ahead. When I was thinking about this today, there are so many things that I wish I knew 20 years ago that I know today.

Autism lasts a lifetime. School services end at age 21. And when they do, people with autism are usually served by states through the same developmental disability system as everyone else who has a disability that's not autism.

So waiting lists don't transfer from state to state. So you also have to be thinking about these things as a parent really early on, in terms of where you are in the waiting list process.

I also think it's really important to understand the Social Security eligibility process early on. So I would recommend that everyone visit the Social Security website or their local Social Security office before you have the need, because it's a very long and laborious process.

So really plan ahead, okay? Medicaid does not pay for rent or housing or food, and social security income is very low, $674 a month for an individual in 2011, and that's been frozen for a number of years now, and I don't know any place in the country where you can pay for room and board for $674 a month. So that's why I am saying I think you really need to plan ahead.

I think it's really important to understand your legal options when your family member becomes an adult, and think about, especially for people that might be more disabled than others, how can you help your family member maximize his or her self-determination and choice in terms of their life.

Also, a home of one's own in the community, I mean, George talked about adapting homes today. But I think it's really important to think about this notion of where is my family member going to live, really early on.

I know that I wish I had. So I am putting that out there. Again, there are long waiting lists for housing choice vouchers and it is, it is really important. It's hard because family members often live -- family members that have a person with autism in their family, it's so easy to just live in the moment and so hard to think about what it might be like in 20 years.

But it's so important. So this is what happened to me, okay? These are my children, Robert and Katherine, exactly 20 years ago, and on the right hand side, you know, you see them today.

I didn't put a picture of myself 20 years ago on here, okay? But I really wish that I had known all these things much earlier on. It would have helped me a lot.

And today I have wonderful children. My daughter is great. She really loves her brother. She is my partner in helping him make self-determined decisions about his own life.

So time flies. So I hope that I am leaving you with some good resources and an easy way to try to understand how you can maximize your use of these services.

And with that, I am going to turn

the presentation over to our partners, from the state of Virginia.

Mr. Price: Thank you Ellen. I appreciate the opportunity to be here and to share a little bit about what is going on in Virginia.

When I spoke to Ellen last week about her needs here, we kind of chatted I guess about half an hour about waivers in general and states in general, and really what was going on in Virginia.

So what I agreed to do is come and kind of profile what we are doing in Virginia, and really pick up on some of the things that we have been doing, particularly over the last five to seven years, under initiatives that we think are fairly significant to us, and what we also see is in the future.

So what I have -- now I don't know what we have here -- Arizona coming up.

Ms. Blackwell: We're going to fix it.

Mr. Price: Okay.

(Pause.)

Mr. Price: Well, I'll continue on. The -- as this catches up. What I -- the overview -- I want to start with a brief -- a state profile, and then start -- then begin to talk about some of the initiatives that we have done in person-centered thinking.

The Supports Intensity Scale is something that's done, a fairly significant event over the last several years that we have been developing, what we are doing with employment issues and also more recently, some state-wide crisis stabilization services which are not necessarily waiver-oriented but are connected to the wavier, we will be using some of the waiver services.

And then also, what we are looking at right now in terms of our waivers, and what for both the short run and also the long term.

I'll touch a little bit about -- on the Department of Justice that is currently, as most of you may know is, currently in Virginia, we are talking with them about a settlement agreement. There were some issues they found in Virginia.

And then I'd like to finish off with some state trends, state and national trends, and then issues for families to know and understand.

(Pause.)

Okay I will keep on talking and we will -- perhaps it will catch up in a little bit.

The -- in Virginia we have a system of local community services boards. We have 40 community services boards in our state that provide -- and they are the local public entity, and they provide all of intellectual disability case management services, as well as behavioral health case management services, and they are the single point of entry for all of intellectual disability services.

We also operate in Virginia five

state training centers. We have about 1,100 people living at our state training centers. They are our state-operated developmental centers, which is related to the slide I will talk about later about the Department of Justice I guess, and what we are negotiating at this point in time, that along with our waiting list.

We also license over 300 private providers in the state of Virginia for waiver services.

And then our department is a DD department, the disability department, and we operate the ID waiver, and which has about 8,700 people on the waiver.

It was created in 1991 and it serves children aged birth through adult. It is a comprehensive waiver including residential services as well.

We have 5,800 people on the wait list for those services, 3,000 of whom are on what we call the urgent needs wait list portion of that waiver.

Our -- the state Medicaid agency is called DMAS or Department of Medical Assistance Services. It's the designated state Medicaid agency. It administers all -- there are seven waivers in Virginia, and it administers all seven of them.

They operate five of those waivers, including the -- what we call the DD waiver, or it's the individual family and developmental disabilities services waiver.

And that was created in the year 2000. It is identical to the ID waiver that we operate except it's not comprehensive in nature in terms of it does not offer the residential component. It does do at home residential services but not an out of home placement service. It currently serves 792 individuals and has 960 people on its waiting list.

There are, and as we are talking about waivers and differences and know your waivers and know your states, some of the things that we are struggling with right now, and I'll talk about that later as we get into some of our waiver initiatives that we are wanting to implement.

Operating two different waivers under two different departments for people with developmental disabilities, one for people with ID and which does serve persons with autism, if they have an intellectual disability, and the DD waiver serves anybody with a developmental disability as long as they don't have an intellectual disability, does create some issues for us.

For instance when people -- you cannot be on both waiting lists, and you cannot receive both waivers. So if it turns out you are on the wrong waiting list at some point in time, you have got to start back over once that is identified; or if you are on the -- if you are receiving services on one of the waivers, there's not an easy way to transfer from one waiver to the other. We don't have an easy ability to do that.

So that does create some problems for us that we would like to address and we have been talking about a good bit lately.

One of the more significant recent initiatives that I really want to kind of talk a little bit about is in our person-centered thinking initiatives, that we really began more than -- really about six or seven years ago with one of the initial CMS systems transformation grants.

Our -- we partnered with our state university youths at the University Center of Excellence, VCU, the partnership for people with disabilities, and bringing in this first grant to develop person-centered thinking strategies in Virginia.

This was not the first time we tried that. We had done this many times before. Back in the mid-'90s I remember this being attempted.

And this time, when we sat down and started mapping this out, we said, this time let's don't stop. Let's make sure we continue this effort until we make this a statewide movement.

And there are many reasons that it failed in the past. I won't dwell on that now. But at this time, we through a series of not just an original grant, but other grant, and other grant opportunities, we continued the person-centered thinking process.

We partnered with Michael Small's organization, the supported development associates, and the learning community which he operates, to really create a systems change initiative in Virginia that really should result in a whole culture change over a period of time.

We have at this point in time as a result of our efforts in this, we have managed now to get person-centered thinking language into our waiver and also into our regulations, and have really moved forward with this, this change in a number of different ways.

What we have found with organizations that really bought into the top to bottom culture change, which is really what we are asking organizations to do, is that they have found that there are tremendous benefits, not only in the lives of individuals, but also in the ways they operate.

Every one of the organizations that have really bought into this have seen tremendous drops, even to the point of reducing incidences of peer to peer aggression all the way down to zero, simply because people's lives have changed, where they are getting more of what they are looking for and more of what makes sense to them, and have meaning for them in their lives.

So I really am a strong believer in this as a movement and something that is really important I think to our entire system as we move forward.

The other thing that went hand in hand with this was our adoption of the Supports Intensity Scale. It is a -- it was developed by the AAIDD as a person-centered assessment instrument. A lot of the assessment instruments that prior to this were deficit-based; this is something that really measures strengths and desires.

And so we began to move forward with that a few years ago and rolled that out back in 2009. We make that something as a part of our system, that a person needs to be assessed every three years.

So we rolled this out as a three-year program. The initial phase that would end in 2012 with everybody now in our Medicaid system by the end of 2012.

But with an intellectual disability we will have the Supports Intensity Scale assessment.

Many states have used that for --

oh good, thank you -- many states have used that for the -- who have gone into individual resource allocation, have used the Supports Intensity Scale for that.

One of the things that it does is that it does help to determine a level of need that a person might have and if you are able to equate that to levels of funding and this sort of thing, many states have been very successful in doing that.

We are currently looking at it as a possible use in determining an exceptional rate for certain individuals if -- for those folks who through the Supports Intensity Scale, and other, and other measures, might be determined to be eligible for something that we are trying to look at and create if we can go forward with this, to develop an exceptional rate for those for whom our current services, the rates do not really support their level of need.

Employment is another initiative

that we have been very much engaged in in the last couple of years. We believe -- I'd like to say that prior to 1991 when our waiver came in, Virginia was beginning to emerge as one of the leading states in developing support in employment initiatives, and we have continued to support employment.

However I think when the waiver came in, one of the unintended consequences of how we funded the waiver and how we developed the waiver services, with emphasis on day supports and how that worked, began to take away from the impact of employment initiatives, of the employment initiative, and many people chose day support because it's much more convenient to families, and much more convenient to individuals to have a 40-hour day where folks were -- could go to a program, many useful activities going on in the day support program, but they were not necessarily employment-related.

And so we are trying now to look

again at what we are doing with employment, and what are we doing that -- and what can we do better that would encourage more of an employment type of an environment for our folks in Virginia.

An Employment First initiative is something that we are rolling out this year. Our governor has adopted this and is going to be presenting a proclamation, or will be delivering a proclamation, announcing one, in October, an Employment First initiative for Virginia.

We are holding a summit in Virginia for that, and part of that summit really is to examine everything that is going on in our current system, what are the pitfalls or what are the reasons that we cannot use or cannot move forward more rapidly with employment as an option or as a first option for individuals with all disabilities.

We see this as something that we really want to move forward with and will be re-imported to the future of where our system is headed.

Another recent development is our crisis stabilization program. Our general assembly session this last year approved $5 million to begin a statewide system of crisis stabilization, really as an alternative to our institutional placements.

A lot of times what had been happening, our state institutions had been the backup for folks who were not easily served in our community systems, and so the -- we have contracted with Dr. Joan Beasley, University of New Hampshire for the START model and we are looking to implement this statewide, beginning sometime after January.

We have sent out RFPs and have been receiving those from the five different regions of our state, and we think this is going to be a very successful model to be used.

This is a program that North

Carolina has adopted statewide as well most recently and it's been used also in Massachusetts and other states.

And by the way, that stands for Systemic Therapeutic Assessment Respite and Treatment, that's what START stands for. It is a system really that uses both mobile crisis teams and respite to keep people in place where they live in the community.

Our waiver review that we are currently doing right now, we are -- as I mentioned we already have the two waivers, the ID waiver and the IFDDS waiver.

We are looking at both of those, and how they -- how effective they are right now in keeping people in place in community and out of institutional environments.

And we are looking that -- we are seeing that we are needing a couple of different things. One is some short-term range -- short-range fixes having to do with some late adjustments, hoping that we can implement this some time as early as next year, with permission from the general assembly or with approval; and also, some longer-range fixes that will coincide with the waiver renewals in 2013 and 2014.

As I mentioned earlier, we see some real promise in operating two waivers. We would like to see if we could combine these. There are some inherent kinds of issues in it we have got to work through. We have two different case management systems. One is a public case management system, one is a private case management system, we have two different ways of doing the waiting list.

So we have some things to work through in order to make that happen, but we do, we have a lot of interest in trying to do that, so that's something we are going to be engaging in over the next several months and hoping that we'll come up with a plan.

And one of the things that has happened also that I did want to touch on is related to our entire system in Virginia, is a study that was done on Autism Spectrum Disorders in Virginia, by -- a legislative study that was done, that really found a number of inadequacies in our Part B and Part C systems as well as our Medicaid system of services, and it really kind of began to create a push for our beginning to develop a more comprehensive system and doing something about this.

Our department was designated as the agency to coordinate the efforts in Virginia along these lines. One of the outcomes or initial outcomes of this was our being able to hire a couple of positions, one of whom is sitting next to me, it's Cindy Gwinn, who is our autism specialist and she will cover some of the next couple of slides for us.

Ms. Gwinn: Okay, thank you. So some of the really big things that have taken place in Virginia just in the last year, and one of them was with the general assembly passed the autism insurance mandate that will now allow families to receive ABA services, up to $36,000 in services a year, through their insurance companies.

There's still some things that we have to work out for that to happen, but it did pass the general assembly, so that is a large piece of -- a systems change within the state of Virginia and the insurance industry.

And with that, I'm going to skip down to bulletin three, our department, DBHDS, also created -- oops, sorry -- click slides, too -- created outpatient service guidelines so that board-certified behavior analysts may provide ABA services through EPSDT in the Medicaid service system for those on Medicaid, ages birth to 21. So that will increase the access to ABA services for those with autism, or suspected at a very young age with autism.

But that also means that we now need to create and build that capacity for

BCBAs within our own state.

The second bulletin, the Virginia Department of Education earlier this year provided a $1.4 million grant for funding to create the VCU Autism Center for Excellence.

And what the Virginia Autism Center for Excellence has done, is going out to school systems and doing an autism-specific, top-down, from administration down to direct support workers, making sure they are aware and understand autism, how to work with them, both in -- work with individuals both with an integrated setting, and within a community-based setting and transition services and everything that you could possibly think of.

Forty school divisions applied for the assistance, and for the first round they accepted 12 applications, but it was a very tight -- they had a very difficult time because the application packets were so well put together.

But the Autism Center for

Excellence also is doing free webinars with national speakers such as Kathy Pratt and -- my mind just went blank -- and other well-known individuals across the United States that are free on the webinars.

They are also doing a -- could you click for me -- yes -- we are also doing free training for Medicaid providers on strategies for working with adults with Autism Spectrum Disorders.

The training was actually created by the Virginia Autism Council, which are volunteers from across the state, across all different agencies and organizations and state agencies also who have knowledge and background with autism. We have some very well-known national individuals that actually reside in Virginia and have helped with these trainings.

We are working to try to make a baseline understanding and awareness across service providers when they are working with individuals with autism.

I have done five trainings so far this year. They are two-day trainings, 12 hours, very interactive. That helps the individuals who are taking the training better understand what it's like to be someone with autism and helps them with their empathy, and then we go into all the different environmental issues, sensory issues, communication and social skills.

So we are trying to get a baseline across the state so that everybody is on the same page before we go into more intensive trainings.

We are also doing these trainings for the Vocation and Rehabilitation Counselors at the Department of Rehabilitative Services. We are doing a train the trainer model.

In the past VRS counselors had not had much interaction with those with autism. Now the Asperger's community is knocking at their door and really need services and are very employable. They just need the appropriate supports put in place and we are teaching the VR system how to do that, and how to best serve these individuals, which goes back with the cell with the Employment First initiative also.

We also have one of our non-profits that's partially funded by the state. Commonwealth Autism Service has nine autism action groups that are created mainly in the western and southwestern part of the state where there are more rural areas of the state.

We get families and providers together to meet and learn each other, to know what their mutual needs are within their own region and talk to each other.

Most of the many times that I have gone to these meetings, they didn't even know any of each other existed. So we are -- come with autism services providing a facilitator for each of the nine groups and that's what's keeping the group going, by having that outside person assist and keep that group going for what their local regional needs are.

Okay? Commonwealth Autism Service along with the Department of Justice has also -- Criminal Justice -- has also created training modules designed for police officers.

All new police cadets must take this new training about autism so that police officers have autism 101 training. They are in the rollout this year of the basic autism awareness training. Next year they well be rolling it out to fire departments, and the year after that, the plan is to roll it out to EMTs for basic autism.

Once those are done, secondary modules will be done with more intensive information concerning autism.

And VCU is heading up a consortium of state universities and colleges in order to help produce capacity for BCABAs within our own state.

We currently have only one

university, and that's George Mason, that is able to provide the training that is necessary to become a certified -- board-certified analyst, and other universities within the state are able to do a class here or there and by bringing them all together we will be able to help create capacity within the state.

Other issues -- another big important system issue with autism is the early intervention system. Part C has created -- which is called Part C, an IDEA, created a free online module on autism in infants and toddlers, what every early interventionist should know.

And we have a draft copy now for parents and providers on how autism can work within the Part C system. Many times, in the Part C system, autism is not the initial diagnosis. It's just developmental delay. But there are signs.

So these are things that we want to get those interventions as we know, as soon as possible, to have the best outcomes for individuals.

And to help with the people who are working directly with the children, we have expanded or are in the process of expanding communities of practices in autism, called CoPAs.

So that gets the service providers together within their local region to talk to each other and learn from each other from what they are doing, addressing such topics as floor-time, pivotal response training, video modeling, iPad apps for children, which is a really up and coming thing at this point, and to talk about evidence-based practices.

We try to make sure that everyone is on the same page using evidence-based practices from the National Center of Professional Development out of North Carolina, and then it provides peer discussion for supports and strategies.

So those are just a few of the

things that are going on right now in the state. I actually have a list of about 41 things across the state, which is wonderful.

The JLARC report that Lee mentioned was a wonderful catalyst to bring things about. Department of Education came out with a wonderful, 100 plus-page document on autism in the school system, a guideline.

They also came out with a guideline for transition for the school system too. So by the end of this year, we should have guideline documents in the state of Virginia from Part C through transition, and then our next thing will be adulthood and how to achieve best services through adulthood for autism. Thank you.

Mr. Price: And my next slide coincides with I think Alison Barkoff coming in the room, who is with the Department of Justice, and my next slide has to do with our, our relationship with them at this point in time in Virginia.

Just very briefly, the Department of Justice did begin an investigation at one of our training centers and not only, their findings later not only found issues with the training center but also in our community system, and really our capacity in the community to provide the services that are needed for folks on the waiting list, and for folks moving out of training centers, as well as the speed with which we were moving people.

We have been in negotiation with them over the last several months, and we do expect a settlement agreement some time probably in October, and I think the results of that settlement agreement will be changing the profile of Virginia as we continue to move forward.

We have been changing all along. I think this will continue that change process. And it will be affecting people particularly in the way folks are served in our communities and are able to access the community system.

There's not much more that I can say on that. This is still in negotiation so I am going to move on to really kind of close out with some thoughts about what is happening with the state and national trends.

The -- I think most of you all are aware that really, resources are not growing in proportion of the population in need, so I think a lot of things that we as states are looking at, and I think the organization of DD directors, NASDDDS, is also trying to encourage states to look at, is really that we have got to take another close look at how we are delivering services.

I think a lot of things -- oftentimes when you create systems, and create services, you tend to stick with the old rather than really adapt to new ways of doing things.

So a lot of the things that we really created back in the '70s and '80s and even in the last decade are perhaps not the ways that are going to keep us on into the future, to sustain systems and really support people.

So I think one of the keys that we are all struggling with is how to begin to nudge the system in a way that really partners with families early on and throughout the life span, in a different kind of way, and that more expensive models of service are not really going to be sustainable for the long run for the numbers of people we have got to support.

Helping families early on support their individual loved one longer, and also as a person maybe is ready to move into services and supports that side of that, the natural family environment, that they are moving into systems that they have learned how that they can work in much more independently.

I think, as I kind of mentioned a while ago about employment issues, I think one of the issues about that when we saw the day supports come in, it became a -- it is an easy place for people to go, as opposed to really working through the whole idea of how do we help prepare people for employment, where they begin to earn more of what it takes to live, and rather than support people for the longer term.

Employment is not for everybody, for those that can move in that direction, that's something that we need to continue to push.

So really working towards greater independence is one of the keys to the future, and I think as far as families, and I'd just like to echo what Ellen said, is get to know your waiver system, know what the regulations say, and know that what drives our system really are the regulations.

They are written mainly to help navigate the system, but sometimes they seem to get in the way, and you need to understand, really, what they are, before mistakes are made, because sometimes things may not make as much sense to you as what it should.

But be an active advocate, and also I think align yourselves with other folks that have similar needs. The idea of being -- of aligning with disability-specific issues I think is something that really splits the resources in the system.

We are far more alike than we are different, so I think if we continue to work along those lines, we are going to be in much better shape.

Thank you.

Ms. Blackwell: Thank you Lee, and Cindy, for your very honest and you know, wonderful portrait of what's happening in Virginia, and I have to say here, you know, we talk about how every person with autism is different. Every state serving people with disabilities is different, and what you have heard from Lee and Cindy today is a portrait of what is happening in their state and you can hear from them you know, that there's dissonance between waivers, and dissonance between waiting lists.

So this is certainly not a unique situation and I think that Lee just summed it up very nicely: be aware, understand, it makes you a much better advocate.

So, any -- actually I think we may -- Lee it's up to you -- but we may want -- does anyone have questions or -- go ahead.

Dr. Groden: Talking about different states, I'm from Rhode Island. And in Rhode Island the governor had put in a $9 million cut for all the adult providers of DD services. The legislature changed that to a $24 million cut for about 40 providers.

So it almost make the programs unsustainable, in addition to new regulations. So I am wondering, you had mentioned that the Federal Medicare agency does really not have any input into that. Do they know about those changes? Do they have any input into something like that?

Ms. Blackwell: Sure. Any time --

Dr. Groden: Other agencies are getting increases so they have taken money away from developmental disabilities and given them to other agencies.

Ms. Blackwell: States have a -- as I said earlier, states have an immense about of flexibility in terms of how they implement these cuts.

States are making cuts in provider rates, in amount, duration and scope of services. So when cuts look like they could impact our beneficiaries and possibly not in positive ways, we always do an analysis of that in our system and work with our state partners to try to make sure that anyone participating in, for example, an HCBS waiver, is still going to remain healthy and safe in that program.

So we do look any time -- remember I talked about how states amend waivers, a rate cut would, if it's significant, would be something that we would look at.

Dr. Groden: So who would we be in touch with?

Ms. Blackwell: I would always -- I would start with your state Medicaid agency, and I alluded earlier to the 10 regional offices that CMS operates throughout the United States. In your region I believe Rhode Island is served by our -- the same office in Philadelphia that serves Virginia.

I am trying to think -- no, that's not right, our Boston regional office serves Rhode Island. So you know, if you look on the web you can actually look at which regional office serves your state, and I think that's actually -- that's another place where consumers and stakeholders can go to get information, and they are listed on the CMS website.

Mr. Grossman: We are going to have to wrap this up because we have to be back for the one o'clock presentation. But I do want to apologize to any of the committee members that are on the phone. We can't see you raise your hand obviously, so if you do have a question, you can ask at this time.

(No response.)

Mr. Grossman: Hearing none, we are going to break for lunch. I think Susan has some details regarding that.

Dr. Daniels: So lunch will be served in the restaurant that is just next door and they have a large table reserved for us that seats about 30 people and they have taken all our lunch orders so your lunch should be there and it will be on a plate.

We need to be back by one o'clock because I don't know if Department of Justice can be any later than their scheduled time.

So if you are not done with your lunch I have been told that you can bring your plate in here around one o'clock and continue and finish up your lunch and then it will be taken away.

And they will come around with your bill during the lunch so you can sign off on that and everybody is receiving per diem to cover their meal.

So thank you very much and we will see you back her at one. Enjoy lunch.

(Whereupon, the Subcommittee recessed for lunch at 12:27 p.m. and resumed at 1:09 p.m.)

Ms. Blackwell: Okay. Welcome back everyone from lunch. We are going to start our afternoon session with a bang, okay? Here we have with us our partners from the Department of Justice, who are doing just amazing work in the area of the Americans with Disabilities Act and the Olmstead Supreme Court decision enforcement.

At CMS, where I work, we work very closely with the Department of Justice and they work very closely with our states to monitor these really important issues that are such critical drivers of services for people with disabilities in the United States.

So we have with us today Alison Barkoff and Kathleen Wolfe. Alison is special counsel for Olmstead enforcement and Kathleen is the acting special legal counsel and trial attorney with the disability rights section.

So with that, I am going to turn it over to you, Alison. Thank you for being with us today, both of you.

Ms. Barkoff: Thank you very much for including us today, and we are honored to be here to talk with so many of the people in this room who are Federal partners in this work and other advocates who share our same values and have really helped with the momentum that the Department of Justice has gained over the last few years in enforcement of Olmstead.

As Ellen mentioned, I am a special counsel on Olmstead enforcement for the civil rights division, and part of my job is working across the entire department with all the sections that do community integration work, and I serve as a liaison in our work with other Federal agencies.

And as Ellen mentioned, we work closely with CMS and many of the other Federal agencies within HHS.

Today I am going to focus on talking about our Olmstead work nationally, on behalf of individuals with developmental disabilities including individuals with autism, and then Katie is going to talk about some of the division's discrimination work, specifically on behalf of individuals with autism.

And one of the best parts of my job, they created this brand new position and I think my existence in and of itself probably says a lot about how the department has made Olmstead a priority, creating a human being to kind of make this -- we have done this in other place in fair lending and so I think that should tell you from the beginning, they very much said this is where we would like to devote a lot of our energies in this administration.

And one of the best things about my job, I'm a long-time advocate, and they wanted to bring someone in who has a long time of experience doing this kind of work.

And part of my job is to reach out and engage stakeholders, and I really appreciate this opportunity to do this. We have reached out to other Federal agencies. We have reached out to advocates. We have reached out to people who have concerns about our Olmstead enforcement, and we have reached out to people who fully support it, we have talked with self-advocates, and every conversation I have is a very important one in informing our work.

Olmstead is a top enforcement priority for the administration. President Obama declared year of community living in

2009, and directed all of the Federal agencies including Department of Justice and HHS and HUD to make this issue a priority.

Over the last two years, we have I think -- our leadership had an oversight hearing earlier this week, so I did a count and I think we are involved in 35 matters in 20 states, and that compares with the past that you could count on one hand over the previous decade.

Our work ranges from settlement agreements, and I am going to highlight some of those, findings letters, and again I will highlight some of those, a huge amount of statement of interest on a wide range of issues, and a number of ongoing investigations and I can mention the ones that are public.

So I would like to talk a little bit about our priorities and the frame of the ADA. As you know, Title 2 of the ADA prohibits discrimination against individuals with disabilities by public entities, and our work in Olmstead is around enforcing the integration mandate regulation, a regulation that the Department of Justice was charged with promulgating and enforcing, which requires public entities to administer services, programs and activities, in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

And of course that one sentence has led to how many hundreds of court decisions, and everyone in this room, has spent you know, many, many hours of time thinking about what does the most integrated setting mean. It's certainly a big debate that is going on within our very own community.

The DOJ's regulations in the preamble define it as one that enables individuals with disabilities to interact with non-disabled persons to the fullest extent.

Twelve years ago the Supreme Court, in its Olmstead decision, interpreted those regulations, and found that unjustified segregation of individuals is discrimination under the ADA, and specifically found that states are required to provide community-based services to people with disabilities when such services are appropriate, individuals don't oppose community placement, and that community services can be reasonably accommodated.

And I think the decision itself really, I'm going to spend much more of my time talking about the values underlying this, but I think the decision itself even captures that.

And I'd just like to say a few of the words from the decision itself. The court said that the holding itself reflected two evident judgments, first, that institutional placement of people who can handle and benefit from community settings perpetuates unwarranted assumptions, that people so isolated are incapable or unworthy of participating in community life.

And I know everyone in this room

spends their time thinking about “how do we overcome those assumptions that people make about the capacities of people with disabilities?”

The second is that confinement in an institution severely diminishes the everyday life activities of individuals including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment.

And again, what we have spent most of our time thinking about in both the legal frame of these cases as well as the type of opportunities we are trying to create is “how do we provide people opportunities to live life like everyone else?”

And that's the frame that we at the Department of Justice have taken in our Olmstead enforcement. We view the integration mandate as requiring opportunities for true integration, that's independence, choice, self-determination in all aspects of life.

It's not just where you live, but how you spend your days. And how you can be a meaningful part of your community.

In addition, in our community there's been a lot of concern and particularly because this is a summit focused on services, you know, we have all learned lessons from the early deinstitutionalization days where it was so focused on let's people out of institutions and there wasn't as much thought given to ensuring that the service systems are in place to meet people's needs.

One of our big focuses is ensuring that there are quality services that meet people's needs, that meet everyone's needs, including individuals with complex medical or behavioral needs. Those are a population of people that have very much been left behind as we have been looking at our service systems, and we very much have embraced across the Federal government, a focus on evidence-based practices.

In our work we have also understood that as part of self-determination, choice is important, and that for people to be able to make a choice, they need to have information.

So we need to ensure that individuals and where relevant, their guardians, have sufficient information to know all of the choices that are available to them.

And that includes providing people and their families opportunities to speak with community providers, to visit placements, and to connect with other families and peers.

There's no other way to really help people understand how people can thrive in the community without making those peer to peer and family to family connections.

Based on those principles, I would just like to highlight some of the work that we have been doing at the Department of Justice on behalf of individuals with developmental disabilities.

A portion of our work has focused on people who are in or are at risk of entering state-run institutional settings. And we have been very active in enforcement in this area.

I want to talk about our settlement agreement in Georgia, which many of you may know about. It was really the first agreement that the Department of Justice has entered into that was an Olmstead-focused agreement.

It was one that focused actually on the entire system in Georgia, both the mental health side and the developmental disability side, people in institutional settings, and people at risk of entering institutional settings.

And in October 2010 the Department reached this comprehensive, court-enforceable settlement agreement and I will just talk about some of the highlights.

Again I think you will see that it incorporates the principles of ensuring that people have quality services, choices and meaningful opportunities in all aspects of their lives.

The agreement called for an expansion of home and community-based waivers for individuals transitioning out of the state's developmental disability facilities, as well as individuals on the wait list who are at highest risk of institutionalization.

As we know, in all of our states, there are far more people on wait lists than there are waivers. And so family supports are key in helping families be able to support individuals while they are at home, before they are on a waiver.

So again, the Georgia agreement included a significant expansion of family supports which in the state of Georgia, had previously been a very cost-effective way to help people avoid the kind of crises that lead to unnecessary institutionalization.

Again, in DD systems the glue is

often support coordination and case management and the Georgia agreement focused on expanding those opportunities and ensuring that case managers had appropriate engagement and caseloads to be able to play the role that they need to be able to play.

The agreement also called for an expansion of crisis services for individuals with developmental disabilities, and many states have kind of an outdated crisis model that is very focused on kind of inpatient crisis services.

But as we know, and really the DD community has learned from the mental health side, meeting people where they are, in their own homes, in their own communities, is the best way to prevent unnecessary, out of home placements.

So the crisis services in that agreement included mobile crisis teams and crisis respite, and quality management oversight.

So that's one example of what we have done, and again that impacted several thousand individuals with a range of developmental disabilities in Georgia.

In February 2010, the division issued a findings letter against the Commonwealth of Virginia, and I want to highlight what that findings letter said and the issues in that case.

This was a case involving the Commonwealth, both individuals who are in their training centers and individuals on their wait list who are at risk of unnecessary institutionalization.

Again, several thousand people on their wait list, and several thousand people who meet urgent criteria and we made findings in our letter that the Commonwealth unnecessarily institutionalized individuals in violation of the ADA, because of a failure to have sufficient community-based alternatives for individuals currently in the training centers, particularly for individuals with complex needs.

And on the at risk side, we made a finding that Virginia was violating the ADA by placing individuals currently in the community at risk of institutionalization because of a lack of sufficient community services to address the long wait lists, including services like crisis services and respite services.

And again, all of these documents, our Georgia agreement, our Virginia findings letter, are public.

In terms of meaningful days we also made a finding in the letter that in the range of community-based services not only were there issues with the lack of sufficient services to meet people with complex behavioral and medical needs, but that there was an over-reliance on segregated day programs and that there needed to be an expansion of integrated day opportunities, particularly supported employment within the state.

We have also been doing a lot, and as many of you know, as states have shifted their systems away from focusing on state-run facilities, we have seen that people have ended up in other type of facilities, in particular nursing homes, private ICF/MRs and that's another area where we have been very active.

And particularly for people with developmental disabilities who often you know, the DD facilities, the eligibility criteria there, particularly for people with intellectual disabilities, we have seen a huge influx of people with developmental disabilities in nursing homes.

The Department of Justice recently moved to intervene in private litigation filed on behalf of a class of approximately 4,000 individuals with developmental disabilities in or at risk of entering private nursing facilities in Texas.

And again, this is a case that very heavily involves a group of people who, many of these people had been supported well in the community, particularly you know, and their parents would age, a crisis would arise, and beds are in nursing homes.

Then people would flow in and there weren't the community alternatives, and the administration in Texas of their wait list also compounds the issues with getting people out of nursing homes and preventing them from coming in.

And many of these named plaintiffs in this complaint -- AHRQ is a plaintiff in the case and then there are some particular individuals -- and if you look at the stories in the complaint, many of these people lived very independent lives in the community. They would like to do that again.

For those of you who do work around nursing homes, if you have a vision that nursing homes are filled with elderly people only, that's not what we are seeing.

As we are going in and looking, we are finding younger and younger and younger people going straight from their homes into nursing facilities and again, this is an opportunity for the Department of Justice to begin addressing the issue of states' reliance on private facilities for people with developmental disabilities.

Employment is another area where I know the community; there's really over the last decade been a renewed interest around employment issues. It was something that in the DD community there was a lot of focus in the '80s and for a whole variety of reasons, many states, if you look at their data of people engaged in developmental disabilities, engaged in integrated employment opportunities, you would see kind of this graph of states going up, and then a huge decline.

And fortunately it's starting to get, again, on the radars of many of us in the disability community.

The Department's principal deputy assistant attorney general testified at the EEOC earlier this year on a hearing of employment of individuals with developmental disabilities and gave a keynote address at Case Western University a few months ago about the application of Olmstead to work.

And again, the Department's position has been how Olmstead isn't just about where people live. It's about how people live, and simply moving someone from an institutional setting into a community doesn't deinstitutionalize them, and it doesn't integrate people.

As we all know, work provides people with meaning in their day, with a way to have natural supports, and frankly a way for people to have some income to buy the small things in life that we all take for granted.

And so employment has been a part of everything that we are looking at, in our system reform agreements at Georgia, our findings in Virginia, and we have had other on the mental health side in Delaware.

Again, it's not just thinking about the intensive supports that keep people out of crisis and support them, but how do we help integrate people?

We have also been involved around children's issues, and I know that's a very big issues for people. In the autism community, there has been a lot of private litigation that involves the overlay of Medicaid's early and periodic diagnosis and treatment provisions, EPSDT, and ADA.

Those have been hugely successful in the private realm particularly around behavioral health and medical needs and the Department has submitted statements of interest supporting those in a number of cases, and you know, children with autism often are kind of cross-system kids and it's, you know, in different states some are served by the DD system, some are served by the mental health system, some are served by both.

But the intensive community supports, the social skills training and the behavioral supports are hugely important to this population, and again, we have been supporting that recently in litigation in Tennessee and Mississippi.

What we are all struggling with now, another area that we have been active is budget cuts, and as states are kind looking at their economic future, we have been really engaged closely with looking at how states are making choices.

And oftentimes we are seeing states look at a very short-term view and making cuts to services that are essential to supporting people in the community, that place people at risk of frankly more expensive institutional care.

We have probably been engaged in half a dozen statements of interest in states where again, we have very much been looking at the kinds of cuts states are involved in, and have been quite successful, private plaintiffs with support from us, in stopping many of those cuts that place people at risk of institutionalization.

And finally, before I turn it over to Katie, one thing that is so important, as we have been building up and ramping up this work, is that we provide guidance not only through our litigation, but literally through guidance, to advocates and consumers, and frankly to states, about the requirements of the ADA.

On Olmstead's anniversary earlier this year, we issued a technical assistance document literally, you know, 10 pages, single-spaced, about what the obligations of states are in terms of people living, working and receiving services in the most integrated settings.

We talk about budget cut issues, we talk about risk of institutionalization, and I would encourage all of you to look at that if you haven't.

And finally, one thing we did, and really messaging and outreach is hugely important, and having been an outsider trying to navigate the DOJ's website we know how hard that can be.

We started a website dedicated solely to Olmstead. It's where you can find every single thing that we have publicly done, our findings letters, our settlement agreements, our statements of interest, our briefs, testimony of our leadership, at www.ada.gov/olmstead, or you can just go to ada.gov and click on the Olmstead site. You can look by region of the country, by topic.

And hopefully, you know, people know by looking at that the priority that the division has made and the department has made to this work.

And I want to turn it over to Katie to talk about some discrimination cases, but again, we really appreciate the opportunity to be here and talk about our shared vision of how we are going to help move state service systems to truly integrate individuals with developmental disabilities.

Ms. Wolfe: Hi. Thank you. Thanks again. I am Katie Wolfe. I am a trial attorney and acting special legal counsel in the disabilities right section at DOJ.

And we really do welcome the opportunity to be here. I told Alison that I wasn't nervous until I walked in the room and saw everyone's names on their placards and it's very intimidating.

So, we -- it's great to be able to piggy-back on the momentum, you know in 2011 at this time, that the Olmstead teams have done such amazing work I believe at DOJ.

And I want to let people know, and our partners in other Federal agencies and state agencies, and families and advocates, that we also are here and ready to work with all of you on other issues related to discrimination against people with autism.

And we have the ability to enforce the ADA with respect to all three titles: Title 1, employment; Title 2, state and local governments; and Title 3, private entities.

And you know, we certainly do receive many, many complaints, particularly with respect to Title 3 entities, private businesses that offer goods and services to the public with respect to autism discrimination.

I thought what might be helpful and would also hopefully leave some time for questions is to just talk a little bit about two matters in 2011 that we have done, sort of two ends of the spectrum of the kind of work that we are able to do for to further the nondiscrimination mandates of the ADA with respect to autism.

And that would be litigation that concluded in a Title 3 pattern of practice case against Nobel Learning Communities, Inc., which is a private for-profit school chain of 180 schools across the country.

And on the other end of the spectrum a statement of interest recently filed in a case involving a seven-year-old child with autism who uses a service animal in his public schools.

So, one Title 3 matter and one Title 2 matter. Before I get to that, I will just say that we do also feel that our work right now in this area has been invigorated by a couple of changes in the past year.

And that includes the passage of the ADA Amendments Act in 2009, which has really brought in the protections available to people with disabilities in terms of correcting some of the missteps that occurred as far as who has a disability under the ADA over the last 20 years.

And what we are able to do now, we feel, is really go right to the merits, rather than wasting a lot of time and energy fighting over whether a particular person is a person with a disability entitled to the protections.

So now we are really getting to the heart of the discrimination cases that we have been wanting to bring and look at and resolve over the last 20 years.

The other great thing that has happened from our perspective is that we recently issued our revised regulations under Title 2 and Title 3 of the ADA, and many of these provisions reflect our experience over the past 20 years in enforcing the ADA, and some of the changes in technology and some of just the practices that we found really needed to be set out more clearly in guidance.

And specifically, some of that occurs in the service animal context. It's been very helpful, we believe.

So, turning to the first matter I mentioned, United States versus Nobel Learning Communities. This matter arose out of a few complaints that we received maybe four years or so ago, from an attorney who represented a couple of families in Pennsylvania whose children had autism.

These children were approximately three years old and attended Chesterbrook Academy School up in Pennsylvania. It was a childcare center/preschool/elementary school.

We spoke with the attorney and what we found, and very quickly thereafter received three or four or five more complaints from Pennsylvania about the same system.

We heard the same story over and over, that these children, these families of these children three years old, their children were enrolled and there was some sort of management change, and then all of a sudden in the course of about six months, the families were each told that their child could not remain at Chesterbrook Academy, never should have been enrolled in the first place, would have to provide an IEP for them to review for them to even consider whether they could remain, and that regardless, they would need to be out in short order.

We opened an investigation. We substantiated the facts from our perspective. We then found, through further investigation, at least by the time we filed suit, we had 13 named children in the complaint that covered seven schools and five states, covering Maryland, Texas, California, Pennsylvania, of course, and Illinois.

And in each case the stories were very, very similar. I believe all the children had Autism Spectrum Disorders. One had Down syndrome, a three-year-old child who was denied admission.

We saw that. We tried to resolve the matter and could not informally, so filed suit in 2009. The discovery and litigation proceeded for two years, and resulted in a settlement agreement issued or entered with the court in early 2011.

Just to give a little background about the allegations that we felt were at issue, we very closely looked at the Title 3 regulations, which also track Title 2. So whether this would be a private school or a public school, essentially we would be looking at the same things.

And we alleged violations of the eligibility criteria regulations and also significantly, the failure to make reasonable modifications.

With respect to the eligibility criteria, what we saw over and over again in discovery that we reviewed was allegations that one of the ways that they were excluding children was by saying that no non-Nobel employees could be on the ground working with children.

So children who had itinerant teachers or people coming in from their local education agency, coming onto the grounds at Nobel, could not then attend the school. That was used as a reason that they could not be there because they would have to have a non-Nobel employee on the grounds.

There were a variety of different purported justifications for why the children couldn't be there; either they couldn't meet the academic criteria, things like that.

So after two years what resulted was a settlement agreement that is on our website. It's a comprehensive approach to dealing with the reasonable modification issues in these cases, and Nobel agreed not to impose eligibility criteria, and also to put in place very clear and specific procedures by which families of children with disabilities could request modifications and then procedures to review those and offer those, where they wouldn't result in a fundamental alteration or undue burden, and that is available on our website at ada.gov.

On the other end of the spectrum, we have also, like the Olmstead team, started using a lot of these statements of interest and recently, shortly after our new regulations went into effect on March 15th, 2011, we were able to issue a statement of interest in a case in California called CC v. Cypress School District.

And that case involved a seven-year-old boy with autism. He was non-verbal, severe autism, and he wanted to bring -- his family wanted him to have a service animal in the classroom with him, and the school district would not allow that.

The IEP team had determined that the dog was not necessary for the child's educational needs, that an aide could do the same things that the service animal would do, essentially, so that they would not allow the dog in the classroom.

The family filed for a preliminary injunction, and this is one of those ways in which we can sort of -- I think the family reached out to the U.S. attorney's office in the area, and we have a U.S. attorney program which allows us to work with the U.S. attorney's offices around the country and sort of leverage our resources, and also learn about cases such as these.

And through that connection, we then worked with the family, and the U.S. attorney's office, and wrote a statement of interest in which we set out very clearly our position that under Title 2, any individual with a disability has a civil right to have a service animal with them in a public entity such as a school, where the animal performs work or tasks for the child.

We did not see this at all as an IDEA issue. We saw this as a Title 2 issue by which the child had a right to have their service animal.

We do have new regulations under Title 2 now on service animals, which help to clarify the matter. Previously the service animal regulations were only under Title 3, but had been routinely read into Title 2 by the courts, but now this definitely makes things clearer for everyone.

The court agreed with the Department's analysis set out in our statement of interest, granted the preliminary injunction and CC and his owner are in the classroom in California today.

So otherwise, you know, we have a very, a large group of attorneys. The disability rights section is one of the larger sections in the civil rights division and we are a section of families and a lot of parents, parents of little children, and of grown children, so issues related to children and grown children with autism are very close to many of us, and we do feel it's a real privilege to get to work on them, so we welcome any partnerships or collaborations that are out there to further that mission.

And now I open the floor.

Ms. Blackwell: Alison and Katie. Thank you so much, it's just so wonderful to hear you articulate these really important precepts, that just drive so much of our work at CMS and so much of the work of the states.

I wanted to point out that Alison, the guidance you mentioned, the statement about ADA and Olmstead, it's in everyone's packet at the table.

And for the people that are listening on the phone and watching the presentation today over the internet, it's also up on the IACC website. There's a link up there already. So I would suggest that you look at it.

And I am going to open the floor for questions but I just wanted you, for one second, and it's in the guidance as well, to mention how easy it is to file a complaint and maybe talk about the importance of letting the Department of Justice know when these sorts of things happen, because I know at least at CMS, we want to know what's going on so we can fix it.

Ms. Wolfe: Yes, thank you, that is a very, very good point, and it is very easy. You can go on our website at ada.gov and there are instructions on filing a complaint. You can fax it in. You can write it in. You can even call.

And I actually receive voicemail messages all the time from people who have a complaint, and I immediately forward those to our intake team and then people get a call back.

There is in fact -- there's a Title 2 complaint form on the website that can be filled out or people can just write a letter or they can send an email, anything that looks like a complaint or smells like a complaint, we consider a complaint, and make sure that it gets reviewed.

Ms. Barkoff: And I'll just add, in addition to the formal complaint, I mean, part of my job as I mentioned is doing outreach, and I probably should have had some kind of handout with my contact information so I can pass around a card of Ellen can put that up on the website.

But you know, I am always happy to talk to advocates about what is going on in their state. I know people feel like it needs to maybe be at a certain place to file a complaint and I do lots of -- and our Olmstead teams do lots of talking to advocates on the grounds about you know, lots of different things that are going on in terms of changes in their state system, and you know, identifying -- they know a problem, they are not sure how systemic it is.

So, you know, I'll also invited you in addition to the kind of formal complaint process, to also use us as a resource. We often talk to advocates who may be doing their own work in their own states and there may be a role for us or not, or want to talk through issues and so again, don't feel like it has to be at the formal complaint kind of place, at least on the Olmstead end of things before you can do some reaching out informally.

Ms. Blackwell: With that do people in the room have questions? Ari, it looks like you have a question.

Mr. Ne'eman: I actually have two questions if I may, one for Katie and one for Alison.

Katie, I am wondering if you could talk a little bit about DOJ's work to do outreach to various communities to educate them about their rights under the ADA.

I know one of the challenges, particularly with regards to the needs of adults on the autism spectrum, in asserting our rights, is that in part because of, you know, the past history, fortunately now fixed by the ADA Amendments Act, of narrow traditional definitions of disability, and in part simply because of a lack of available information, people are often not aware of what recourse they have available when they are discriminated against.

So could you speak to DOJ's capacity to do that kind of outreach, and you know, who are some of the people -- who the people in this room can be speaking to when we want to work with DOJ to communicate that information out to our communities.

Ms. Wolfe: Absolutely, I mean, that is a great question and a great point. We have a speaker's bureau in the disability rights section. We also have Sally Conway is the deputy chief of technical assistance and mediation, and she really spearheads the section's outreach efforts and coordinates.

Through the speaker's bureau, anyone can request that a DOJ attorney or investigator or staff member appear at their event and speak, and we get many, many requests and we do as many as we can.

We also use the U.S. attorney's offices to do outreach, and each of the U.S. attorney's offices involved in our program, and that's most of the attorney's offices, have an individual who does affirmative civil rights enforcement and works on ADA issues, and they know their local communities and they do outreach in each of the 50 states.

We do try to attend what we can, and when we get invited, we were at the White House conference where we met many, many families and advocates of people with disabilities during the autism awareness month in April.

But absolutely we could do more, and we would like to do more, so ideas are welcome, and invitations are welcome as well.

Mr. Ne'eman: Thank you so much for that by the way. My other question for Alison, was so we know that a few states have not only shut down all of their large state-run institutions, but have or are moving to shut down all of their ICF/MR settings as well.

Is that a trend that DOJ you know is or can be doing anything to get behind in advance?

Ms. Barkoff: You know, I think from the perspective of Olmstead, you know, there's two principles there, I mean, the first in terms of people's rights is that people have the right to be served in the most integrated setting appropriate, and I talked through some of those.

And what we have seen in virtually every state that we have gone to that has a system that is heavily invested in institutional care, is that people in those situations don't have other options, and many of them prefer other options.

So you know, to the extent that our work is certainly about creating other options, and helping people have those opportunities.

You know, from a policy perspective and certainly a lot of the work that we are doing with CMS, and when we are looking at states, and states are going through rebalancing and literally that is the term that CMS uses, I mean, certainly MFP and other types of programs, there are now new enhanced matches for states that are working on rebalancing.

And so part of what we are looking at in trends in states is states that are rebalancing their long-term care systems from ones that are traditionally very focused on institutional care to providing other alternatives.

I know there's many, many CMS people in the room who are far more fluent than I am, although I am kind of a Medicaid-y person myself, but you know, there have been, there are some great new options.

And one issue that we found in many states that we go to is for individuals with non-ID developmental disabilities, there really has been a problem with the use of waivers, because often, finding the traditional waivers require cost neutrality and identifying the institutional you know, alternative.

And so if you are in a state that has ICF/MRs, not ICF/DDs, then what is it that you are going to be using.

And so there's some great new opportunities and one of them being the 1915(I), that had been out earlier, you know, as part of the Deficit Reduction Act, and then was, because of ACA, you know, there's going to be new guidance at some point around those.

And you know, as someone who, my background before coming here was at the Bazelon Center for Mental Health law, and so again in the mental health community, because there wasn't Medicaid funding for example of psychiatric facilities, waivers just didn't work for people, really, for mental illness.

And there were a lot of populations that got left behind on the traditional 1915(a) waivers which is -- really helps states rebalance.

And I think there are a lot of great opportunities with the 1915(I), other types of opportunities to help do the rebalancing, the MFP

So I think it's a combination. Again, I am a systems person and I look at both what are the legal hammers we have. I think Olmstead requires states that are overly invested in institutional long-term care, to do rebalancing.

And I think frankly on the carrot side, thankfully we have kind of shifting policies in Medicaid to help create incentives for states to do that. And I hope that answers your question.

Mr. Ne'eman: It does thank you.

Ms. Blackwell: Daniel.

Mr. Davis: Yes, thanks to both of you for your excellent presentation. I wanted to get a sense, because we are hearing a lot about the states right now and budget challenges, what would you say is what you are hearing from the states right now in terms of are states cognizant of the fact that even in times of tight budgets, they still have legal obligations to meet, or is it really taking a lot of work to get that across?

Ms. Barkoff: I think the answer to both of those questions is yes. I mean I think states are cognizant and I think frankly CMS has done a good job in terms of stating -- you know, there is a difference between -- you know, the incentives around Medicaid when it was drafted many, many, many years ago is of course you know, all the mandatory services are not the kinds of services that now, many, many, many years later are the services that we want our systems to really focus around.

And all the optional services are the -- the rehab services and the waiver services are where we really want states to invest.

And as states are kind of looking at what can we do with our Medicaid systems, unfortunately the things that are in the optional side are the things that we all need.

You know, again, I think CMS has done a lot on the policy side to create some incentives, financial, you know FMP and enhanced FMAP on community first choice and other types of services to incentivize.

But I do think that as reflected by our half a dozen statements of interest over the last year, the reality when states you know, a governor says to a DD agency, 10 percent across the board cuts, that happens.

And so you know, I think for the most part, again, putting on a policy hat, it has in some ways, it's very problematic particularly when states are cutting services that are essential to supporting people in the community.

On the other hand, I do think it has given, particularly in states where their agencies can collaborate with stakeholders, a chance to step back and say how do we better use our money, and what are the services that are most important?

And particularly on the DD side, where states are heavily invested in very expensive institutional care, I think some of the shifting we have seen you know, hopefully is mostly driven by wanting to do the right thing.

But the money makes sense on those sides, and again, maybe some of the shifts that we are seeing in the mental health system is reflective too of all state money paying for a state psychiatric facility versus being able to Medicaid-ize some of the community services.

So I think as advocates on the

policy side, helping -- helping states understand you can make the pot bigger by leveraging Federal funding, is an important message and helping to work with your agencies to figure out what are the essential services to helping support people are really important.

But you know, we have had to be there with the hammer and we have done it and frankly successfully, in probably about half a dozen suits at this point.

Mr. Davis: Thank you.

Ms. Blackwell: I would just add, to build on what Alison said, that she is absolutely right. At CMS we are always willing to work with our state partners to strategize about how they can use some of these new flexibilities to optimize what is happening in their systems.

But in addition to fiscal stress, I think there is also an element of stress on state staff, because their staff has also been impacted by these budget cuts.

So there's sort of an additional layer of challenge and I also wanted to mention, Alison, I said this earlier, and I think it bears repeating again, that in terms of families planning ahead for where their family member will live, it can't start early enough because of, you know, what are the mandatory benefits in Medicaid and what are the optional benefits.

So it's really important to think about you know, what will happen 20 years down the road. Do we have any questions from our IACC Services Subcommittee members that are with us on the phone?

(No response.)

Ms. Blackwell: Anyone else in the room?

(No response.)

Ms. Blackwell: Okay, well thanks you guys. That was really great.

(Applause.)

Ms. Blackwell: Okay. So next we have a panel on managed care delivery systems and people with disabilities, and this is a topic that I talked about a little bit earlier, really important in terms of what's happening in the Medicaid program right now.

And I think we have some excellent representation today from our states. As I said this morning, states are really looking at ways to maximize their bang for the buck, and managed care presents a lot of opportunities in terms of predictability of expenses, increased care coordination and just overall fluidity within state systems.

So our first presenter is from the first state that really effectively used managed care delivery systems for people with developmental disabilities, the state of Arizona, which in 1981, joined the Medicaid program using a Section 1115 demonstration waiver.

Our second presenter is Chris Butt,

who is with the Hawaii department of human services, and as Chris will tell us, Hawaii went to managed care delivery systems for its home and community-based services several years ago. Its developmental disabilities population remains in a traditional fee for service system.

But Chris's state has a lot of experience with moving four of its five Section 19158 waivers into managed care, and interesting stories, I'm sure Chris, we will hear from you.

And yes, poor Chris, you win the prize for coming the longest today, the longest trip.

And Pia Newman and Nina Wall-Côté are from the Commonwealth of Pennsylvania and they are going to talk about -- Pennsylvania is unique in that it actually has a Section 1915(a) waiver that is targeted to adults with autism, and the state also operates a Section 1915(a) contract that is looking at using managed care delivery systems to deliver the same -- virtually the same set of services that people in fee for service get.

So I am very interested, and all of us are, in hearing about Pennsylvania's experiences as it stepped into the world of managed care delivery.

So with that, Jami, I will let you kick off. Jami, again, is with the Arizona Health Care Cost Containment System. It's sort of a mouthful. And we really appreciate your coming to be with us today Jami.

Ms. Snyder: Well, I understand that Chris gets the award for coming from the state that it is farthest away, but I certainly get the award for coming from the hottest state.

It's really a pleasure to be here with you, particularly to have some brief respite, if only brief, from the 106 degree weather that we are still experiencing in Arizona.

I am going to talk a little bit today about the history of our waiver, and also talk to you about what I think really helps to make our program a successful managed care program that serves people with disabilities.

And I really think there are a couple of components that need to be in action if you are going to -- in order for a managed care system to be successful in serving individuals with disabilities.

That first component really is a commitment to individualized care that meets the needs of each member within the system.

And then I think the second component that we focus a lot on at Arizona's Medicaid agency is stringent oversight that really balances the interest in ensuring efficiency and cost containment, against the interest in providing quality care to members.

And so we are always sort of keeping our eye on that quality component as we factor in the efficiency measures that we need to factor in in order to effectively manage care.

Okay, just to give you a little bit of history and Ellen gave you some as well on our waiver. In 1982, HCFA at that time anyway granted Arizona its 1115 waiver, and the Arizona Health Care Cost Containment System, which creates fear in and of itself, the name does, although it shouldn't, began serving people in its acute care program.

So the acute care facet of our Medicaid program rolled out first in 1982, and as Ellen mentioned, Arizona was the first state to implement a statewide Medicaid managed care program with capitated payment arrangements.

The long-term care portion of our state Medicaid program, managed care program, rolled out in the late '80s, so it's been around for a little over 20 years.

In 1988, we began phasing in the

component of our program that serves individuals with developmental disabilities, and in 1989 phasing in the segment of our long-term care program that serves individuals who are either elderly or have physical disabilities.

We have four guiding, or five guiding principles rather, in our long-term care system, that we focus on a lot, even in the midst of providing oversight to our health plans, to our contractors. We are always referencing to our guiding principles.

In fact we recently completed a procurement, a procurement on the side of our program that serves individuals who are elderly and have physical disabilities, and we asked our bidders to reflect upon these guiding principles in their proposals notably in their written proposals, but they also had an oral presentation in which they had to reflect back these principles through a couple of case management scenarios.

So we are really always trying to reference back to these, and I think that's really an important part of ensuring quality care in the midst of a managed care system.

So, member-centered case management, consistency and continuity of services, accessibility of the network and I'll talk a little bit about what we do in that arena shortly, service in the most integrated setting possible, and collaboration with stakeholders.

In our long-term care system in Arizona, we really pride ourselves on working really closely with our health plans to ensure that their interest is the interest of the member.

So our relationship, while it remains a regulatory relationship where we are providing really stringent oversight, there's also a pretty strong technical assistance component to that relationship with our contractors as well.

To give you a sense kind of of our model, we receive over 2,700 applications to our long-term care system a month.

Our financial -- of course there's financial and medical eligibility criteria for a long-term care system, and you can see those criteria up there.

Individuals must be at or below 300 percent of the Federal benefit rate, which is about two thousand -- just over the $2,000 mark in income per month.

And then we have a medical assessment tool that is conducted by either registered nurses or social workers, and if there's questions around the assessment, it's reviewed by a physician to determine medical eligibility for members, and of course the threshold for medical eligibility is at risk of institutionalization.

There are two components to our long-term care program, one component that serves individuals with developmental disabilities, including individuals with autism, and that's a component that is administered under the state Medicaid agency in partnership with the division of developmental disabilities, which is housed in our department of economic security.

So it's a sister agency so we have an interagency services agreement that guides all of our oversight work with the division of developmental disabilities.

And then the other side of our long-term care program is the component of our program that serves individuals who are elderly or have physical disabilities.

And currently we have four contractors that work on that side of our program: Bridgeway Health Solutions, a Centene company; Evercare Select, a United company; Mercy Care, an Aetna company and SCAN Long Term Care Services.

Up until -- and I should mention that those four entities will begin serving as our contractors on that side of our program on 10/1. They are all current contractors, but until -- up until the present, we have also had county-based programs that served members in certain counties in the state of Arizona. Those entities were not successful in their bids during the last procurement process, so this is really reflective of our 10/1 contractor array.

And the contractors all hire case managers, which work very closely -- and on the DD side they are called support coordinators which work very closely with members both at the onset of enrollment and throughout their tenure with the Medicaid program, to ensure that members are getting the services that they need.

You can see the service array much reflective of Ellen's presentation earlier, which talked about the sort of the standard service array in an HCBS program, and I will talk a little bit about the acute care component in a moment.

Acute care services, nursing facility services, ICF services, hospice, behavioral health, and then really the full array of HCBS services as I mentioned, homemaker, personal care, respite care, attendant care, is the most used service within our HCBS program.

And in terms of when you look at -- and this is something that Arizona really prides itself on, in terms of our Medicaid program, and we really believe that what you are seeing here is a representation of our commitment to serving people in the most integrated setting possible.

On the elderly and physically disabled side of our program, we have just over 25,000 members, and over 72 percent of them are served in an HCBS setting, and on the DD side of the program we have almost 24,000 members and 99 percent of members are served in HCBS settings.

So that's something we are very proud of, and I think it has to do with a couple of factors. It really does have to do with our commitment to integrated care, but it also has to do with the fact, as you may know, that Arizona is a fairly new state and did not ever institutionalize at the level that other states did.

In terms of the components of a managed care system, the key components of a managed care system, in terms of serving individuals with disabilities successfully really, for us, one of the most important aspects of our system is that it's really representative of an integrated continuum of care.

Our system under our waiver program, our long-term care system, not only provides long-term care services which are largely HCBS-based, but we also provide acute care services as well as behavioral health services.

So it's a comprehensive, long-term care program which really allows for more continuity for the member, both in terms of their services but also in terms of care coordination as they work closely with their case manager or support coordinator.

Of course, an important component is the commitment to serving members in the most integrated, appropriate and cost-effective setting possible, and even beyond the service planning process which is very extensive, and is updated on a quarterly basis, in order to determine cost effectiveness, we have what's called a cost effectiveness study, which we implement with every member who is appropriate for a home and community-based setting, which really determines whether home and community-based services could be implemented more cost effectively than the most appropriate institutional placement.

And that's really highly successful

overall in keeping individuals in their home.

Of course the ongoing commitment to self-directed models of care, we are very, very fortunate in Arizona on the EPD side of our program, to have a program called self-directed attendant care where individuals with disabilities are able to hire, fire and manage their own attendant care worker, with the help of a fiscal employer agent that manages kind of the withholding and all of the liabilities associated with just sort of the paperwork of employment, or sort of guiding an employment situation.

And we have a similar structure on the DD side of our system, where they have a very expansive independent provider network and in that case, members or their representatives also are able to hire and fire their own service providers with the assistance of a fiscal intermediary, which is basically the same as a fiscal employer agent on the EPD side of the program.

We also allow for spouses to act as caregivers. We have a spouses caregiver program. The maximum number of attendant care hours rather that a spouse can provide in a given week is 40 hours.

And we are now in the process of pursuing community first choice as an option under the Affordable Care Act, which we are very excited about.

And we think that that option will allow us to expand our service array one more level to an agency with choice model where the member -- I'm sorry -- the provider acts as the employer of record but the member has the full authority to dismiss or to hire the employee.

So it's really the provider working in concert with the member and providing a little bit more security to the member, but allowing them to be self-directed as well.

And then of course coordinated and informed case management, that goes without saying, broad array of community settings, we have very strict network standards, where we dictate for all of our health plans, our contractors, that they have a minimum number of nursing facilities, assisted living settings, or alternative residential settings in HCBS providers in every county in the state of Arizona.

And then for our larger counties, where Phoenix and Tucson are based, we actually break it down into regions and have minimums according to region.

And then finally, the availability of resources to facilitate the transition into the community. Just last year we were approved to implement a community transition services program, which provides up to $2,000 every five years to a member who is transitioning from an institutional setting into a community setting for things like security deposits, essential furnishings, moving expenses and how to set up fees for utilities, and that's been very successful as well.

As I mentioned, sort of that second tier I think in terms of a successful managed care system serving people with disabilities is state oversight.

And we are very committed to oversight within the Arizona Medicaid program. We have very detailed contractual agreements with our health plans, as well as policies outlining both operational aspects and care management aspects of our program.

Annually, we conduct operational and financial reviews of our health plans, and we look at things such as, in the case management arena, the maintenance of caseloads -- we have very strict case load ratios -- training and orientation of case managers, whether the cost effectiveness study is being implemented according to policy, whether time lines for both initial contact and visitation are being met.

We conduct chart reviews in conjunction with this operational and financial review, and we in addition to those chart reviews, we conduct member satisfaction surveys where we speak directly with the members about their experience in working with the health plan and specifically with their case manager, and whether they feel that their services are representative of their needs.

We also look at things like the plan's delivery systems, their encounters, encounter submission, administrative requirements, grievance systems, time -- in terms of meeting timelines and processes, of course quality management measures, because we have an acute care component to our program we look at things such as PCP, primary care physician, record maintenance, training of primary care physicians on things such as behavioral health referrals and how to make appropriate behavioral health referrals within the system, and components such as that.

Of course our quality management system is essential to oversight. We have very robust quality management measures. One measure that we look really closely at is the initiation of HCBS services within 30 days of enrollment and we regularly produce reports on that.

The benchmark, or I should say in our last report, our last quarterly report on that particular measure, our contractors on average were at 97 percent in terms of the initiation of HCBS services within 30 days of enrollment.

So we were really happy to see that kind of outcome from our contractors. Regular case management monitoring and training, monitoring of claims payments, of grievances, our monitoring of grievances I feel like is sort of our -- our most -- sort of the most direct feedback that we receive from members in terms of how they feel the health plan is performing and whether they feel like they are obtaining the services they need.

We look carefully at the grievances and specifically upward trends in grievances from month to month and if we do see an upward trend, we confer immediately with the health plan and talk with them about why they are seeing that trend, and try -- immediately implement corrective action if we feel that there is -- there's a situation which requires further review and ongoing review of the health plan.

Medical management, utilization management of course is important in a managed care system, looking carefully at their notices of action, making sure that notices of action are -- are produced in a timely fashion and produced in a manner that's understandable to the member, so they can clearly understand what the notice of action is telling them when a service has been denied or reduced.

And we have very carefully constructed targets for HCBS placement, which

I think is one of the reasons we have been successful as well in terms of our percentages around HCBS placement.

We watch the contractor's performance on a quarterly basis to ensure that they are maintaining the threshold that we have established, and that placement, that HCBS placement rate of course gets factored into their capitation rate -- the capitation rate-setting process each year as their new capitation rates are set by the -- set by the agency.

And I think that that covers -- covers most of what we do in terms of contractor oversight on a really general level, but certainly as the panel wraps up I would be happy to answer any questions about how in Arizona, we have implemented a managed care system that we feel serves individuals with development disabilities and individuals with physical disabilities, in a way that is consistent with our values.

Ms. Blackwell: Thank you Jami and I am sure people will have questions at the end. So Chris, I am going to pass the mic to you, and maybe you could tell us a little bit about what Hawaii has done.

You know as I said, Arizona started down this road first, so Hawaii has now gone down the same path so we want to hear more.

Mr. Butt: Well and again, thank you. It is a pleasure to be here and again to finally put some faces with names, and of course like I said, it's a delight to follow Arizona, who we are so closely aligned to.

I am here to briefly talk about I guess managed care for our ABD population in Hawaii, so let's get started.

Our ABD population gets managed care through what we call QUEST or QUEST Expanded Access in the state of Hawaii, and that's a relatively new program we got in 2009.

Just to give you some basic

figures, our Medicaid population in Hawaii for QUEST is about 225,000, and our QUEST Expanded Access is about 40,000. So all together our Medicaid population is about 265,000.

Just a quick distribution by age. As you can see, we don't have that much under the age of 21 and a pretty fair even breakout from 22 to 64 and 65 over, so again, mostly adult population.

And again, I don't know if you are familiar with Hawaii's geographic breakout, but we are an island state so again that's our distribution by island.

And you can see here our ABD population, or I'm sorry, our DD/ID population out of our total ABD population so we are looking about 3,500 ABD people, I'm sorry, DD/ID people.

And again, our DD/ID members receive Medicaid services through a managed care organization as part of our 1115 waiver, and Ellen, you kind of alluded to that earlier.

So our case management, home and community-based services, and DD/ID services are carved out of the 1115 services and provided through a 1915(c) waiver operated by Hawaii department of health's DDD division.

Again, access to the system. An initial evaluation is provided by the state of Hawaii department of health developmental disabilities division.

If DDD determines a member is Medicaid eligible and would benefit from DD/ID services, a referral is made to the state Medicaid agency for determination. The member is enrolled in a health plan if not already enrolled.

Now again, the unusual thing about Hawaii is in we are kind of a hybrid as you mentioned. So our DD services are through a fee for service program.

That has caused some issue that I'll talk about later, but basically, the

DD/ID member in QExA has both a case manager assigned by DDD, and a service coordinator assigned by the health plan.

The case manager is the primary person to help the member navigate the healthcare system, and the service coordinator is responsible for coordinating the medical-related issues.

And again, so the medical services are through managed care, but again our DD services are through fee for service.

The case manager develops the ISP and conducts the annual meetings as needed, whereas the service coordinator attends the ISP meetings if invited.

The Med-QUEST Division facilitates communication between the health plans and DDD. So again, we are kind of that conduit between the two elements of our system and the state agency basically acts as a broker or coordinator for those two entities.

Again, MQD meets -- that's the

state agency -- meets with DDD regularly for status updates and resolution of any operational issues, and again, we meet monthly with the MCOs to discuss any kind of operational situations that arise.

Med-QUEST has facilitated joint training for health plan service coordinators and the DD case manager counterparts, and again, this was a key component of our implementation.

As I'll talk about later, with frictions within the system, it has been essential to basically make sure that roles and responsibilities are clear. So again, we do a lot to coordinate between those two.

So, issues. As I have alluded to, issues that came up, or obstacles implementing the program. Again the main, primary thing was confusion over roles and responsibilities. How we addressed that mainly was training with the health plans, MQD, DDD.

Again, in these trainings we try to

facilitate the fact that both the case manager and the service coordinator were together at the same time, so the same groups of the same geographic areas, would meet, would discuss these things, and make sure that there was some at least face to face interaction, and that the respective agencies knew their counterpart.

Again we have training, the regular meetings, to resolve, problem solve and resolve issues. And again, we -- the key is that MQD acts as a liaison between the two organizations.

Another issue that came up too was anxiety over the change in programs. Again, like anything else, people don't really -- are resistant to change. There were some concerns about bringing in managed care to Hawaii, resistance, because again there was a perception that these agencies were for profit. Both winning bidders were from out of state. They were UnitedHealthcare and

WellCare.

So again, there were some concerns about that. There was some backlash or resistance by the public.

That was overcome again by numerous informational community meetings and we encourage outreach by the health plans to our -- the new members.

Another issue that came up, again sort of related to the other one, is concerns about continuity of care or remaining with the same providers.

Again, when we implemented managed care, there was some reaction or concern that people would lose providers they had existing, ongoing relationships with, change of their PCP, things of that nature.

And again, Hawaii responded by again encouraging our new vendors to contract with existing providers, and the members when they are entered into QExA, were given up to 180 days to transition.

So in the event that they couldn't remain with their primary or their previous PCP, they had the opportunity to either find a new one or encourage that PCP to join their -- the organization that they joined.

So in conclusion, although managed care was a challenge to implement, we have been somewhat successful and I think after a year and a half or two years, the program seems to be getting traction, and we are doing okay. So now I'll turn it over to --

Ms. Newman: Hi, I'm Pia Newman from the bureau of autism services in Pennsylvania department of public welfare.

And good afternoon. It's nice to be with you here today, and to be among such a distinguished group of presenters. It's a little intimidating.

And I feel a little guilty having come from the next state -- the state next door after my colleagues here have traveled so far.

This slide means -- managed care means to an end, not an end in itself, is kind of my take home message and Ellen may have second thoughts about her decision to invite me to speak. But we will see.

In Pennsylvania, we took what we had learned from other service delivery systems, which shall remain nameless, and what we wanted to do differently.

And some of the things that we learned were lack of team cohesion, lack of flexibility around rules or times or places and approaches, lack of consistency across environments and people, and people fitting the services rather than the services fitting people's needs.

And what we wanted to do differently was to create a meaningful team concept, maximize flexibility to individualize support programs, to leverage expertise and learning opportunities for staff members, and to balance the responsibility of state oversight with the possibility of provider initiative.

In Pennsylvania, as Ellen mentioned, we have two autism-specific adult programs, both Medicaid programs. The first is the adult autism waiver, which is the 1915(c) waiver, which I am primarily responsible for.

And the other is the adult community autism program, which is a managed care program. The adult autism waiver is fee for service waiver with capacity for 300 participants and it's a statewide program.

And ACAP is available in four contiguous counties and because this panel is about managed care, the ACAP program will be the focus of my remarks.

ACAP uses a PIHP funding mechanism which stands for prepaid inpatient health plan. Ellen can explain that better than I can. But so the question, what's so special about PIHP, that we chose it for this program, the first of its kind?

I don't actually know. I would say we don't really know what is so special about PIHP, but -- perhaps nothing, but people who know a lot more about Medicaid than we did, or than we do, in the bureau of autism services, suggested that this might be a mechanism to achieve the goals that I mentioned earlier that we were interested in achieving.

So, prepaid inpatient health plan, it is prepaid, that is capitated, and the provider is paid for each participant per member per month.

It's a community-based program so inpatient is a very confusing part of the term for a lot of people, and it is a health plan as well as a home and community-based supports program.

It covers healthcare needs, most healthcare needs except hospitalization and prescription medication. Healthcare providers including doctors are part of the ACAP network.

Autism-specific training is required, including of the doctors, and experience -- it is our expectation and hope that experience surveying members of participants with autism is going to create expertise among those clinicians more effectively than a didactic training would do and we think that's pretty cool.

Also, the burden of finding and recruiting those hard to find clinicians who are willing to work with the population with autism, falls to the ACAP provider instead of every family and consumer having to fend for themselves to find those clinicians.

This is a snapshot of ACAP and I will -- I was going to go through these slides quickly but I see we have got a fair amount of time left.

So ACAP was approved by CMS in January of 2009 with an (a) authority, that is a 1959(a) authority. We now have, I was just told, 83 people currently enrolled. Funding exists in our budget allocation for 108.

And here is the eligibility criteria. It's very similar to the eligibility criteria for the 8 waiver with the exception of the 16 hours of awake support per day. That is not an eligibility criteria in the waiver. Also, ACAP is an optional alternative to our 8 autism waiver.

Here's a list of the core services that are part of the ACAP program, meaning that the ACAP provider must be able to be prepared to provide these services.

Whether or not any particular one of these services is received by a particular participant depends on their need and their -- the configuration of that individual's need.

The one exception is behavioral supports. Every ACAP participant has a behavioral support plan which is to be implemented across all settings and all services.

Before our two service programs were launched, the bureau of autism services sponsored the development of the SPeCTRUM nine module online web-based course, which we developed using nationally known subject matter experts.

Every staff member in both programs with ongoing contact with participants are required to complete this training.

We have also developed some service-specific trainings using our own clinical consultants, and just to put a plug in here, we also conduct an annual Pennsylvania autism training conference every spring. This coming year it will be I believe the first week of June.

Regarding program design, from the -- in terms of the provider, as I mentioned, obviously managed care capitated, administered by the provider and monitored by the state.

That's one of the -- one of the advantages of ACAP is intended to be that it places a lesser administrative burden on the state without reducing the state oversight.

The core services -- we are on the other slide so you have already seen those. Those must be provided by the ACAP provider. They may not subcontract for those core services.

And I mentioned also the network of contracted providers for other services including medical.

There's a single provider for a particular geographic area. So far we only have one ACAP program in the state and that covers four counties.

From the services perspective, ACAP is designed to be a team-centric program. Supports can be meaningfully coordinated across a single network.
Behavioral, community and medical services are integrated into a single plan.

Providers -- each participant has a behavioral support plan. There's greater consistency across settings and greater consistency of that behavioral support plan being implemented because it is a single provider, and because there is a team-centric approach.

And also this model is designed to have greater flexibility and a faster response time to emerging concerns, in part because all the services that a person, and all the supports that a person is receiving through the program, are in communication and in regular communication.

So there should be greater efficiency of internal communication within the support team.

And other -- one of the, one of the great potentials of the ACAP model is that if -- if the support team deems it necessary, services outside that core list of services can be provided.

So whereas in a 8 waiver, you are limited to the menu of services that are defined in the program, in the ACAP program, you can actually go outside of that predefined menu of services on an individualized basis.

The two -- our two programs share outcome measures and I will let you look at these at your leisure. Baseline measures are taken during development of the initial support plan or intake.

These outcomes will be analyzed over time to judge the effectiveness of the programs. Unfortunately we have had some assessment reliability issues in the first couple of years which we are in the process of addressing, and -- but that means that it is going to take us a little longer before we have sufficient data to make that comparison and that analysis.

These are the assessment tools that are used. They are administered annually. The first is the scales of independent behavior revised, or SIBR, the quality of life questionnaire, and the parental stress scale.

These are all validated for use with population with autism. They are administered by the supports coordinator before service plans are updated or reviewed, and we -- we expect them to help the support plan team focus on specific areas of need, as well as providing a measure of program effectiveness over time.

So we -- and if you compare them to the outcome measures, you will see that there is -- there is some correlation there, so over time, you would hope to see reductions in family stress levels, increases in perceived quality of life, and greater independence, self-sufficiency and reduction of maladaptive behaviors.

Managed care is how services -- is a mechanism to deliver services, but it doesn't answer the what services need to be delivered.

And if I can make a plug here, there's been a lot of conversation today about adults and a lot of focus on adults, and that is very heartening to hear, because there are few forums about autism where the focus is on adults, although that is increasing.

We need the same kind -- the same intensity of focus on the needs of adults as we have put on the needs of children and if one considers that 73 percent of the life span is spent in adulthood and that individuals with autism have a full life span, then for those of us who are focused I would say virtually entirely on adult services, it behooves us to -- to answer the question of what are the services that are needed.

We have heard today a lot -- I don't know about the rest of you, I'm feeling rather overwhelmed after all of the presentations from today.

We -- the issues that we are facing are things like insufficient evidence-based practices or applied research on supporting adults with autism, insufficient expertise among providers and capacity of providers, turnover of staff, challenges posed by co-occurring mental health conditions.

We see emergence of mental health conditions in adults with autism that did not emerge in childhood. What's different about supporting an adult with autism who also has a mental health issue as opposed to -- as opposed to someone else with another -- another adult with mental health issues or what's different about -- what's unique about the supports that an adult with autism needs as opposed to other populations.

Insufficient housing options, we have heard a little bit about that. Barriers to meaningful employment, challenges of coordinating with other supports, including mental health services, the expiration of educational entitlement that has, until a person is 21, supplied structure and a legal framework to operate in, and that's just from the service delivery side. That's not even the challenges faced by families and individuals, it's even more difficult from that perspective.

So I leave you with the question, what is the what? And I -- Ellen, in her opening remarks this morning, talked about services and how the IACC has -- has focused its energies increasingly in services, and I know the future of the IACC is apparently in flux.

But whether it is this forum or some other forum, I urge that that focus on services continue, that the wonderful information that has been shared here today be dissipated.

We have to create that culture that has been referred to, the best practices. I kind of feel at these meetings that we are all reinventing the wheel ourselves and we need to try to -- the challenge, I think, is to raise the bar and make it easier.

So how are we looking to address

these needs? We are still changing the wheels on the bus while the bus is moving. We problem solve and brainstorm on a case by case basis.

Once up on a time these programs were an abstract concept. They are now real. We have flesh and blood people receiving services that we have a commitment to.

We are also doing this in a fiscal environment where resources are dear and time is not on our side, that tsunami of adults with autism is coming.

We agree on where we need to go -- more meaningful community engagement, more truly person-centered planning and supports, greater independence and self-direction, more personal growth and competitive employment, and the question is how -- what's the means to get there, how do we get there?

You may have heard the saying, when you don't know where you are going, any road will take you there? Well, we do know where we want to go. And we sure could use a better map to get there, and with fewer false starts.

This is who we are and how you can find us, and thank you very much.

Ms. Blackwell: Okay. Pia, Chris and Jami, I know that I have questions, but before I open up the floor, I just wanted to say before other people ask questions that I think that again that this idea of the managed care delivery systems being attached to Medicaid services is indeed very important, and the perspective that our three panelists have is also very important.

As more and more states take their carts and their horse down this road, we will be having many more -- many, many more -- of these discussions and we are already having many of these discussions about integrating managed care delivery systems with traditional fee for service services at CMS and with our state partners.

So this is a really important conversation. So with that, questions? I knew Ari would have a question.

Mr. Ne'eman: Well, first thank you all very much for very informative presentations on a critical topic.

I don't want to distract too much attention from the more immediate issue of looking at how to make managed care work for people with disabilities and autistic people in particular.

But I do want to raise one question particularly directed to Pia Newman on your remark on the incoming tsunami of autistic adults.

You know I find that curious, in part because one of the things I had always been impressed by with regards to the Pennsylvania bureau of autism services work, is some of the research you have conducted, finding substantial populations of undiagnosed autistic adults present now, including one landmark study I believe that you did finding high populations in the criminal justice system, and recognition that you have had from other studies internationally, including the United Kingdom's National Health Service study finding large populations of undiagnosed autistic adults in the general population as well.

So I guess the question that I have here is you know, obviously transition and meeting the needs of those that are transitioning to adulthood, is a major question and concern for policymakers regardless of the numbers.

But what are you doing to meet the needs of adults on the autism spectrum who may not currently be identified, and to sort of acknowledge the fact that rather than looking at the needs of autistic adults as some incoming future problem, or something that is going to suddenly increase in size, as to look at it as an issue that currently exists and that our response to is by no means sufficient.

Ms. Newman: Well, we do not -- we in the bureau of autism services don't diagnose. We don't have diagnosticians. We have supported an expert work group on diagnosis I think maybe even before we were a bureau.

The challenge of adults who are undiagnosed is a challenge that the medical community, the diagnostic community, those who are acknowledged to be qualified to make the diagnosis, are struggling with.

How many adults in Pennsylvania there are who are either misdiagnosed or who just don't have a diagnosis of autism, I don't know that we will ever know.

That's a very difficult thing to figure out. We did do a census. We did conduct a census. And we bumped into the problem of, if individuals are outside any kind of a service system, how do we even know to poll them, or ask them?

So that was certainly a limitation of our census project that we acknowledged, and so when I referred to that, that wave of individuals who are coming, those -- that refers to individuals who we know have a diagnosis of autism who, many of whom are already getting services or have gotten services through either education or behavioral health services.

And so we do know that they are there, and we do know that they are starting to age into adulthood. So who is out there who is unidentified or un-self-identified, I don't know how one discovers that.

So I don't think that we would dare guess. I don't think we are qualified to make that estimate of how many people are out there that we don't -- whom we don't know about.

Mr. Ne'eman: So, I appreciate that response and I do want to clarify. It isn't that I don't see transition as a critical issue. But you know, I would urge us not to forget that large population of adults on the spectrum who have gone without diagnosis or have been misdiagnosed maybe in the mental health system or the law enforcement system or other service provision systems, and particularly given the British government's study which found a comparable rate of Autism Spectrum Disorders in adults as the children, you know, I really think that's just as large a question of unmet need as the incoming wave of transitioning adults. But thank you very much for your response.

Ms. Blackwell: I have a question that is really sort of aimed at all three of you. I think a lot of us, when we talk about managed care delivery systems, immediately start thinking about cost savings.

So I know it's harder for you Jami, but even Arizona has experienced fiscal stress, let us call it, and all three states -- Hawaii, Pennsylvania and Arizona -- in this environment.

I am curious about the cost savings and also the impact if any on quality, and I am well aware in terms of managed care, there are by the way certain requirements for quality in managed care so there are some big safeguards built in.

But I would like to know, you know, how has the cost -- have you seen cost savings by using managed care delivery systems, for example Chris, since you first implemented you know, managed care through physical healthcare in Hawaii?

Mr. Butt: Unfortunately I think our system is a little young to really have that measure. Again, we do use capitated rates although that capitation is subject to adjustment based on, you know, if the population adjusts or --

So again, unfortunately I can't really answer you yet, because it's kind of too early to tell.

Ms. Blackwell: Pia what about the difference between what you are -- and I know it's the same, probably the same answer for you. It's too soon Ellen, but okay --

Ms. Newman: I'm with him.

(Laughter.)

Ms. Blackwell: Okay. But you know, with --

Ms. Newman: I did want to add, and it is too soon and I can't really answer that question. But cost savings as compared to what?

When we were developing the estimates of what our autism waiver was going to cost, which is part of the application, and/or developing the rates for ACAP, compared to what?

We really had no autism-specific cost, certainly not for adults, and so we looked at other DD populations but they really weren't comparable. But we didn't know how comparable or not comparable they were.

So part of what we are learning is what does it cost to support an adult with autism with the kinds of services that we are offering?

And we are finding, we are finding situations that we didn't expect, so we are finding people who are reluctant to accept services that we believe that they should have, other ones that you know, we didn't think it was going to go that way.

I mean it's just -- we are really learning by doing and we are finding out that some of our assumptions were incorrect. So I think we need a few more years of just to get kind of get that baseline, and then say okay, now we have a better idea of what people's needs are as a group, and how much it costs to deliver those services.

Ms. Blackwell: Okay, other questions on the phone or in the room? Daniel.

Mr. Davis: Yes. Thanks to all

three of you, first of all for this informative presentation. I have a couple of questions about some issues that -- and that are basically challenges that I have heard that certain programs providing managed care to people with disabilities or developmental disabilities are experiencing.

Basically, one of the challenges that I have heard a lot about at least in one or two states is network adequacy, that providers sometimes have a very hard time being convinced to go into these systems and then if you don't have the right providers, how do you -- how do you serve the right, how do you provide services?

You need to -- and so how are you addressing that is something that is something that is of profound interest to me.

And also, how you are approaching stakeholder engagement and person-centered planning in this context, would be another item that is of interest to me.

Ms. Snyder: And I can speak to your question of network adequacy from a program that is fairly mature in terms of its managed care model.

We have been very fortunate to have a very robust network in Arizona throughout our tenure as a managed care, long-term care system.

However, it's a really pertinent question given the economic climate that we are currently facing. We are on our third round of provide rate reductions in Arizona, constituting a total of a 15 percent reduction to provider rates.

So now we are faced with a situation where, while we have enjoyed a very robust network to date, we do have concerns that that network is going to be impacted by the rate reductions that have been taken over the course of the last two years.

And so we have started, we have implemented some reporting mechanisms to track network adequacy or provider losses due specifically to rate reductions, and so we are looking at that on a quarterly basis.

And in response to your question, the force of your question related to stakeholder engagement too. What this has done, you know, sort of the surrounding economic climate and some of the pressures that we are feeling on the system, it has really caused us to ramp up our stakeholder engagement efforts in a significant way, particularly in the long-term care system, because we understand that network gaps can pose a real problem for our membership.

And so we have started to engage stakeholders, be it in the DD community or in the EPD community, or in specific segments of the communities, say the nursing facility administration, administrators throughout the state, to talk with them about when they are going to reach kind of that critical threshold, where network adequacy is going to be impacted.

So far, to date, we haven't seen a tremendous impact to network adequacy. But we feel as if this last reduction, or this most recent reduction, which is actually due to go into effect on 10/1, could have that kind of impact.

So we will be watching very closely as we move forward.

Mr. Butt: In Hawaii's regard, I think the network adequacy problem actually translates -- I mean it's not really altered by managed care.

We found that basically the same pool of providers in the fee for service network pretty much joined our two MCOs.

However, then again on our outlying areas, certain like, for example, hard to serve areas like Hana or the big island, that provider pool has remained unchanged.

So managed care coming into the mix hasn't really altered the available pool of providers, either for the better or for the worse.

Ms. Blackwell: I think Daniel just alluded to a really important piece of this discussion, which is as states start to you know, engage in managed care, it's not just the stakeholder engagement with the state, it's also with CMS and with our other HHS you know, entities, so we can have a broad discussion about what these concerns are.

What happens is a lot of times when CMS engages in these agreements with states, the issues stakeholders have raised, migrate into the contract that governs the managed care or you know, contract, or waiver or demonstration.

So it is really important to pay attention to these things from a consumer perspective, because we do, states and the Federal government want to know what the concerns are.

Any other questions, on the phone?

Oh, Ari, go ahead.

Mr. Ne'eman: One question building on Daniel's question and the response to it. You mentioned hard to serve areas, and I am wondering, actually since all three of your states have either rural areas or otherwise hard to serve areas, if you could speak to some of the strategies that you have utilized to help to build provider networks there and also speak to the -- this recent accountable care organization trend, and how that may have been, may be useful, or may have been useful, or any views you have with regards to enhancing the effectiveness of that, given the relevant provisions regarding accountable care organizations and the Affordable Care Act.

Mr. Butt: I'm sorry, the first part of your question again was --

Mr. Ne'eman: What have you been able to do to help build provider networks in parts of the state, particularly rural and otherwise hard to serve areas, where they did not previously exist?

Mr. Butt: In the past, under fee for service, there have been some state initiatives to basically try and recruit or encourage or pay differentials for doctors to go out to those areas or providers to go out to those areas.

Now in the managed care arena, we have basically passed that responsibility on to the MCOs. However, you know, it's -- again, we encourage them to be creative.

So again, we have, again, we partner with them to the extent possible, but really yes, it continues to be a problem because provider pay or just the, the delay, I mean, there are some initiatives in the schools to try and train providers but there's a delay in people getting through school and basically getting licensed in the profession.

So I don't know if really managed care has impacted it in Hawaii's case, very much at all.

Ms. Newman: And what I can say about Arizona, we do have, you know, a large percentage of our state, really outside of the Phoenix and Tucson area, would constitute a rural, you know, rural area.

We have historically had some challenges regarding network adequacies in those more rural areas of the state, and also areas which serve the state's native American population.

What we are seeing is a little bit of a shift. As I mentioned during my presentation, we have historically contracted with both county entities and private companies to act as our managed care organizations.

The county entities in this latest, latest procurement process, were not successful in their bid for contracts, so now we will be working with private companies going forward, as our MCOs, particularly on the EPD side.

And what we are starting to see a trend of now as they build up their networks in preparation to assume some of these more virile GSAs, is they are working with providers that have historically been urban only providers, to set up satellite offices in various parts of the state so that they can maintain their network adequacy, the required network standards that we have in those more rural areas.

So whereas we had some trepidation about how that was going to play out in the beginning, I think we are feeling optimistic now that we have seen some of this sort of creative thinking around network buildup in the more rural areas of the state, utilizing some of the providers that have historically been based primarily in rural areas -- in urban areas rather, and we have particularly seen that happen on the in-home care side of our business.

Ms. Newman: The ACAP program is

not a statewide program. It's only in four counties which are not rural counties. There are three counties around Harrisburg, the state capital, and Chester County.

The autism waiver program is statewide, it's not managed care, and we do cover all 67 counties, and -- but it's not the only, the only waiver program that is statewide.

So what we usually do is recruit providers who are already providing other services in other programs. Our waiver is quite small, 300 individuals, so we don't -- we don't offer sufficient business to a provider for them to only be serving our participants.

So the managed care in a rural setting is not something we have yet had to tackle, although Pennsylvania does have other, other Medicaid programs that are statewide, and some of which are managed through managed care.

So when that time comes, we will probably -- we won't be the only, would not be the only services in those areas and that would probably allow us to leverage access.

Ms. Blackwell: I just have one more question about -- and this is kind of a general question and I am not sure that the managed care delivery system makes much of a difference.

But how do you deal with the waiting list issue any differently, Pia, in terms of the 1915(a) contract and Chris, I don't really think it impacts you at all, because you know, you have one HCBS waiver left, and the waiting list, if you, you know, is the waiting list.

And Jami, I am just curious how you deal with the waiting list in Arizona as well.

Ms. Snyder: We don't currently have a waiting list at all, so it's a non-issue fortunately at this juncture.

Ms. Newman: ACAP doesn't have a

waiting list. We do have a waiting list on the waiver.

Ms. Blackwell: And I should point out that you know, Pennsylvania, like many other states, runs other home and community-based waiver programs that could potentially meet the needs of people with autism, other than an autism-directed program, and I am assuming that those programs have waiting lists as well, Nina? I see her nodding.

Okay, well I think that wraps it up for our managed care panel, and I am going to suggest -- oh go ahead Lee -- I am going to suggest that we take a 15-minute break and then reconvene for our provider panel.

Thank you so much to all of you. I am sure there is more to come on this topic in the coming year or two.

(Whereupon, the Subcommittee took a brief break starting at 3:09 p.m. and reconvening at 3:33 p.m.)

Mr. Grossman: I have the privilege

of introducing our next panel, which is a panel on service provision to people with autism. We are going to be hearing from three very wonderful presenters, one of which is Tom McCool, who is the President and CEO of Eden Autism Services.

Eden is a program in Princeton, New Jersey. It has been around for oh, what, 30 -- 30 years?

Dr. McCool: Thirty-six.

Mr. Grossman: It is -- when my son was first diagnosed in the early '90s, that was one of two programs that we modeled his programs after. One was Eden, the other one was Division Teach from the University of North Carolina.

And Tom probably doesn't even know this -- in both those programs we were able to put model facilities in Honolulu and sustain them for a little bit of time, and enough time to get some traction there for fairly good autism services in Honolulu, and I have always been grateful to Eden for their leadership in developing innovative therapies across the life span.

We are also going to be hearing from Nancy Murray, who is the President of the Arc of Greater Pittsburgh which is also known as ACHIEVA.

ACHIEVA is remarkable in one essence just by the sheer volume of people that they deal with and that they serve. But what makes ACHIEVA that much more remarkable is not only are they dealing with a tremendous volume of people across the life span, and particularly in adult services, they do it at an extremely high level of quality, and they meet the top standards of any service provider in the country, and I am very interested to hear what your -- what program delivery ACHIEVA is accomplishing.

And then, we are also going to be hearing from June Groden, who is the Executive Director of The Groden Center from Rhode

Island.

June is certainly one of the pioneers and legends in the autism community. She has always been known as a true innovator, particularly in behavioral management, and her program has served as a model for many, and very grateful for the three of you to be here to present to us today. Thank you.

Dr. Groden: I'll start. Today I am going to talk about self-regulation, stress reduction and positive psychology. We have heard a lot about systems and how important it is to get people with autism out into the community and included environments when they are children; when they are adults getting them jobs.

But those people who have some very severe and challenging behaviors can't just automatically go into these settings. They really have to have the right kind of services and procedures.

And we stress a lot our work in

self-regulation and self-control. First I will tell you a little bit about The Groden Center network which is made up of four different corporations.

The Groden Center, which is a day treatment in-school program has a wide range of services starting with early academics and early intervention, an included preschool, a school, community outreach.

We are the largest respite provider in the state of Rhode Island, and a large span of residential services, group homes, foster families, supported living and independent living.

We also have a charter school, Kingston Hill Academy, which is an included environment, 80 percent typical kids and 20 percent children with special needs.

Two adult programs, the Cove program in Rhode Island, and the Halcyon program in Massachusetts, in which we do a vocational training, assessment, community placement and jobs. We do job coaches and the natural supports and lately we have started working creating our own enterprises. We found that our adults were the last hired, first fired, and we wanted to create something that was more stable for them.

So we have a number of our own enterprises. We have food services called The Ladle. A number of the participants own their own window washing business. We have a business center, a greenhouse, so we do a lot of related plant services, and recycling and, again, a large span of residential programs.

So, one of our interests from the beginning of our program, was to focus on programs that promote self-control, and we have become well-known for our work in developing relaxation, picture rehearsal and other imagery and scripted programs.

And we were the forerunner. We started back in the '70s using scripted programs. A lot of people know are using programs called social stories. And at that time, when we started, people said these are very sophisticated procedures that people with autism couldn't possibly learn.

But we have found them to be very effective, and now we are extending this philosophy of positive programming to the area of positive psychology.

The people that we support have very severe, challenging behaviors. So when they bite, they don't just leave teeth marks, but they take out pieces of skin. Aggression, self-injury. We have one person that blinded himself before he came to our program. I don't know where he was that let him do such a thing. But that's the type of people that are in our program.

I'll start off by talking about stress reduction and self-regulation. And we feel that the most overlooked problem with this population is stress and anxiety.

And stress we define as a

physiological reaction of the body to life situations which can be both happy or unhappy events, or it's a demand that is placed on the individual that disturbs homeostasis and requires an adjustment on the part of the individual.

We all know the characteristics of autism, and that really makes them more vulnerable to stress in areas such as communication, socialization, sensory, physical factors and executive function, which is goal-directed, future-oriented cognitive abilities that affects planning, organization, flexibility, self-monitoring and inhibition.

And something in the stress literature, you see a trait called hardiness, which means accepting challenge, having commitment and control, and that is something that people with autism have a hard time with.

So how do we get a handle on stress? And most people don't like to use that term, because you can't really pinpoint it. It's not easy to look at and to treat.

So first we do a multi-modal assessment, first a functional assessment, which is direct observation, scales and interviews, and we have just started using physiological measures.

Here is our detailed behavioral report. It's a functional analysis where we look at what happened before the problematic behavior and we look at all the things, all the antecedents that could impact on what happened to make that behavior occur. Then we analyze a number of our reports and come up with patterns and identify the stressors.

I have developed this stress survey schedule for people with autism and it's now -- I am getting requests from people all over the world. They are using it in research.

It's the only stress survey for people with autism, and it has items such as waiting, we find that a big stressor, could be waiting to talk about a desired topic, waiting for preferred events, having personal objects moved, and it's about 42 items.

When we did a principle component analysis, the stressors were ritual-related stress, social environmental interactions, food-related activity, sensory, personal contact, pleasant events, anticipation and uncertainty, changes and social threats, and unpleasant events.

Because it's so difficult to do -- work on stress with people with autism because of their communication -- they really can't fill out the stress survey themselves. We have teachers, parents and caregivers do that.

And so it's hard to find out what exactly are the stressors. We looked around to see what we could use as a physiological measure and we chose heart rate because that is the most robust measure of arousal.

And we have done a number of pieces of research, and this is one of them, where we took 10 participants, used the items on our stress survey, and looked to see if there was a change in heart rate.

The items that we used were unstructured time, receiving a tangible reinforcer, a change in staff, losing at a game.

On this particular piece of research, unstructured time was the item that the majority of people showed a response to. We also found in doing our work in heart rate, that the resting heart rate of people with autism is much higher than that of their typical peers.

And you could see this, the bottom line, the typical peers, and the same age-matched group for autism, much higher resting heart rate.

So what do we do? What kinds of procedures can we use to reduce stress? And what one of the procedures that we have developed is relaxation, and we are using Jacobson's progressive muscle relaxation, where we teach the individual to learn the difference between what a muscle feels like when it's tense, what it feels like when it's relaxed, and then learn to relax in stressful situations.

And here's a little clip that I will show you, and you will see it was done a little while ago.

(Video plays.)

Dr. Groden: So, first they learn to tighten, then relax. And then they drop the tighten, and just learn to relax, and then use it. We teach them when to use it, in what situations.

The second procedure I am just going to briefly tell you about. It's called picture rehearsal, where the clinician verbally presents a carefully-developed script accompanied by pictures and then the learner repeats.

So this is a young girl who is in an included class in first grade. She has autism and had a severe phobia to bugs to the point that she would not go outside because she was afraid there would be a bug and it would do something to her.

(Video plays.)

Dr. Groden: So this is -- these are some of our books -- "Coping With Stress Through Picture Rehearsal." We have the stress survey and for every item on the stress survey, there is a picture rehearsal scene.

"Stress And Coping In Autism" was published about two years ago, Oxford University Press, and it's an edited volume.

And then a manual showing how to do the relaxation procedures. So what we are saying is to do a multi-modal stress assessment to identify the stressors and then, from that, to develop and implement proactive coping strategies which are used before the stress occurs, using procedures such as I showed you -- relaxation, picture rehearsal, being assertive, doing some environmental changes, and that leads to prevention.

So we are doing these procedures before the maladaptive behavior occurs.

Our new work is in positive psychology and this is our new book, just off the press, "How Everyone on the Autism Spectrum, Young and Old, Can Become Resilient, Be More Optimistic, Enjoy Humor, Be Kind, and Increase Self-Efficacy."

And positive psychology is an umbrella term for the study of positive emotions, positive character traits and enabling institutions.

It begins to catalyze a change in the focus of psychology, from preoccupation only with repairing the worst things in life to also building positive qualities.

So what we are doing instead of only centering on decelerating some of the inappropriate behaviors, we are building character traits, and we are really emphasizing values.

So we want to change attributions and beliefs. We want to foster positive strengths and that will have an impact in the community, the home, and the person themselves, and should lead to increased autonomy.

So we don't want to develop procedures that you always need a person there to be doing, like giving a reinforcement, or giving directions.

We would like the procedure to be within the person. They learn the self-regulation, and they have the means to change their own behavior.

So I am just going to focus a little bit today on resilience and that is the process of, capacity for or outcome of successful adaptation despite challenging or threatening circumstances.

So we think about it mainly as bouncing back from adversity or trauma. And we consider these some of the important steps in building resilience: changing attributions; teaching our children and adults to be more flexible, to have self-control, to have optimism, to problem solve; and we do skill-building.

In changing attributions, we want to change the negative attribution to something positive. So if someone makes a mistake they don't say "I'm so stupid I can't do this," to "everybody makes a mistake. I can correct it. It's not that important."

And we want them to learn to use self-control. So, for example, in developing self-control through relaxation, we identify the stressor, we incorporate the relaxation program. First they have to practice it every day. Everyone in our program comes in in the morning, the adults, the children, they start their day with doing a relaxation exercise.

And then we identify stressors for them and first the teacher or the staff or the parent cues it, and then they reinforce the relaxation response in the stressful situation, and then the individual learns to self-cue, and we have many, many of our people out on jobs. They know when something is stressful to them. And we see them start using the relaxation response.

And the same thing with using the scripts in the picture rehearsal program. We create a lot of opportunities for problem solving. It's very important to becoming resilient to be able to recognize a problem and to think of options to solve problems.

So it includes flexibility, learning how to make choices, being goal-directed, and here are some of the activities that we have been doing.

Here's one using our picture rehearsal, and we want to change the attribution, so he -- this little fellow has trouble with trying new things, and we have that very often. People in our program, when we want to start something new or give them a new task, they find that very difficult. We see a lot of tantrum behavior and aggression.

So he says I'm in the classroom. My teachers asks me to do something new that I haven't done before. We incorporate relaxation. I take a deep breath and relax and I say, "I know I can handle it. Trying new things is a great idea."

I say, "Sure, and do a good job learning the new activity." And then we have them imagine something pleasant.

Here's someone who is -- has trouble being flexible, having self-control. He says I am finishing up my reading program. Transition is a very hard time. We identified that as a very big stressor.

"I am finishing up my reading program. It's time for gym. I get in line. I don't have to be first."

We have a lot of our children, they have to be first on line. So we want them to be flexible. They can stand anywhere.

"I wait patiently and then walk with relaxed hands," instead of hitting, and we try and put it in a positive way, "and I walk with relaxed hands to the gym, showing self-control.

"I am happy to be in the gym." So we want them to have the attribution of the gym as a fun place to be. "What fun." And then again, he can think of something very pleasant.

For some problem-solving activities, this is for our young children, we do things like give them an empty jug and their job is to fill cups of water and so they have to learn to ask for something to say what's missing, instead of crying.

And we have a number of different things that we do to prompt them to solve problems. Also, we find it's very hard for the kids in our program to tell you what they like and what they don't like, and so we have activities to teach them to just make a choice.

Very often, if we say to someone, would you like a soda or would you like an ice-cream they will say ice-cream. Then if you say would you like an ice-cream or a soda, they will say I want a soda.

So they are just picking what they heard you say, so we want to make sure that they are really able to tell you what their likes and dislikes are.

So we have this little board and they make choices, and for example this would be leisure time. They have a lot of activities they can choose from, and they have to put it in the likes and dislikes column, the same with chores.

In our group homes, for example, we want them to pick what chore they would like to do so they have the choice of that and they could tell you that's what they really like.

And then we have them make the choice of where to put it on their schedule.

It could be when they come home or after dinner, so we are giving them as many choices as they can take for their developmental level.

This is physical activities. The other area that we work on is building what we are calling islands of competence, and that is identifying and nurturing special abilities and talents.

So we want to build on the capabilities they have that can be appreciated by others, and we chose photography as one of the areas to build an island of competence.

And so we taught our students and adults how to use digital cameras, computer printing processes. They do matting, framing and photographic displays.

And here is a picture that someone took of our statehouse, and he is someone who loves vertical objects. He will only draw vertical objects, he loves vertical objects.

And when we said to him that's a

beautiful picture of the statehouse, he said, oh no, that's a picture of the street lamp.

And here's this young man. They very rarely take pictures, almost never, of people, it's usually objects. But this person took a picture of one of his staff people, but we said how come you didn't take the whole face?

And what was he interested in? The pencil on the ear.

Here's some pictures that we have taken. We participate in the Rhode Island flower show. You could see how beautiful some of these photographs are. And patterns, they like patterns. This person found a beautiful pattern in a tree trunk. So here we are participating in the flower show. We won second prize two years ago and third prize this year in our vignette.

We presented at City Hall. We had a photography exhibit and the mayor gave everyone awards. So it really helped increase their self-esteem.

And what was particularly nice was that this wasn't really beautiful photography from people with autism. It could have rated with anybody's photography.

So again, to build a stairway to resilience we want to look at attribution using cognitive restructuring, increase flexibility by making choices, and resilience through adaptation, teaching self-control, teaching optimism.

We do a lot of work in positive scanning, and teaching people how to positively scan at the end of their day, they have a journal and they write all the nice things they did that day during the day, and skill-building, building islands of competence, working our communication skills.

So I just want to end up, because I would be remiss if I didn't tell you, and I mentioned to you briefly in my question this morning about what is happening to us in Rhode

Island.

Forty-eight agencies were reduced in the adult -- who do adult programming, adult providers were reduced $24 million. That hit our program, The Cove Center. We were cut $350,000 two years ago. In July we got a cut of $744,000 and in October, another $830,000.

It will bring just this year's reduction to only our adult services to $1.5 million, which may make that program unsustainable.

In our children's program we had a contract for 37 years. They actually started us for $1 million, which they cancelled. Fortunately, the schools picked up most of that. We had to discontinue our Saturday program.

Our children's residential and foster family, again cut $500,000. So I think it's important for everyone to realize what's happening to programs with autism and developmental disabilities that we have worked for years and years to build.

And it's really being decimated, in the state of Rhode Island, at least. I am hoping other states are faring better.

So if you want to contact me, here is my contact, and now I would like to turn it over to Nancy Jess Murray.

Ms. Murray: Well I was feeling very relaxed until she talked about the budget cuts.

Dr. Groden: I hated to end that way, but --

Ms. Murray: I thought I would begin by telling you a little bit about ACHIEVA. ACHIEVA was founded 60 years ago. This year we are celebrating our 60th birthday.

And it was founded as many Arcs were at that time, by family members of children with intellectual disabilities.

Today we serve more than 10,000 people throughout western Pennsylvania and we provide services from early intervention all the way up through programs for senior citizens.

We provide very person-centered, traditional services. We have about 1,500 children right now in early intervention. We have about 400 people in our recreational programs, about 400 in our residential programs and they are a range of programs from your traditional three-person group homes all the way up to more independent programs.

Vocationally, we provide services to now over 500 people, and we are very proud of the fact that we are moving away from facility-based employment to supported employment.

Right now the 500 people are actually in supported employment and I think we are up to about 76 percent of our vocational services are now supported employment.

We are hoping that while some of us

are still there we will actually close our center-based services.

Vocationally, we provide -- we have cleaning and janitorial crews, we have lawn service and snow removal, which as you might imagine is very big in western Pennsylvania, and we are actually one of the state's largest pallet manufacturers. You know the wooden pallets that industries use? We are the largest pallet manufacturer. And we are the second largest mail service in western Pennsylvania.

ACHIEVA has really been known for a lot of innovative services throughout our history. We actually played a lead role in establishing special education in the United States. That began with something called the PARC Consent Decree in Pennsylvania.

We provided counsel to the Department of Justice at the time that they were passing the Americans with Disabilities Act.

We have been the plaintiff in numerous pieces of litigation that closed state centers in Pennsylvania. Unfortunately we still have five rather large institutions and I was very happy to get the business card for Alison this morning. I will be calling her probably Monday morning.

We actually developed and we have internationally replicated our parenting education program. This is a program where we provide childcare and home care and parenting skills to mothers and fathers who have intellectual disabilities.

We created Pennsylvania's first funded respite support program and of course, now multiple organizations in the state have respite programs.

We were the first non-profit organization in the United States to become a court-appointed fiduciary, and I am going to talk more about this in few minutes.

We initiated one of the first

Federally-funded family support service programs in the country and we were one of the first to initiate conductive education in this country.

Conductive education is an early intervention therapy very well known in Europe, and we had a group of family members in Pittsburgh -- they have children with cerebral palsy -- and they came to us and asked if we would be interested in working with them to bring conductive education to western Pennsylvania, which we did.

So that's just a brief history of some of the innovations that we have created and developed, and the innovation continues.

First is our -- we provide lifetime family supports and advocacy. I have made it almost a rule that all of my advocates are family members of people with disabilities.

So right now we either have a child or an adult with a disability and I think it's very important so that when the phone rings, and there's another parent of a child with a disability on the line, we actually have people in the office that can say I know what you are going through. I have been there. Let's talk about it.

Our educational advocates focus on providing information to families as you might imagine on IDEA and [section] 504 of the Rehab Act.

We provide a lot of technical assistance to early intervention providers in school districts.

And, unfortunately, if the advocates are not successful in mediating through the IEP process, we do provide counsel during pre-hearing conferences, due process mediations when we are not able to help a family to get a free and appropriate public educational setting for their child.

However, we provide lifetime support, so that means that we are there supporting families and providing information and assistance to them as their family member, their child, transitions from early intervention to preschool to school to high school, and then to adulthood.

And when it comes time for adulthood, we are there with the families to provide help and assistance and support as they navigate the adult world, government benefits, vocational programming, transportational hurdles, residential services, whatever issues they are confronting at a particular time.

As I mentioned before, we were the first organization in the country to establish a family trust and it was created in 1998.

Today we serve over 1,800 people and we manage about $50 million. And we operate those three kinds of trusts -- common law, pooled and payback trusts.

We have an attorney, who is the president of our family trust. We distribute an average of $120,000 in funds per week to our trust participants.

So you might imagine, what could we possibly, you know, distribute $120,000 a week for?

People will establish a trust, oftentimes it's mom or dad who put money into a trust. Oftentimes it's a settlement from an accident. Oftentimes, as in the case of my daughter who has a disability, her wages go into her trust.

And the trusts are there, they are special needs trusts, to pay for things that government benefits do not cover.

So, for example, somebody needs hearing aids, or eyeglasses, and their medical coverage does not cover those things, people can dip into their trust accounts.

So we write out checks for on average $120,000 every week for things like hearing aids and eyeglasses, winter coats, vacations, things that government benefits do not cover.

Oftentimes if a person is moving into an independent living situation, they are moving into their own apartment, they need to buy furniture and household equipment for that apartment, they will go into their trust for funds to do that also.

Unfortunately I can't say we are A to Z yet. But we are up to W. We have produced dozens and dozens -- I think we are well over 100 now and we only started about two years ago -- webinars for families.

In the past we always had parent support groups, or family support groups. And what we noticed a couple of years ago was, you know, with both mom and dad working, more and more families where they are single parent-headed households, people are just busier than they were a couple of years ago.

So what we decided was we still need to get information to people, people were still calling us for information. But the notion that people were going to come out to these group meetings -- not so much.

So we now produce at least one webinar a week on a whole host of topics, and we actually ask for feedback from families and professionals in terms of what kinds of webinars, what kind of topics, what kind of speakers they would like to have.

And what's amazing is I had written a lot of grants to cover the webinar expenses, and as I mentioned, I think we are up to about 120 in our library now, so far we have only had to pay one speaker.

Speakers have literally come to us and they have said you know, I'd really like to do a webinar on this topic. We have a recording studio -- well, I call it the recording studio -- in our headquarters, and people just love to come and I think they love to sit and hear themselves talk and they love the bright lights, and we have just been blessed by the number of you know, experts and national -- both nationally and locally -- who have come to do webinars.

So this gives you an idea of the breadth of the webinars that we are doing. And after each webinar -- well, I should also say we do these live, so some of these are actually done in front of audiences of 50 people. Some are done just the person speaking in the recording studio. Some are done at a distance, where we might have a professional in another state and we do it over the internet and by Skype, and we also do some of these during what we call lunch bunch, when we will do them at noontime when moms and dads might be at work and they may be able to take a half hour, an hour for lunch, and that gives us the opportunity for questions and answers during the webinar.

Following each webinar there is a very short questionnaire, so we get feedback from people on was this helpful, what other topics would you like us to do, and I think we are up to probably about 50 topics that people have still given us that we are looking for speakers on, and after this morning, I have got a lot of business cards so I am going to go home with a lot of other good ideas for webinar topics and speakers.

The partnership is a really neat project. We were one of five organizations that the state chose a couple of years ago to provide training for families and self-advocates.

And what is really unique about this, is the trainings are developed by families and self-advocates, and the trainings are given by the families and the self-advocates, and a lot of the webinar topics are also the topics that are offered through the partnership.

We go out to schools. We go out to provider organizations. Wherever people are meeting, we go out and give these presentations.

And again, these are topics that

families of people with all types of disabilities have said, we need to know more about whatever the topic happens to be.

The partnership, as I mentioned, we are one of five organizations. The team leaders from each of the organizations gets together a couple of times a year. They create the trainings so that all the trainings across the state given by whichever partner, is always very consistent.

As I mentioned before, we have really, really, really focused on supported employment. We now have a person who does nothing but ticket to work counseling because we knew that a lot of people were not focusing and looking into supported employment because they thought they were going to lose their benefits.

So we have one person, a young man, who does nothing but Ticket to Work counseling. He meets with individuals and families, he meets with people in school districts, and he will explain to people, you know, you know, how much they can earn so that they are not going to lose any of their government benefits and he kind of puts all the puzzle pieces together for people.

The other thing that we have done over the last couple of years, we have really increased the number of contracts with school districts that we have, so that ACHIEVA is really providing services to students that years ago, school districts tried to do.

So we are actually paid by the school districts to provide you know, instruction, resume writing, job interview skills, so that when the kids leave school, they are ready to go out and get a real job in the community.

And we know that this has been very successful, because the number of students leaving school who are coming to us talking about day programs, has fallen dramatically, you know, in just the couple of years, and I am going to say five years.

It's just fallen dramatically, the number of kids going into day programs is almost negligible. And if they do go into a day program, the rule is that the first day they enter the day program, is the first day we start planning for their discharge from the day program.

Something that we started only about five years ago now is ACHIEVA's disability healthcare initiative, and this is probably one of the most creative things we have done in the last couple of years.

And this is a total private-public partnership, this is all grant funded. And we started out with policy work on access to dental care. Believe it or not, access to dental care is the number one unmet healthcare need for people with all types of disabilities.

We have put together information on access to healthcare for Pennsylvania's legislators, and in this last budget cycle, when the governor's budget came out, and dental care for people on Medicaid was about to be decimated, we mobilized our network, which is now about 200 people across the state, 200 family members, people with disabilities, policy wonks, state government folks, dentists, you name it, across the board, and we were able to reverse some of those budget cuts. Not all of them, but it's a lot better than it was when the governor's budget first came out.

About a year and a half ago, we started our second project on access to healthcare for women and girls with disabilities, because what we -- what we know is that especially for women with physical disabilities, oftentimes it's virtually impossible to get good healthcare, especially in rural areas.

So we are working again with our policymakers in Pennsylvania, we are providing education to people with disabilities in families, and we are also involved with creating a lot of videos for medical -- as part of medical education, all related to access to healthcare for people.

And last but not least, right now in the state of Pennsylvania, just for people with intellectual disabilities, which includes people with autism, we have a waiting list of over 16,000 people, and when we started counting people on the waiting list we started at about 19,000 and that was about 10 years ago, and what's happened is although we have made progress and people have come off the waiting list, people continue to come on the waiting list, so that we know that you know, first of all not everyone wants to move into a three-person group home, and there's never going to be enough money in the system even if they did.

So we have begun to think about a different way to do this. What we know is that there are groups of families who have known each other for years, their kids want to live together, and we are working with them as I speak, to design what they want to -- where they want to live. Do they want to live in a house? Do they want to live in an apartment?

You know, what kind of waiver funding do they have, how much is their social security, what are their wages, we are putting puzzles together. These are all the puzzle pieces.

And then we have also recently gone to the state to get some of our service definitions amended so that we will also be able to creatively use some Medicaid dollars to make this a reality for people as opposed to them sitting on the waiting list for the next couple of decades. Thank you.

Dr. McCool: Eden Autism services -- there we go. Our mission is to provide high quality services, life span services, for children and adults with autism and their families.

Eden was founded in 1975 in Princeton, New Jersey; that's still our headquarters. We have special education programs, adult residential, adult employment programs.

We have programs in New Jersey, Florida, Pennsylvania, Connecticut and California, and the latter two are outreach programs.

Our outreach programs, which I'll talk about a little bit more, are now serving people both nationally and internationally.

That's a basic look at our group homes.

Our adult employment program, right now we are serving 100 adults in New Jersey and 16 in Florida. And all of our adults, we call our adults in our residential and day programs participants, are either in gainful employment or volunteer service.

We have work crews, supported

employment, and most recently we have started a business where the participants are actually scanning photographs for people. People bring them boxes of old photographs and we arrange them and provide them back to them on discs, and it's a great task that the guys like to do, and for many people it's something they have meant to do for years and years and now they are getting it done.

Okay. Outreach services -- outreach services actually began because Eden realized it couldn't serve everyone who came to us in school programs or adult services programs.

So we looked to see if we can help people who aren't in our residential or school programs. So we have diagnostic and consulting services, training, intellectual properties which I will talk about, and we also partner with other organizations for professional development, with -- we just celebrated I think the 25th year of our Eden

Princeton University lecture series, where we bring in three of the top autism researchers annually to provide up-to-date research on autism, and it's just absolutely amazing to see the kinds of research that are being done. Usually two of the presenters are biomedical research, and the third one is more on education.

Innovations. One of the things Eden has developed is intellectual properties. We have online training programs and a curriculum. We are now working with something I will talk a little bit more about called edWeb -- I don't know if people have heard about edWeb but it's a social networking system -- and our supported living program, which is in the planning stages.

I mentioned we have, you know, what we are doing, the curriculum, online learning programs, but we are also doing webinars both on our website and with edWeb.

The curriculum is something that we

have just gotten put into electronic format, and we are very excited. It's being tested actually this week.

But it's something that we developed over the 36 years of our existence so that it's something that we have been selling to other schools around the country, and there are several skill areas that are highlighted here.

There, where is it -- and what we are finding is that many of the schools that we go into and they are looking for help, we find the teachers have gotten some training but most of the training has been in behavioral interventions and when we go and observe these classrooms, there seems to be a focus on behavioral control and there's not much of a focus on skill acquisition and actually teaching skills.

And our curriculum is really designed for that skill acquisition and when we couple that with behavioral training, it makes for a good, rounded program.

EdWeb, I don't know how many people here are on Facebook and Twitter and other social networks. There was a -- I think there is an attempt for people to network and share information, but it seemed that a lot of teachers were not feeling that those were as effective as they could be for them.

So about two years ago, a company was formed called edWeb and it's a social network specifically for educators, and last March, edWeb asked Eden to set up what they call their autism community.

There are actually two groups, one from preschool to 5th grade, the other is from 6th grade to 12th grade, and it's an online community, a practice, but what has been fascinating is since March, we have grown to have 2,700 members of edWeb on the Eden autism community.

And what we have been able to look at is its real-time information sharing that is focused and specific. I was using one example earlier today. We had a teacher from Texas signed on, said my special ed director just came in and handed me an iPad, any suggestions?

And probably over the course of the next three weeks, the topic going back and forth on edWeb was applications for the iPad that people were finding useful and, as important, those that they found were not useful, that -- so it's been a very interesting kind of experience for us, and we -- two weeks ago, Anne Holmes, who is head of our outreach program, and I presented at the technology conference in Washington about edWeb and the impact it has had on teachers.

These 2,700 people who have signed up across the country are in public schools, private schools, segregated classrooms, integrated classrooms, and it's been a real opportunity for them to connect directly.

Supported living. And this is

actually something George Braddock and I started working on in California about eight years ago.

And when I came to New Jersey from California in 2005, looked to see if we could expand this program in New Jersey, and it was not something that was really in the repertoire of the state funding mechanism.

So it's taken this amount of time. We are now working with families who are funded by the Division of Developmental Disabilities for a supported living program.

And supported living is a program designed around the individuals, adults. The individual lives in the community with necessary supports. They can rent or own their home or apartment, and providers bring the program to the participant, rather than as we have talked about in some of the models before.

These can be single person homes, shared homes, they can be leased or rented, or they can be purchased. There are a lot of options for this particular model.

In this model, the maintenance is the responsibility of the property owner, not the provider of support services. And there's many options to ensure that necessary maintenance issues are addressed.

Many individuals living in supported living are eligible for housing grants from the local housing authority. Homes leased or purchased through these programs must meet standards set by the local housing authority.

And this is a chart that compares group home responsibilities with supported living responsibilities, dealing with the ownership, state licensure, and the licensure issue was the big obstacle in New Jersey, because supported living homes are not licensed and there's no regulations dealing with state funding for unlicensed residential programs.

SSI and SSD funds and how they are utilized differs in these two models, the determination of services and payment for services, food, transportation, maintenance and day programs.

And really this is an attempt to see if state funding agencies like DDD in New Jersey can have the majority of their money going directly to services, and organizations like Eden can primarily be involved in the resources that we have, into the service provisions and not having to spend time, money and resources on facilities.

So the -- so this requires collaboration, this kind of a model, and I think George alluded to more in the home design for supported living.

But it -- the attempt here is to bring more resources to the table. The SSI money that currently comes to our participants, 75 percent of that is given to the state to help support the residential program, and in supported living it is able to be used for food, clothing and partial housing.

Many of them are able to secure Section 8 housing vouchers and get in-home support services. Insurance and Medicare funds can help pay for some of the program entities, and some have IHP services that also bring to bear.

So some of the qualifications for SSI and what it can be used for.

The housing vouchers -- and this varies, I know, from really state to state and county to county, but families, at least in New Jersey, are trying to apply for housing vouchers as soon as their children are eligible, not waiting until they actually want to utilize them, because they have been told that it could be several years on the waiting list.

I think people may be familiar with IHS services that can be utilized in this kind of a model.

And so we are really looking at -- right now, we are working with two families who have been given the go-ahead to actually lease a home for their two adult children. We have the staff that we are providing, and they will be -- it will be -- it will look like a two-person group home but the difference is that they will be in their own home with their own furniture, and again having the opportunity for a lot of choice in the kind of programming and activities that they are involved with.

So we are really excited that it is going to be something that we are able to do a pilot program for, and let people know that it is viable.

I will say in California, unlike New Jersey -- New Jersey perceives this program as primarily for very high-functioning people who need little supervision -- in California they started it with the other end of the spectrum, those who are the most intense and have demonstrated that this kind of a model does allow people to, even if they need a lot of supervision initially, once they are integrated into the community, and can use community supports and generic supports, that the actual state funding requirements are able to go down.

So there are a couple of things that Eden is looking at right now. One of our exciting projects we started, almost six years ago, with Princeton University, was designing and constructing a school for children with autism. And we are happy to report that project's moved forward. We have about 30 days left for construction and we should be moving in probably sometime the end of October.

Thank you.

Mr. Grossman: Any questions?

Ari.

Mr. Ne'eman: My question is

directed towards Tom. You talked about inclusion into the community, but I also heard you mention work crews and the construction of a new segregated school, which certainly I find a little bit concerning, in part because of our presentation -- the presentation we heard earlier today from the Department of Justice on the Olmstead decision's applicability to employment services, and, you know, also what I know coming from New Jersey, knowing New Jersey has the highest rate of segregation for autistic students of any U.S. state.

So I am wondering if you might respond to that and speak to those concerns.

Dr. McCool: Sure, I think IDEA guarantees a free, appropriate public education in the least restrictive environment, and the children that are referred to Eden are the best served in the setting that we have.

The -- right now, I know New Jersey

is identified as having the highest number of people in private schools, but they also have the highest success rate in dealing with children with the most difficult behaviors.

Mr. Ne'eman: As measured through what?

Dr. McCool: As measured through outcome studies.

Mr. Ne'eman: Which outcome studies?

Dr. McCool: Well, the -- the Association of Schools and Agencies, ASA, in New Jersey does an outcome study for all of the children that graduate from private schools, specifically so that we are able to demonstrate the effectiveness of the -- of that particular program.

Mr. Ne'eman: Could you speak perhaps to any of the metrics that compare New Jersey's performance to the performance of other states, such as the IDEA state performance plan indicators, or NAEP scores, or graduation rates, or anything with regards to that?

Dr. McCool: Specifically, the graduation rates are higher in the non-public schools than they are in public schools, particularly with students going into employment from the private sector.

Ms. Blackwell: I just wanted to capture for a moment Tom, this notion that you were -- that you really talked about the most, at the end of your presentation, which I brought up also in my presentation, which is you know this whole idea about owning your own home.

This is a really important concept and I am glad to hear that your organization is beginning to support people who live in their own homes, because you know, what we are seeing at CMS and what we also heard from Charlie Lakin, who is now a colleague, our next presenter, is that as the provider-based residential funding dries up, we are seeing people remain in the home longer and longer.

So I think that it's really important for people to really focus on this idea, long before the time these services are needed, that they need to be thinking about where their family member can live and there are so many benefits to owning and living in your own home.

Like, for example if you don't like your provider, you don't have to move to another place, which is really a punitive part of the system that we have in place now.

I can't think of any other circumstances where people are forced to move the way people with disabilities are. So I just -- I mean there are many ways to get a home and Tom talked about a few of them, housing choice vouchers, and I would have to say that waiting lists for these vouchers are not a few years. In some state they are decades.

So it's never too soon to get on a

housing choice voucher list. And then also this idea that families need to be thinking about owning or transferring property or purchasing property, especially in this very favorable real estate market, for their disabled family member really early on, is another good tip, because it does free up this ability to choose providers and you know, have a more self-determined approach to services.

So that's my, that's my comment.

Dr. Groden: We have a number of people who share houses. So a person with autism finds someone who needs a house-mate, and they live with them. And that's worked out very nicely.

Mr. Grossman: Any other questions? People on the phone?

(No response.)

Mr. Grossman: Hearing none, thank you very much. If you could stick around, after our next presenter we will still be having a Q&A section then. And thank you very much for your presentations.

Ms. Sheehy: Okay. Hi everyone.

Ms. Blackwell: Oh, Jennifer I was going to introduce you. I am so happy to be introducing Jennifer. I have been waiting all day because she has been sitting patiently with us since this morning and I am so happy that she is here.

Jennifer Sheehy is the director of policy and planning for OSERS, the Office of Special Education and Rehabilitative Services. OSERS' chief of course is Alexa Posny who has been with us before at the IACC.

Alexa and Jennifer work for the U.S. Department of Education and Jennifer is going to be talking with us about a part of OSERS that many people, you know, I don't think realize, falls under Education's purview, which is the vocational rehabilitation services system in the United States, which is really an artifact, I believe, and Jennifer, please correct me if I am wrong, it's late and I am a Medicaid policy geek, but I believe it was established in the Rehabilitation Act of 1973.

So these two laws, the IDEA and the Rehabilitation Act of 1973 -- three -- the Americans with Disabilities Act -- drive so much disability policy in the United States.

So we are very happy to have you with us. Thank you for coming and sharing your day with us and we look forward to hearing from you right now.

Ms. Sheehy: Well, and thank you very, very much, Ellen and Susan, and Lee, when he comes back. I am very happy to be here and I actually stayed the whole day and asked staff to go to my other meetings because I was so fascinated by the presentations.

And I really appreciate the opportunity to be able to listen today.

I neglected to tell anyone that I use a wheelchair so I don't have a ramp and that's good because I am afraid of heights anyway, and I guess I should probably see June after the presentation, so we can clear that up.

So I am going to talk to you about the vocational rehabilitation program, the assistive technology program, the independent living program, and the National Institute on Disability and Rehabilitation Research.

And I am going to speed present, because I know it is late in the afternoon and I would love to know -- you guys are probably familiar in your own worlds in different ways with the vocation and rehabilitation program. So I would be very curious to, you know, entertain questions or kind of talk through it more informally.

So I am going to just start putting kids with autism, students with autism in context in our programs. As Ellen said, we start with the special education program, and in 2010 there were over 300,000 students with Autism Spectrum Disorders in ages 6 through 21 out of 5.9 million students, so that's about 5.6 percent of the student population we serve, and this kind of gives you a sense, this graph of the distribution over the last -- from '05 to 2010 of students with autism, so this has -- obviously the rate has been going up.

Transition age students with autism. In 2009 there were 101,000 students with autism ages 14 to 21. This next slide gives you an idea of how many students with different disabilities are enrolled in post-secondary education and this is from the National Longitudinal Transition Study.

And to give you the percentages, students with intellectual disability, 28 percent of those surveyed were enrolled in post-secondary education; I won't do all of them. Students with autism, 47 percent said they were enrolled in some kind of post-secondary education. That can also include vocational training, community college, four-year college, it doesn't break out.

And then the highest percentage of students with disabilities in this study were students with speech and language disabilities, and that was 63 percent, so that kind of gives you a range of different disabilities and involvement in post-secondary education.

Moving on to VR services, in 2011 the funding for VR is three billion. To give you kind of a comparison, the funding for special education was 11.2 billion, and that 11.2 billion represents about 17 percent of the money spent on special education in the country. The rest of course is state-funded.

For VR, $3 billion, the VR program, 80 percent of the funding comes from the Federal budget. So about 20 percent is state-funded or other funding, state or other funding.

In 2009, the program received an additional 540 million which they have until this September 30th to spend. So get back to your states and tell them to write you a check, because they can spend it on -- the VR program is very flexible on its funding and it can spend money on infrastructure, it does a lot of subcontracting, and they do have a little more time to spend it.

In fact I think they can obligate the funds through December 31st, so they can make the commitments until September 30th, and they can obligate it and actually write the check out until December 31st.

In 2010, there were 300,000 cases closed after individuals received services. That is all individuals.

And that's -- I will read this slide to you -- actually I will show you the graph that accompanies this slide, because it is a little easier.

This just gives you a sense of -- from 2006 to 2010, the prevalence of people with autism in the VR system. So the first two columns show the number of people with autism who had some contact with VR.

They applied for VR services, but it was before their IPE -- that should say IPE -- was developed. And then all the way to the employment outcome, you can see that people with autism, there are of course larger numbers of people with autism in this system, but -- and the employment rate for people with autism, there were successful outcomes even with the increase, has improved over the last four or five years.

So that's good news. What you can't really tell from this is the number, on the employment side, the number in 2006 of people who received an employment outcomes, people with autism or ASD, was 1,400, and in 2010 was 2,500.

So that's actually low numbers. That's across the country, out of 300,000 closures. So people are identifying potential candidates for VR with autism but -- and obviously that identification is increasing.

But I think there is still room to connect people with autism, with the VR services.

Okay. In our review of the state plans, states have to submit state plans every year that talk about the different services and some of their successful partnerships and models.

And some of the things we have learned that are specifically related to outcomes for their customers with autism, and these are all from different states, so one thing we really have to work on is bundling the successful models and making sure that they are working together and trying to really coordinate better for streamlined services.

States are doing targeted outreach in identification. Like specifically networking with organizations that serve people with ASD and trying to make sure that they are aware of the VR services.

Creating an expanded and specialized service delivery system. Basically, looking at the needs of people with autism, and making sure that they are either contracting for services that meet those needs, or finding out you know, training counselors to make sure they are providing the counseling that can meet the needs for people specifically with autism.

Increasing training for staff. Now, almost all of the training, the VR does for staff, is contracted out, and you know, just being here today I know there are a lot of organizations represented that could provide that kind of training. So I think that would be a wonderful opportunity for partnership with VR.

Partnering for a seamless system of service delivery, and this has to do with partnering with the, you know, the state agencies, local agencies, schools, non-profit organizations, service providers, and of course businesses, in order to provide the best individualized service.

Implementing a package of group services for career development. This was a state that actually said okay we are going to look at a cohort of customers with Autism Spectrum Disorders, figure out what the services that are fairly common that they need in order to develop you know, the soft skills, social skills, the job readiness skills, and career counseling, and then the supports on the job that they would need, and put them in, kind of group them together so that they create a program for people with autism. That was one of the successful models we identified.

And then of course providing paid internships. The VR program has really come a long way in just the last two or three years in developing relationships with the employer and with businesses.

In fact they have established what

they call the net, which is an online national program of business developers that are the VR staff, and they connect with employers, national employers and local employers, but they can share jobs, they share practices, and they are really doing a lot to provide supports to employers for hiring individuals with disabilities.

VR can actually pay for the internship. You can tell an employer if you want to have an intern, they need an individual, but they don't have the money right now, maybe because of the economy or they don't have internship programs. VR can actually pay the salary of the individual on the job because it can be considered training.

And often, that individual becomes a full-time employee of the business after they have, you know, proven their skill level.

And then of course partnering for long-term support with a lot of the Medicaid supports that, and long-term supports that we have identified today.

Some of the services that are provided by VR are, as you can see, job placement, job supports, helping with the job search, all those are higher now, higher rates now than they were even five years before, because they are really focusing in on connecting with employers and placing people in jobs.

Diagnosis, treatment, transportation, and then only 16 percent of people who have Autism Spectrum Disorders have received post-secondary education services.

I think that's low and kind of comparing it with the statistics that I have later, most of the people who have ASD who come to VR, are referred in school.

So if they are referred in school, and they can take advantage of post-secondary education, they are not necessarily getting that through VR, and I think we need to kind of look at that and see what we can do, especially with the new law, the Higher Ed Act that allows students with intellectual disabilities to be eligible for Pell grants and what we call Title 4 funding, so basically grants to go to post-secondary education.

Okay. Almost all individuals with ASD with employment outcomes receive competitive employment -- oh I skipped a slide. Sorry.

I'll just read it because I have obviously lost my place here. Okay. Individuals with autism who have an IPE are actually slightly more likely to achieve employment outcomes than the VR population as a whole.

And there -- basically people with autism in the VR system tend to have a two to six percent higher employment rate than the VR population as a whole, and there's a graph that kind of shows you what that looks like.

So people with autism are the red line and then all the VR clients are the, whatever that color is, mustard, I would guess.

Now, a little bit about the employment outcomes. Ninety four percent, 95 percent of those employment outcomes are what we call competitive, integrated employment.

It doesn't tell you how many of our -- what percentage are supported employment, but a high percentage of those are also supported employment.

Average hourly wage has risen from $7.33 in 2006 to $8.65 in 2010. Now, this is an interesting -- what I found interesting is the average hours worked per week has gone up from 22 or 23 hours about 22-1/2 hours, to 24.7 hours in five years.

So that's still not full-time. Forty-eight point seven percent of all Transition youth had employment outcomes, so now we are talking about the Transition age group, versus 51.6 percent of youth with Autism Spectrum Disorders in the VR system.

So this mirrors the adult statistics in that they are finding employment at a higher rate comparatively. However 19.4 percent of young people with autism work full-time versus 45 percent of all Transition-aged youth that were served by the VR program.

I think it's -- I mean my conclusion of course is that people who are very much dependent on Social Security, Medicaid, are going to basically maintain, if they do seek employment, are going to maintain employment below substantial, gainful activity, to maintain their benefits.

So we, I think it's great to hear what some of the organizations are doing to work with the Ticket to Work program and then some others, so they can increase their economic self-sufficiency.

Now I want to talk a little bit about NIDRR. I think Alexa presented to this committee a little about a year ago, and mentioned that we have 26 research projects that are related to autism.

But the three that I am mentioning here, and I am just going to mention them and you have their websites in your packets, are three new, or two new grants that are focused on really identifying evidence-based practices in the VR program for people with autism.

One is at SEDL and one is at the Virginia Commonwealth University in Richmond. And then the Kansas University has done an interesting study, and you can go line and actually look at the papers, on self-determination outcomes.

And I think that's wonderful that that is supported by a lot of what you have seen in your own programs.

Eleanor Roosevelt said that you can't make someone inferior unless they give you permission. And I think it's a wonderful kind of illustration that we all need to hold high expectations for all people with disabilities, and that goes from you know, the families, the service providers, and certainly people themselves.

And by learning self-advocacy skills and self-determination, you know, they will not give someone permission to let them feel inferior.

Independent living services. Our program is about $103 million a year. They did receive significant money in 2009, well, significant for the program, and the centers actually have five years to spend that.

So, they still have money for the next three years, that they be able to spend to improve and increase services. I'll just go to the graph for this one.

To show you kind of the range of services, they have as one of their core services, the requirement to help people move from institutions and nursing homes into the community.

So if you know, you are -- can be connected with your independent living centers in your area, they are trained and skilled and required to help Transition people out of institutions, and we measure them on their success in that.

And that's -- it's a small piece of what they do, because it is very time, money and labor-intensive as you know. But it's a significant -- it's also extremely important.

So those other services are the core services that the independent living centers provide, and of course there are over 350 of them around the country.

And this slide talks a little bit about our state assistive technology program. This -- the Assistive Technology Act is another act that the Department of Education administers.

So we have got the rehabilitation act, which is part of the workforce investment act, IDEA, the Assistive Technology Act and then the Randolph-Sheppard Act is also under our purview.

So we do have quite a few programs related to disability that people aren't always aware of under the Department of Education.

These examples are really just to show you that people in the state assistive technology program are doing a lot even targeted to people specifically with autism.

So if you don't have one of those states identified, and that's South Carolina, Ohio, Illinois, Missouri and Vermont, let me know. I would be -- and you are interested in connecting with those programs, I'd be happy to make that connection as well.

And then finally I just wanted to talk about a couple of individuals that are what we consider success stories through the VR program.

One is in Alabama and his name, for our purposes, is Duncan. But he was in a situation where he was not employed to his potential, and he was connected with VR's business relations team. That's the new team that I was talking about that VR has available in the states.

And they had a program that they had started with the VA Medical Center in Birmingham, a youth employment program, and they work with the student to really identify the skills, the tasks and the interests.

One tenet of VR is that the job, the goal, has to be designed with the person according to their interests and abilities of course. But their interests almost outweigh their abilities at times, because the VR program can provide the training and the education and job skill development to see if the person has a potential in the career of their choice.

So Duncan was able to figure out what he was especially good at. They carved out a role for him at the VA hospital. The VR program provided the post-employment services to ensure that he was really successful in the, you know, first 90 days of his program, and then the hospital actually provided or offered him a full-time position and he is working there at this time.

Now this -- we have success stories that are in retail, and in the hotel industry. All of the VR outcomes are in what they call competitive, integrated employment, so they are going to be in a job that's in a typical labor market setting, like you know, a hospital or a bank or just any company that you can think of.

And then the other success story is Alex, and he is local, and he was -- the VR program really pulled together all the partners that were necessary -- the schools, the service provider, NIH was the employer and they had a Project Search program, you guys might be familiar with the Project Search model.

And so he had -- he was someone that really needed assistive technology in order to be independent. His family was reluctant to let him ride the bus by himself and even to work, because they were worried about his safety, of course, and whether he could be focused and really take on transportation travel training.

But with the assistive technology and the apps that they found and the training, he was successful, he was so enthusiastic and proud of himself when he was able to do these things by himself as well.

The Project Search model is actually education in the morning, and then work-based experience in the afternoon, and then he became a full-time employee at NIH, in the materials management department, and still uses the assistive technology.

So those are those two stories. I am again very delighted to be here. I have a -- my godson has autism, and my four-year-old niece has a significant developmental disability. They are in Santa Barbara so that is why I was connecting with George a little bit earlier.

But my godson Patrick, they started his Transition, he is going to be 16 in a couple of weeks, when he was 14, and started thinking about you know, where he was going to live, and what he was going to do, and looking at supported living type arrangements, and it's you know, they are not there yet of course, and I don't even know if he is thinking about it yet.

But you know, he is a 15-year-old boy so he has got a lot of other things to think about.

But this was -- it's wonderful to hear all the different models and advances and services that are available. I feel like myself, obviously, I have a personal experience with disability. I was also -- lived in a nursing home, was on social security, SSDI, and Medicaid and Medicare.

So I'm very, very appreciative of

what you all do to help individuals Transition out of those programs into employment or you know, into those programs so that they have some long-time support.

So thank you very, very much for all you do and I am happy to take questions.

Ms. Blackwell: Thank you Jennifer. I have a question, because in our family we also have experience with the VR system. For people who don't connect through the Department of Education at transition, because there are some hits and misses there sometimes, how would a consumer connect with the VR at the state level in terms of you know, say they live in Maryland, what do they do to get into the VR system?

Ms. Sheehy: All they have to do is go to the VR program, to the field office or to the state level, and we have I mean, if they have any connection to the web, they can just go to vocation and rehabilitation in the state and if they Google it, or they can contact us and we can give them a phone number and then they just talk to a counselor who helps them with the eligibility process.

Are you thinking of like a different way that they might find out about it maybe through --

Ms. Blackwell: I was just trying to help people understand how they would connect at their community level, with the system. Because I think sometimes it's hard for people to understand what office do I go to. There's a lot of -- there's sort of a lack of seamlessness at the present time in terms of you know, case management for voc rehab, case management for social security, case management through developmental disabilities, I mean, there's this, you know, kind of mish-mash in our system, that we of course at some point hope to make more seamless.

Ms. Sheehy: You know, and that's, that's -- we struggle with that all the time because people should be aware of services when they are in school and doing their Transition planning and certainly VR should be at the table with the IEP team at that age, you know, at 16 of not earlier.

And if they do have services through some of the waiver programs, they should be connecting them with VR. VR, one of the things, that they, a counselor might do, is make sure that that individual is receiving benefits that they are eligible for that they know of in the states.

I mean, it's very hard for an individual to keep track of those things, I know, I mean, you always feel like you were the first person in the country to have to navigate this, when it's you and your family, and you are not a professional in the field.

And it's hard for some of us who are professionals in the field to even navigate the system.

So we do coordinate at the Federal level with our colleagues in you know, HHS, health and human services, social security, Department of Labor, Department of Justice, EEOC, but we are still not there yet with making sure that, at the state level and at the local level and in the schools, they are always aware of all the different services and programs that are available.

But we are trying to do a better job with you know, making sure that education happens.

And also, as more people become connected to the internet, if they can get to one, they can often find the others because they will have features on their website for other programs and resources.

Ms. Blackwell: Daniel.

Mr. Davis: Yes, first of all, thank you Jennifer, for a very helpful presentation, also I appreciate the mention of Project Search. I know we have been, at HHS, we have been working with that model in terms of some of our work on expanding employment of people with disabilities within the department, and I think that -- I know that both the Administration of Developmental Disabilities and NIH have, as you mentioned, have been working with that.

One question that I had is regarding order of selection, but where does autism fall in terms of states that have an order of selection for VR services?

Ms. Sheehy: Well, it varies by state. The states actually determine what their order of selection is going to be. And it's based on functional ability, or functional disabilities at the state level.

But we can like, if you are interested in a specific state, we can look that up or find out for you.

Mr. Davis: Thanks.

Ms. Blackwell: June.

Dr. Groden: We do a lot of work with voc resources in Rhode Island, but it's usually, in fact it's all the time, short-term and time-limited, and you mentioned something about long-term supports, so -

Ms. Sheehy: Well, long-term supports -- a VR counselor has a requirement to find long-term supports for someone who needs supported employment.

So they have -- the statute allows them to work with a person 90 days after employment, a successful employment outcome.

But if they need long-term supports, they are supposed to identify those. And it could be the home and community-based waiver, or Medicaid or the DD agencies, mental health agencies, in that state.

In circumstances, too, where they can't find those supports but they need the vocation and rehabilitation for longer than 90 days, they can make exceptions too.

So if you have a specific situation where they have said they can't do something for a certain period or help until the person --

Dr. Groden: Well I'm thinking of the population with Asperger's. They are not funded by anyone at all, not by DD, not by mental health.

We just ran a very successful job club which was an Earmark grant, with very good results, and -- but some of those people need a little bit longer coaching, or at least working with them, on specific things.

But I have heard that it's only short-term supports that they give.

Ms. Sheehy: And they were definitely eligible for VR?

Dr. Groden: Yes.

Ms. Sheehy: So they became VR -

Dr. Groden: Yes.

Ms. Sheehy: customers. Uh-huh. Okay.

Dr. Groden: But it's just short-term. But as you know, people with Asperger's need continued support.

Ms. Sheehy: Yes. They are not

statutorily restricted from providing longer-term supports. I would have to look at the specific situation there to see you know, what they are providing and what they are saying.

But they can provide services until an employment outcome and then 90 days after the employment outcome. Training doesn't count. That's part of the services before an employment outcome. People are in the system for years before they have an employment outcome.

I am an example of someone who was in the system for four years before I had my employment outcome and my case was closed 90 days after that.

So I would be happy to work with you or talk to you about that specific situation and see you know, what they are providing, and how they could have longer-term supports.

Ms. Sheehy: Thank you.

Dr. Groden: It may have something

to do with, if they have a waiting list, then they are allowed to have some restrictions beyond what we require. So we can look at that too.

Mr. Ne'eman: Yes, I'm wondering if you could speak to what type of technical assistance RSA provides to state VR systems around autism and other under-served disability categories?

Ms. Sheehy: Well we have a system of technical assistance and continuing education centers. Probably starting in the mid-2000s we were, started really focusing on autism in particular.

There was an Institute on Rehabilitation Issues paper that was written in 2007 I think that is on our website, on VR services and autism and those papers are written by the VR providers, like for -- by the state VR providers to share with their colleagues, and with universities and other outside experts.

And we -- the two grants that I talked about through NIDRR, that was in collaboration with the Rehabilitation Services Administration saying we really need to know what the evidence says about services to people with autism. And so those were awarded I think two years ago. They are developing -- they are conducting their studies now, which also involve demonstration projects, and so that was, you know, kind of part of our focus on our newest focus on autism.

And then the particular technical assistance and continuing education centers do have TA for VR agencies on serving people with autism. I can find them on the website for you if you would like Ari, and send you some links.

Mr. Ne'eman: I'd appreciate that. Thanks very much.

Ms. Sheehy: Sure.

Ms. Blackwell: Any questions from our audience on the phone?

(No response.)

Okay, thank you Jennifer. Thank you for being the last presenter today.

Ms. Sheehy: Thanks for you bearing with me.

(Applause.)

Ms. Blackwell: So with that, we actually have reserved a little bit of time for committee members to bring up any areas of discussion that people want to bring up today.

As I said at the beginning of the day, this is our last Services Subcommittee meeting under the Combating Autism Act so thanks to everyone who participated today and other IACC members who are not members of the Services Subcommittee, thank you for participating as well.

Comments from people in the room or on the phone?

(No response.)

Ms. Blackwell: Any other questions for any of our speakers who are still with us?

(No response.)

Ms. Blackwell: Okay then. I am just going to say thank you to everyone and also I am going to turn over the mic to Dr. Daniels for a moment because she has an exciting announcement.

Dr. Daniels: Yes, up on our screen and in your folders you have a flyer for an upcoming event, and this is not an IACC event per se, but it's related to the IACC, because this is a workshop that the NIH is going to be holding to look into a question that was posed by the IACC in one of their objectives in the strategic plan, and that objective is: convene a workshop to examine the ethical, legal and social implications of ASD research by 2011.

“The workshop should define possible approaches for conducting future studies of ethical, legal and social implications of ASD research, taking into consideration how these types of issues have been approached in related medical conditions.” (quote from the 2011 IACC Strategic Plan.)

So, the NIH is going to go ahead and do this and they are holding a workshop, I believe a week from Monday, on the 26th of September. It's open to the public. We will be webcasting it live and archiving it, and wall the presentations will be up on the web, and today all of these presentations will also be up on the web and we will archive the videocast and the materials are up on the web.

So we invite anyone and everyone to participate in this workshop either via webcast or in person if you are available. So we look forward to that.

Ms. Blackwell: Okay, well I think we will call it a day with one last tip of the hat to the staff at OARC and its contractors for supporting the Services Subcommittee throughout the years. Thank you very much.

(Applause.)

Mr. Grossman: And thank you

presenters for being here and all of those that are watching on the worldwide web. George Braddock said to me earlier today that there is such an immense amount of information, it's like taking a sip from a fire hose, and yes, we are all feeling the pain right now.

But it has been a great day and we are looking forward to seeing this information being utilized as we go forward in developing services -- improving services in the U.S. Thank you everyone.

Dr. Daniels: Thank you for being here.

Ms. Blackwell: Thank you.

(Whereupon, at 5:26 p.m., the subcommittee adjourned.)